Getting the benefit from electronic patient information that crosses organisational boundaries

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## Glossary of terms/abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>A&amp;E</td>
<td>Accident and Emergency</td>
</tr>
<tr>
<td>CECS</td>
<td>Community Elderly Care Service</td>
</tr>
<tr>
<td>CfH</td>
<td>Connecting for Health</td>
</tr>
<tr>
<td>CQC</td>
<td>Care Quality Commission</td>
</tr>
<tr>
<td>DMP</td>
<td>Disease Management Pathway</td>
</tr>
<tr>
<td>ERDIP</td>
<td>Electronic Record Development and Implementation Programme</td>
</tr>
<tr>
<td>FEP</td>
<td>Frail Elderly Pathway</td>
</tr>
<tr>
<td>Hybrids</td>
<td>Staff attached to IM&amp;T Departments who have a clinical background</td>
</tr>
<tr>
<td>ICP</td>
<td>Integrated Care Pathway</td>
</tr>
<tr>
<td>ICT</td>
<td>Intermediate Care Team</td>
</tr>
<tr>
<td>IM&amp;T</td>
<td>Information Management and Technology</td>
</tr>
<tr>
<td>KPI</td>
<td>Key Performance Indicator</td>
</tr>
<tr>
<td>LHC</td>
<td>Local Health Community</td>
</tr>
<tr>
<td>LHE</td>
<td>Local Health Economy</td>
</tr>
<tr>
<td>MIaMi</td>
<td>Minor Illnesses and Minor Injuries</td>
</tr>
<tr>
<td>NPfIT</td>
<td>National Programme for Information Technology</td>
</tr>
<tr>
<td>NSF</td>
<td>National Service Framework</td>
</tr>
<tr>
<td>OOH</td>
<td>Out-of-Hours Service</td>
</tr>
<tr>
<td>PACS</td>
<td>Picture Archiving and Communication System</td>
</tr>
<tr>
<td>PAS</td>
<td>Patient Administration System</td>
</tr>
<tr>
<td>PCT</td>
<td>Primary Care Trust</td>
</tr>
<tr>
<td>QIPP</td>
<td>Quality, Innovation, Productivity and Prevention</td>
</tr>
<tr>
<td>QOF</td>
<td>Quality Outcomes Framework</td>
</tr>
</tbody>
</table>
SAP      Single Assessment Process
SCR      Summary Care Record
WALDOC   Walsall Doctors on Call
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***

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Executive Summary

Background

- The implementation of large-scale electronic patient information systems that effectively communicate and coordinate care across organisational boundaries (e.g. primary, secondary and social care) to provide ‘seamless care’ is very challenging. Internationally and nationally very few such systems exist and any that do tend to be limited and/or localised.

- Care pathways provide a means of integrating health service delivery across organisational and occupational (e.g. medicine, nursing and social care) boundaries and are a good basis for integrating e-patient information systems across local health communities (i.e. supporting multi-disciplinary working across organisational boundaries).

- There has been much debate around implementation strategies and the relative merits of top down and bottom up implementation strategies for these e-health systems. More recently there has been interest in a so-called ‘middle-out’ strategy based on local priorities within an agreed framework of national standards and guidelines.

Aims

The primary aim of this study has been to examine whether the sharing of e-Health records between Primary Care Trusts (PCTs) and related agencies within Local Health Communities (LHCs) can contribute to improved clinical care and better management.

The second aim has been to examine the factors in the design, implementation and subsequent evolution of these systems that have facilitated or blocked successful inter-organisational uptake of the systems by all organisational partners.

The objectives of the study have been as follows:

1. To explore by longitudinal study the barriers/facilitators in the development of e-health systems and the outcomes achieved when used across organisational boundaries in two PCTs.

2. To explore, for each PCT, the differences between systems created as a result of national and local strategies to produce platform-independent electronic systems and those locally developed as a result of inter-organisational initiatives.

3. To examine whether an action research framework in which feedback sessions to managers and end users, can promote effective take-up by providing an evidence base of benefits and barriers.
Methods

The project studied the processes and experience of computer specialists and health professionals implementing and using IT supported care pathways ('e-care pathways') that crossed organisational boundaries. The research was inductive, contextual and processual in design being longitudinal, qualitative, socio-technical systems (STS), organisational research and evaluation.

Originally, the research was intended to include systems that were top down designed within the National Programme for Information Technology (NPfIT), but with the national programme waning we adjusted our selection of cases to reflect more the priorities within the two PCTs.

We adopted a five stage research process:

1. Understanding the role of informatics in the two PCTs.
2. Mapping nine care pathways to plot the systems and identify the user communities of existing electronic care record systems.
3. Studying user experiences in six selected pathways through interviews of boundary-crossing roles for patient information sharing.
4. Following in detail system (re)development in four pathways.
5. Engaging in ‘action research’ activities to develop a framework for the ‘practice’ of developing IT systems to serve pathways.

The specific methods of investigation were as follows:

- mapping IT supported pathways through discussion with, and assistance of, Information Management and Technology (IM&T) and Informatics managers and Business Change and Clinical Change Management ('hybrid') staff and health professionals,
- observations of information management and care pathways meetings
- interviewing I.T. and health professionals,
- action research workshops and meetings

Findings

1. The deployment of e-health systems

- Nearly everybody makes use of an electronic system of some kind but most systems cannot share information with other systems.
- There is ‘no one best way’; different strategies have been adopted in the two LHCs to promote the sharing of electronic records; one has followed the NPfIT
approach of adopting a single (database) system for all to use whilst the other has adopted a portal approach.

2. The Significance of Pathways

- Healthcare pathways are the major highways that patients travel which lead to situations where close co-ordination across boundaries is needed.
- In all the cases we examined there was an assumption that e-health systems would be developed to support the delivery of integrated care in the pathway.
- Different pathways involve different kinds of task interdependencies (pooled, sequential and reciprocal) at the organisational boundaries in the pathways which has implications for the type of co-ordination that is necessary.

3 Top Down National Influences on e-System Development

- The national roll-out of NPfIT applications had relatively little impact on the LHCs studied. Nevertheless there was evidence of the use of NPfIT general database applications (SystmOne and iPM) and specific applications (PACS and Choose and Book). Two conclusions about the general database applications can be drawn.
  
  a) installing the application is only a small step on the way to the successful harnessing of its potential to contribute to healthcare. Much local design work is also required.
  
  b) the general-purpose system has to be flexible and resilient. Even so, local design teams have to show considerable ingenuity and a readiness to use middleware products to meet the requirements of users.

- Three national policies had a profound effect locally:
  
  a. policies for healthcare pathways lead to multi-agency process design projects and to new multi-agency resourcing arrangements. These are underpinned with the assumption that e-health system developments will be needed to enable information sharing across each pathway.
  
  b. policies for information governance in the cause of protecting the confidentiality of patient records can impede efforts to share information, especially in time critical situations and where shared care requires the sharing of patient information across agencies and disciplines.
  
  c. NHS organisational changes have created frequent requirements to change the organisational configuration of agencies in the LHCs with the result that the ownership, role and technical configuration of projects changes radically with negative consequences for their direction and momentum.

- Insufficient attention is paid to the requirements of the front line staff who need to share information to co-ordinate care in the pathway and there was no direct voice for the patient in these developments.
4 The Experience of Using e-Health Systems

- Front line staff reported general benefits from using e-health systems.
- The majority of benefits obtained or desired tend to be highly contextual i.e. specific to the work of the particular healthcare staff.
- The benefits of e-health systems reported by the managers of pathways were considerable. The reports provided gave managers better information tools to assess the benefits of the pathways and how performance could be improved.
- On the other hand, there is considerable evidence, that careful, focused definitions of key performance indicators (KPIs) are necessary to avoid misleading conclusions about performance.
- The needs of those who commission and manage pathways are for structured, aggregated information that demonstrates, for example, whether performance targets are being met. However, pre-structured records may not enable operational staff to record particularly salient patient information.

- Inputting data to e-health systems was contentious for a number of reasons.
  a) there was often a need to re-enter data that had already been recorded in another system.
  b) much of the data input may be of little service to the person doing it but was intended for use by a manager or a person in another agency,
  c) data input could be treated as the ‘formal’ record used for assessments against targets, audits etc.
  d) there was some concern that there could be too much information available making it difficult to locate critical information.

- System development was dominated by the top down approach which meant the need to share information by frontline staff had less influence than the needs of management to manage the pathways. As a result frontline staff developed ‘workarounds’ to achieve information sharing and, after implementation, engaged with ‘hybrids’ in ‘bottom up developments’ to modify the system so that it evolved in a way that met more of the needs of operational staff.

Conclusions

Within the two LHCs studied, there are areas in which substantial progress has been made in creating working forms of integrated care in healthcare pathways. These islands of progress have produced solutions that are quite different from one another and they are the result of evolutionary processes over several years in the face of many difficulties. As a result, there are parts of the systems development process that are mature in the ways in which the challenge of integrated design is tackled. We would single out, for example, the long tradition that has now built up for engaging ‘hybrids’ as the go-betweens in the endless dialogue between informatics specialists and the healthcare user community. However, current electronic support for integrated
care can only be described as patchy and, to build on what is already in place, there is a need to create more mature systems development processes that can cope with the many challenges of bringing together a diverse set of stakeholder interests across a number of different healthcare agencies to create the sociotechnical systems necessary to serve the specific needs of healthcare pathways.
The Report

1 E-health records in the pursuit of ‘seamless’ healthcare

1.1 Introduction

Our research reported here examines how best to get benefit from electronic patient information that crosses organisational boundaries. The key benefit this could deliver would be ‘seamless care’, with a patient moving between their home, community, hospital and across medical disciplines without their clinical notes being lost, investigations being duplicated or their treatment being delayed. As the later chapters will show it is not easy to achieve, indeed there are very few examples where this has been achieved, but where it happens real benefits do flow for patients, practitioners and managers. The practical way of employing e-patient information systems to support the provision of ‘seamless care’ is based around care pathways, for these are integrally designed to deliver integrated care across boundaries (Chapter 2). However, the marriage of I.T. and care pathway does not automatically assure success that cannot be easily guaranteed by a technical solution alone. The two components (care pathway and the I.T.) need time to bed down together in order to ensure together they provide good quality, integrated, health care. The ‘give and take’ within the marriage will vary depending on the characteristics of the care pathway (and the disease trajectory and/or patient journey it represents) and the technical facility of the I.T. system(s) to provide support.

In this research we have studied a range of pathways and their I.T. support across two Primary Care Trusts (PCTs) within their Local Health Communities (LHC) over, at least, a 12 month period in order to identify and track what works and what does not in the pursuit of ‘seamless care’. Our results show that real benefits are worthwhile and achievable, but not necessarily easily or in a short time frame. The pathways we studied in detail here (Chapters 6-8) clearly demonstrate the potential and sometimes the actuality to improve the quality of care. Our investigations also evidence that these I.T. systems are already providing timely management information. Indeed, practitioners on occasion feel that the systems are designed more for management than to improve health care services.

1.2 Aims and objectives of the research

The main aim of this study has been to examine whether the sharing of e-Health records between Primary Care Trusts (PCTs) and related agencies within Local Health Communities (LHCs) can contribute to improved clinical care and better management. The secondary aim has been to examine the factors in the design, implementation and subsequent evolution of these systems that have facilitated or blocked successful inter-organisational uptake of the systems by all organisational partners.
The objectives are as follows:

1. To explore by longitudinal study the barriers/facilitators in the development of e-health systems and the outcomes achieved when used across organisational boundaries in two PCTs.

2. To explore, for each PCT, the differences between systems created as a result of national and local strategies to produce platform-independent electronic systems and those locally developed as a result of inter-organisational initiatives.

3. To examine whether an action research framework in which feedback sessions to managers and end users, can promote effective take-up by providing an evidence base of benefits and barriers.

1.3 **The structure of the report**

The report is organised into three parts.

Part 1 sets out the rationale and background to the research including, in Chapter 2, a selective review of the findings from previous research that focused on the design, implementation and use of e-Health systems nationally and internationally. In chapter 3 we set out our research design and methods based on case studies constructed to capture the emergent practices and improvisatory behaviour that have been commonly associated with the implementation and use of I.T. within professional settings\(^1\)\(^,\)\(^2\).

In part 2 we present the findings of the research. Here we ‘drill down’ by adopting an emergent approach to collecting data in order to identify where information was being shared across important healthcare boundaries. The report of the findings follows this ‘drilling down’ process. Chapter 4 reports on the organisation of the two LHCs, Walsall and Northamptonshire, and the informatics strategies that they have adopted. Chapter 5 presents the pathway mapping approach we adopted for the analysis of nine healthcare pathways, three in Walsall and six in Northamptonshire. The maps enabled us to summarise the ‘state of the art’ in sharing electronic information across the pathways and, as a result, six healthcare pathway cases were selected for investigation in more depth by exploring the experience of healthcare workers in these pathways. These are reported, two at a time, in Chapters 6, 7 and 8. For four of the cases we also explored the way the current e-health systems had been developed and these design histories are reported in Chapters 7 and 8. A key selection criterion was that of task dependency\(^3\)\(^,\)\(^4\) and the chapters are organised according to that principle as well as local contingencies.

Part 3 draws together the results presented in part 2 and discusses the ‘state of the art’ in providing e-health systems to support integrated care across organizational boundaries. In chapter 9 an analysis is made of the IT
strategies in place in the two LHCs to support integrated care and of the design processes by which specific systems are produced to support healthcare pathways. Chapter 10 presents a summary of all of the findings and identifies a number of key themes that need addressing in further research and in policy making if the challenges of providing e-health systems to support integrated care are to be successfully addressed.

The final part of the research programme was to feedback the results of the research to stakeholders in the two LHCs in an action research cycle; i.e. to provide feedback in a way that might influence further action in developing e-health systems. A presentation of this part of the programme is provided in Appendix 3 on the pragmatic grounds it meant we could remain within the official word limit for SDO research reports.
2 Research on the Design, Implementation and Use of e-Health Systems

2.1 Chapter summary

In this chapter we summarise the findings from previous research which has focused on the design, implementation and use of e-Health systems. We begin with an overview of large-scale, national programmes (UK, USA, Australia and Europe) and attempts to implement Electronic Health Record (EHR) systems (section 2), followed by an account of the types of strategies which have been used to implement healthcare information technology (section 3). We then examine in more detail the impact on front-line health care staff following the implementation of e-Health systems (section 4). Research focusing on the role of e-Health in supporting collaboration and exchange of patient-related information is reviewed in section 5. Particular attention here is given to care pathways. A final section introduces a set of additional constructs which are used to interpret the results from our case studies (chapters 4-9).

2.2 The implementation of large-scale, national Electronic Health Record (EHR) systems

Drives to implement large-scale e-Health systems such as EHR systems represent something of a ‘holy grail’ for many countries around the world. Despite huge investment on the part of health care providers in these countries, very few national-scale systems exist. The reality within most countries is that the EHR systems that have been implemented or are under development cover patient data from within their own organisational boundaries or regions. Sharing or exchange of electronic patient information across organisational boundaries represents the exception rather than the rule. At the same time, the urgent clinical need for large-scale national systems is being questioned more and more.

The primary driver for the implementation of national EHR systems is to improve the quality, safety and efficiency of affordable healthcare. This includes the perception that national EHR systems increase efficiency in healthcare organisation and delivery through (i) improved data sharing, (ii) improved data quality, security and availability, (iii) reduced errors, (iv) patient empowerment, and (v) time-savings for staff. Morrison, Robertson, Cresswell, Crowe and Sheikh argue that early evidence from national implementation programmes suggests that the problems...
associated with introducing EHRs on a small, local scale may be magnified several-fold in larger-scale implementations. In other words, there is a need to maximise understanding of the approaches that are being taken to implement EHR systems nationally, the rationale for choosing one implementation approach over another and early lessons that can be drawn from international experiences.

2.2.1 United Kingdom

Approximately 60 million patients in the UK have access to the NHS, each of these patients will have a healthcare record and the NPfIT was intended to provide healthcare practitioners in England with electronic access to patients’ records through the creation of the NHS Care Records Service (NCRS). This service includes two applications the Summary Care Record (SCR) and the Detailed Care Record (DCR). The SCR would allow healthcare providers in any part of the country to access electronic information on patient demographics and essential healthcare matters such as allergies and current medication. The Detailed Care Record was intended to provide all healthcare staff in a region with a comprehensive account of the healthcare history of each patient. It is this application that, if fully implemented, could replace the need for vaults of paper-based medical records to be held in hospitals. In 2009 the estimate for the full implementation of the Detailed Care Record was 2015, with some experts (e.g., Brennan) doubting that a full roll out of the programme would ever be achieved. Table 1 is a summary timeline of some of the key developments in the NPfIT for the time period 1998-2011 (based on Robertson, Cresswell, Takian, Petrakaki, Crowe, Cornford et al) and in 2011 the National Audit Office concluded that the DCR would not be fully implemented. Later in the year the Department of Health announced that the NPfIT would be dismantled.

Brennan reported that the objective of a single detailed patient record was not considered in initial planning but became a central requirement as the NPfIT was developed. Throughout the programme it proved to be the most challenging aspect of the NPfIT. It is estimated that the ‘roll out’ of the NPfIT across the country will have cost £12.4 billion and that it will require considerable additional staff, changes in working practices and training for the technical systems to be adopted by healthcare staff. The costs, however, were to be balanced against the expectation of very considerable benefits. It is argued that EPRs will have direct benefits through improved use of test results and reduced transcription costs by use of templates and structured flow sheets with more control over allocation of resources. Indirect benefits are also anticipated; the improved access to full patient information, and other information using internet resources; sharing of information between health care providers; improved patient safety by building in safeguards (e.g., reducing drug errors by highlighting inappropriate decisions); improved traceability and research access and allowing patient to participate with their own care by direct access to information.
Table 1. **NPfIT timeline 1998-2011 (based on Robertson, Cresswell, Takian, Pettrakaki, Crowe, Cornford et al.)**

<table>
<thead>
<tr>
<th>Date</th>
<th>Key Developments</th>
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<tr>
<td>1998</td>
<td>NHS Executive commits to detailed health records</td>
</tr>
<tr>
<td>2002</td>
<td>NPfIT starts, NHS IT Director appointed</td>
</tr>
<tr>
<td>2003</td>
<td>British Telecom (BT) awarded contract for the national data spine; Local Service provider 10 year contracts awarded</td>
</tr>
<tr>
<td>2004</td>
<td>BT awarded NHS broadband network contract</td>
</tr>
<tr>
<td>2005</td>
<td>NHS Connecting for Health (NHS CFH) set up to deliver NPfIT</td>
</tr>
<tr>
<td>2006</td>
<td>Withdrawal of major contractor (Accenture) from local service provision</td>
</tr>
<tr>
<td>2007</td>
<td>NPfIT Local Ownership Programme (devolves responsibility for local delivery of the programme from NHS CFH to local strategic health authorities)</td>
</tr>
<tr>
<td>2008</td>
<td>Major contract (Fujitsu) terminated, legal dispute continues</td>
</tr>
</tbody>
</table>
| 2009 | NHS CFH integrated with Department of Health Informatics Directorate  
Director of CFH Programmes and Systems Delivery resigns  
Parliamentary announcement of contract negotiations with major contractors – seeking NPfIT cost savings |
| 2010 | March deadline for deployment of Lorenzo (NPfIT EPRs) across acute trusts in UK not met  
May: UK general election – new coalition government |
| 2011 | May: National Audit Office Report concludes that ‘the core aim that every patient should have an electronic care record under the Programme will not now be achieved’  
September: Department of Health announces that the NPfIT will be ‘dismantled’ |
Surrounding the changes to the information technology were the many political changes within the UK which impacted upon NPfIT and the NHS as a whole (e.g., the recent election of the coalition government in 2010: see Table 1). Mark considers that the strategy adopted in the NPfIT has been dominated by political and IT industry perspectives and that the patient was not at the centre of the scheme. The programme for NPfIT required that a limited number of predefined technical systems were put into existing organisations where there were a huge variety of existing sociotechnical systems serving users who have different requirements. In the UK, many trusts were at the stage where some aspects of patient care were recorded electronically, such as test results or prescriptions, but the paper record remained the key form of documentation. The reasons for this may include lack of confidence in electronic systems, problems in data entry, and the existence of well-established work practices.

2.2.2 United States of America

Within the USA there has been an early, strong commitment towards involving multiple stakeholders (including patients) in decision-making regarding policy at local, federal and state levels. A key focus has been funded incentives to ensure basic standards of interoperability within the implementation of locally chosen systems. The role of federal government is evident in drives to implement government policy objectives, strategies and actions relating to data privacy and security, interoperability, adoption and collaborative governance.

An important potential barrier to EHR implementation in the USA is the risk of purchasing a product locally that does not allow for data exchange between different care settings. In order to deal with this, the Certification Commission for Health Information Technology (CCHIT) developed a set of certification criteria through a voluntary, consensus-based process engaging diverse stakeholders. By mid-2009, more than 200 EHRs had been certified by the CCHIT, which represented 75% of the EHR marketplace. However, both the American Medical Association (AMA) and American Hospital Association (AHA) have expressed concerns that the costs of EHR systems and meeting the requirements needed to qualify for the incentive payments might be out of reach for many American physicians and hospitals. While similarly broadly supportive of moves to develop and implement healthcare IT, the concerns of the AMA have focused on the privacy of EHRs and local implementation costs. As Wilson points out, in Morrison, Robertson, Cresswell, Crowe and Sheikh, large healthcare practices and hospitals could afford EHRs but many smaller ones – which were in the majority – could not. Such concerns were borne out in a recent study highlighting that only two per cent of USA hospitals reported having records that currently met the national Meaningful Use Criteria.

2.2.3 Australia
In 2000 a top-down MediConnect programme (based on the earlier Better Patient Medication Management System) had been intended to provide an Australia-wide, secure electronic system for medication management. In 2004 MediConnect was incorporated into another programme, HealthConnect,. HealthConnect was conceived as a national change management strategy, and was to include a move from paper-based records to standardised, digital patient records held at the point of care. The latest development within Australia is a new programme for Internet-based Person-Controlled Electronic Health Records (P-CEHRs). In the current P-CEHR plan, it is envisaged that from 2012/13, those patients who wish will have a secure access point (portal) through which to view information about themselves, stored on their various healthcare providers’ IT systems. The intention is that the P-CEHR webpage will show a health summary, containing the individual’s demographic information, medical conditions, medications and any allergies. It is also planned to show an index and searching function for accessing a range of personal healthcare information, such as referrals, test results and prescriptions. Access to summaries of detailed, personal information is expected to increase over time as more healthcare providers implement and adopt P-CEHR system data exchange functionality. Government investment and support for national infrastructure, governance, standards development and tools are to be combined with local choice and responsibility for compatible, clinical IT systems. The National E-Health Transition Authority (NEHTA) was set up in 2005 to drive the approach. NEHTA also leads the development of a security framework to control authorised access to data. A primary task for NEHTA at the moment is to continue to lead collaborative work with stakeholders to develop the national standards that will be necessary to achieve interoperability between diverse, existing and new clinical systems.

2.2.4 Within Europe

A recent publication from the European Commission (January 2011) reports that most European countries are attempting to implement some form of EHR or patient summary system. So far, however, a few countries have operational patient summary or limited, EHR-like services deployed at the national level. Denmark for example, launched its first eHealth/EPR strategy in 1996 and the use of electronic patient records is well established. Danish GPs and specialists now have access to patient data regardless of where it was created and almost all GPs’ offices are computerised. In the Czech Republic, the IZIP system provides a nationwide web-based EHR containing information on laboratory results, radiology reports, emergency care and other data where in-formation for more than 20% of the population are recorded and available to connected care providers if the patient agrees. In Sweden, a National Patient Summary (NPÖ) has been piloted since April 2008. The NPÖ contains current care contacts, personal information, chronic disease diagnoses, and medical alert information such as allergies, current examination results, and a list of dispensed drugs. In Bulgaria, a personal health record (eLAK) system has been integrated into the national health portal. eLAK is a
patient's web-based health data storage facility, where an emergency care data set and copies of prescriptions, immunizations, physician’s letters, X-rays, ECGs can be uploaded. Implementation of these pilot applications depends on a comprehensive assessment of their effectiveness and a detailed scale up strategy. There are current plans to link eLAK to hospital and GP information systems.

2.3 Top-down, bottom-up and ‘middle out’ strategies for implementing e-Health systems

Much of the current debate on large-scale, national e-Health systems has been taken up with discussions centred around ‘top-down’ and ‘bottom-up’ implementation strategies. Against the background of the top-down NPfIT attempts at implementation many UK NHS trusts have for example, resorted to developing their own ‘home grown’ solutions, which are partially electronic and partially paper-based and focus more on specific health care pathways or parts of them. This includes the Walsall case discussed in this report. This ‘bottom-up’ route to the development of electronic health records is now being more widely advocated; see, for example, the independent review of the NPfIT conducted by the British Computer Society Health Informatics Forum.

One of the dangers of ‘bottom-up’ or ‘home grown’ strategies is that data interoperability between systems can be difficult to achieve. However, it is increasingly possible for local systems to be developed in compliance with data handling standards that will permit the sharing of data with other systems. Coiera has characterised this as a ‘middle-out’ approach: neither top down nor bottom up but bottom up within an agreed framework of national standards and guidelines. Similar guidelines and standards need to be developed relating to data sharing and information exchange between healthcare staff and other agencies involved in the care of patients (e.g., social services). The ‘middle-out’ approach to EHR implementation is sometimes used to describe the approach taken by Australia whilst the UK and USA are viewed as interpreted as example of the application of top-down and bottom-up approaches (see Table 2).

Coiera (2009, 2011) has stressed the value of a ‘middle-out’ approach to the development of EHR systems and points to the following attributes of the approach and its realisation within Australia:

- The need to acknowledge that government and providers have different starting points, goals and resources;
- Stakeholders share agreements to agree on common health information technology functions, standards and strategy;
### Table 2: Characteristics of approaches to implementation of national EHR systems

<table>
<thead>
<tr>
<th>Approach</th>
<th>Examples</th>
<th>Characteristics</th>
<th>Problems</th>
</tr>
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| Top-down     | England  | ‘One size fits all’  
Standard architecture  
Standard compliance and procurement policies | ‘One size doesn’t fit all’  
No easy migration plan  
Non compliant systems shut down and replaced when local systems may fit user needs  
In order to meet emerging needs service providers will build workarounds added unwanted local variation to singular national design |
| Bottom up    | USA      | Service providers form coalitions to interconnect existing systems into regional health information exchange (HIEs)  
Standards not mandated but adopted in a business needs basis. Little central intervention.  
Legislation to protect privacy and interests of citizens | Incompatible data models may make reconciling information across different systems arbitrarily complex  
Unlikely to be aligned with national goals  
The price of preservation of local systems is a weaker national system which may have data holes and data quality problems |

- Providers bring existing systems up to national standards (e.g. customized interfaces);
- The end product has a rich capability for information sharing, resilient over time, preserves what works;
• The middle-out strategy allows government to pursue policy goals.

In order to realise the benefits of the middle-out approach Coiera\textsuperscript{30} argues that national governments need to carry out the following activities:

• Define policy framework to converge public and private, local and central systems into a functionally national system;

• Provide funding to the public sector to join the National health information system;

• Implement incentives for the private sector where the business case is weak but national interest is strong;

• Develop public goods e.g. standards, broadband, health informatics workforce);

• Implement legislation to protect the privacy and interests of citizens;

• Avoid as far as possible what governments are not good at (e.g. designing, buying or running large-scale IT systems).

Much of this has direct relevance to the fate of NPfIT and suggests a different policy direction than the one that underpinned that national programme.

2.4 Impact of e-Health on the conduct of health care work and working practices

Morrison, Robertson, Cresswell, Crowe and Sheikh\textsuperscript{5} argue that even on a small scale, the limited literature available suggests that, in practice, attempts to implement EHR systems in healthcare settings frequently encounter difficulties. The reasons for these difficulties are typically multi-faceted, most often resulting from a complex interplay between organisational, social and technical factors. In essence, however, they often reflect a failure to appreciate fully the disruptive nature of new IT systems, which can alter many aspects of healthcare professionals’ routine working practices and patients’ experience of care\textsuperscript{27}.

Marc Berg and colleagues in a series of papers\textsuperscript{31, 32} describe the implementation of information systems within health care work environments as a ‘politically textured process of organisational change in which users have to be put at centre-stage’\textsuperscript{32} (p.87). In particular, Berg argues that design should be informed by careful observation of actual work as it happens in the department, rather than rigid, pre-fixed notions of the organisation and content of the administration of medical records\textsuperscript{31, 32}. Furthermore, Berg stresses the need to move attention away from over-ambitious attempts to replace paper-based medical records and to ‘clean up’ medical decision making\textsuperscript{32} (p.96). An
important part of this argument is that system designers have focused too much upon what they perceive to be the need to invent information system 'solutions', whilst at the same time failing to recognise the skills which are already present in the actual practice and conduct of medical work. Berg and Toussaint\textsuperscript{33} use the example of the use of detailed work process modelling by system designers to illustrate the danger of underestimating the necessarily 'messy', flexible and 'fluid' nature of work practice, as compared to the types of formal, standardised models which are often characteristic with information systems development. Research from studies of work practice similarly emphasise the fact that use of e-Health and EHR systems evolves over time and is subject to considerable change. In many case these changes are difficult to predict and medical work is hampered by information systems which attempt to enforce strict, predetermined workflow models and 'rules of engagement' between medical professionals.

Further evidence of the impact of the impact of inflexible health information technologies on medical work is given by Harrison, Kopell and Bar-Lev\textsuperscript{34} in their analysis of the unintended consequences implementing EHR, CPOE (Computerised Physician Order Entry) and other types of decision-support systems within health care. They provide a number of examples of 'workarounds' where poorly designed technologies made it necessary for health care staff to ignore advice provided by the technology (e.g., system data entry requirements or authorisation requests) and invent ways of circumventing these. Harrison, Kopell and Bar-Lev\textsuperscript{34} put forward the Interactive Sociotechnical Analysis (ISA) model as a way of explaining why 'workarounds' occur so frequently as a consequence of using new technologies within medical work. The ISA model predicts that many of the consequences of using new health care technologies arise as a result of attempts to fit them into the existing sociotechnical system. Some of these consequences may lead to breakdowns in health care work, in other cases where the technology has been designed to support emergent patterns of use the consequences may not be so disruptive. Harrison, Kopell and Bar-Lev\textsuperscript{34} suggest that the key factor in ensuring that new health care technologies complement and integrate with working practices is to ensure that local requirements are addressed and users are consulted throughout the implementation, adoption and subsequent evolution of new systems.

\textbf{2.4.1 Research within the NHS}

Only a few studies in the UK have examined in detail the implications for working practices or the new flows of information within health care contexts that are likely to occur as a result of the NPfIT\textsuperscript{35}. Most studies within the UK describe broad conceptual frameworks for understanding the barriers and enablers of successful EPRs implementation\textsuperscript{6, 36} and the barriers that are identified tend to more concerned with issues raised by the healthcare users of the systems, e.g. what input load it places on them, what access they can have, how patient confidentiality is protected etc. Another feature of existing research in the UK is that it has tended to focus on specific applications (e.g., imaging technologies such as PACS – Picture Archiving and Communication System\textsuperscript{37})
rather than large-scale EPRs. Two of the most recent studies which have looked at larger-scale systems include research on the introduction of the NPfIT Summary Care Record (SCR) within the UK\textsuperscript{7,8} and implementation and adoption of the NPfIT Detailed Care Record (DCR) within secondary care\textsuperscript{13}.

Greenhalgh, Stramer, Bratan, Byrne, Russell, Mohammad et al\textsuperscript{6,9} analysed quantitative data relating to usage of the SCR within the UK as well as qualitative data in the form of an extensive set of interviews with policy makers, clinicians and software suppliers. Their findings indicated that SCR adoption rates have been slow and that uptake has been patchy. For example, a large number of primary care General Practice (GP) record systems were not compliant with the SCR. The reasons for this non-compliance included the costs of replacing existing GP IT systems, concerns about inadequate data quality, opposition to NPfIT and other competing priorities. Where the SCR had been adopted clinicians reported greater confidence in the quality of information in the record and the care given to the patient. Overall, Greenhalgh, Stramer, Bratan, Byrne, Russell, Mohammad et al’s study\textsuperscript{6} concluded that a set of complex set of interdependencies and tensions existed between the various stakeholders in the SCR (i.e., software developers, suppliers, NHS managers and NHS clinicians). The planned introduction of the SCR nationally (assuming this is taken forward by the new coalition government), was seen to be associated with increasing these already fraught tensions and relationships, alongside expected high implementation workloads for the stakeholders associated with the SCR.

Similar conclusions were drawn from the qualitative data gathered by Robertson, Cresswell, Takian, Petrakaki, Crowe, Cornford et al\textsuperscript{13} in their evaluation of the implementation and adoption of the Detailed Care Record (DCR). They found that implementation of the DCR within hospitals has been far slower than originally envisioned and that despite considerable delays and frustrations amongst clinicians, support for EPRs remains strong. However, convoluted communication channels, unrealistic deployment timelines and delays, alongside the recent announcement of plans to reorganise the delivery of care within the NHS as a whole (e.g., the move to GP Commissioning\textsuperscript{38}), were seen as major barriers which threaten to further jeopardise the introduction of the DCR. Robertson, Cresswell, Takian, Petrakaki, Crowe, Cornford et al\textsuperscript{13} conclude that a ‘middle-out\textsuperscript{29}’ strategy for implementing EPRs in the UK, combining government direction with increased local autonomy and restricting the sharing of health records to local health communities, may be the best way forward.
2.5 E-health systems and sharing of information across organisational boundaries

In general, little has been published in the field of e-Health on the subject of electronic patient information sharing across organisational boundaries. As indicated in earlier sections of this chapter, the focus of research has been on sharing information within one setting (e.g., GP surgery, acute hospital), rather than between health care organisations or specialisms. Within the field of Computer-Supported Collaborative Work (CSCW) much more work has been carried out, however, this has tended to focus on technological issues as outcomes related to the delivery of patient care. A set of recent international studies have focused on diverse issues concerning computer-supported collaboration and coordination in healthcare, e.g. designing applications to support digital clinical documentation\(^{39,40}\), investigating multidisciplinary team meetings within healthcare settings\(^{13}\) and researching information management in emergency medical service settings\(^{41}\). Typically, empirical CSCW studies have been characterised with a case or design study approach and focus on a selected organisational unit or a particular phenomenon (e.g. documentation practices) under research, thereby aimed at increasing the understanding of the role that collaboration plays in healthcare and the types of technologies that can support collaboration among healthcare professionals.

In the medical informatics field, studies have attempted to support healthcare technology development by researching the current changes and challenges from the end-users’ viewpoint and reporting summative findings on user acceptance, effects of technology implementation and usability evaluation. For example, recent review studies by Christensen, Faxvaag, Loerum and Grimsmo\(^{42}\) and Ammenwerth, Rauchegger, Ehlers, Hirch, Schaubmayr\(^{43}\) applied quantitative surveys to evaluate general practitioners’ use of EHR functionalities in clinical work and the effects of electronic nursing documentation system on nursing work. The questionnaire study by Christensen, Faxvaag, Loerum and Grimsmo\(^{42}\) showed extensive use of EHR systems and indicated that primary care systems were found to support clinical tasks far better than hospital systems. In their study on the effects of the nursing documentation system, Ammenwerth, Rauchegger, Ehlers, Hirch, Schaubmayr\(^{43}\) found improvements in many areas such as support for care planning and availability and completeness of documentation. On the other hand, mixed results were reported for time efforts for nursing documentation and the related impact on patient care.

Another viewpoint relating to communication comes from the clinical work itself: Professionals are supposed to rely on the information in the computer-based systems and must continually balance and integrate medical and organisational information in decision making. As illustrated by Reddy and Dourish\(^{44}\), the processes of seeking and providing information are seamlessly interwoven with other clinical working activities. These aspects have also appeared in recent studies. For example, Benham-Hutchins and Effken\(^{45}\) and Hertzum and Simonsen\(^{46}\) have researched the perceived effects of technology adoption on multi-professional
communication during patient handoffs. Based on their findings, the researchers suggest converting all the collaborating healthcare units to the EHR, electronic communication modules and asynchronous multi-professional communication logs\textsuperscript{45}. The introduction of electronic applications is also highly supported by Hertzum and Simonsen\textsuperscript{46}; based on their rather positive findings, they found the observed EHR system supports cross-disciplinary communication and coordination in two simultaneous ways: (a) through the EHR system, especially when used with laptops by patients’ bedsides, and (b) face-to-face at team conferences, where a shared display was used to support handoff activities. Alongside these findings, several studies show that collaborative healthcare information systems, such as EHR and computerised provider order entry systems, suffer from severe usability problems which make the systems difficult for the physicians and other clinicians to use\textsuperscript{47, 48, 49}. In general, one of the main concerns in EHR has been with the ease of use and the amount of time taken up by clinical documentation and record-keeping\textsuperscript{50, 51, 52}

2.5.1. The role of e-Health in delivering ‘seamless integrated care’

Information technology such as e-Health and EHR systems has the potential to provide a means of linking disciplines together and improving information sharing and exchange. One of the main conclusions from the NHS Next Stage Review (2007-08) led by Lord Darzi was the need to provide greater integration of primary and secondary care, as well as other organisations involved in the care of patients (e.g., community and social care). The vision involved greater levels of integration resulting in integrated care organisations which would bring together health and social care professionals from a range of organisations – e.g., community services, hospitals, local authorities and others, depending on local needs. The advantages of introducing new models of integrated care are seen as responding more effectively to the needs of patients with long-term conditions; ensuring more ‘seamless’ care for patients’; and, and improving the effectiveness and safety of care. The role of eHealth in delivering this vision is currently underexploited and needs to be better understood\textsuperscript{53}.

Research on the design of new models of integrated care and the potential role of information technology (e.g., Ham, Imison, Goodwin, Dixon, and South\textsuperscript{54, 55}; MacAdam\textsuperscript{55}) in shaping the redesign of care pathways, all point to the importance of balancing social and organisational alongside technical concerns. By far the most influential work in this area is Leutz’s model of integrated care\textsuperscript{56, 57} consisting of three levels: (1) linkage – integration which works on an ‘ad hoc’ basis and is characterized by fragmentation and loose coupling between care providers and specialists; (2) coordination - integration which involves organisations putting in place defined structures and processes to overcome fragmentation; and, (3) integration – the most radical form of
integration, which involves establishing new programmes and units in which resources are pooled and information shared\textsuperscript{58}. Kodner and Kyriacou\textsuperscript{119} used Leutz’s framework to evaluate two case studies of integrated care for the frail elderly. More recently Thistlethwaite\textsuperscript{60} has developed a framework for integrated care based on work carried out within the NHS at Torbay.

2.5.2. Integrated care pathways and information technology

The most notable development that has occurred within the NHS, which has direct relevance to delivering ‘seamless care’ has been the introduction of care pathways. This development represents two sometimes contested possibilities:

1. A professionally, typically nurse, led system designed to ensure high quality of care.

2. A management led strategy to re-engineer the organisation and delivery of good quality health and social care as efficiently as possible.

There is no reason why the two cannot co-exist, but equally, they indicate why care pathways cannot be seen solely as technical ‘devices’ for the delivery of integrated care. Instead, they are instruments that facilitate the integration of multi-disciplinary and managerial expertise for improving patient outcomes.

Allen\textsuperscript{61} (p.354) argues that care pathways represent the ‘classic example of a boundary object’ for they are ‘multidisciplinary care management tools, which map out chronologically key activities in a healthcare process’; they structure the relations between several different groups of social actors and technologies\textsuperscript{62}. In actor network theory terms\textsuperscript{63}, 64, care pathways can be inscriptions of care processes. The ‘instructions’ for the care and treatment of patients are delegated to the care pathway (whether as information technology or paper documents or a mix of both). These in turn remind, or instruct, the health professional, manager or patient, what is to be done (prescription). This provides the means of assuring a good standard of care for all patients, but at the price of potentially undermining the discretion (autonomy) of the actors involved. Care pathways are designed to provide a standardisation as well as a standard of care and in this respect they can be recognised as having their roots in the rationale of the ‘audit society’\textsuperscript{65}, 66. As Allen\textsuperscript{61} (p.354) explains:

*They are simultaneously a workflow system and a record of care. Unlike [clinical] guidelines, pathways specify the activities to be accomplished and require documentation to indicate compliance or non-compliance with the planned trajectory of care. Their growing popularity reflects the emergence of new modes of governance in the context of a shift away from trust in professional expertise to confidence in systems and auditable rules and procedures*
These pathways provide the means by which individuals can be held accountable for care delivered (or not) as well to support case management; to monitor the patient’s journey through primary and secondary care and across all the care boundaries (e.g. hospital discharge to intermediate care or home). Care pathways originated as a nursing tool for managing care with the consequence that nurses have gained a degree of jurisdiction over their use and development. They were first developed in the New England Medical Centre, Boston and were introduced in the USA to support managed care organisations in their attempts to control escalating health care costs and provided a tangible response to the increasing pressure from the healthcare insurers. As de Luc has pointed out care pathways go under a number of different names including:

- Anticipated recovery pathways
- Critical pathways
- Clinical algorithms
- Care maps
- Patient pathways
- Multidisciplinary pathways of care

The most common terminology in use, and the one which describes best the intent of this technology is ‘Integrated Care Pathways’ (ICPs).

ICPs constitute a reconfiguration of health care services that has the potential to dissolve organisational and occupational boundaries and rearrange the ‘communities of practice’. Thus community nurses, GPs, hospital specialists, social services may work together to design and deliver ‘ICPs’ that can effectively cross organisational boundaries. The driving logic for the growth of ICPs within the English NHS is much the same as North America, Australia and other European countries and that is to meet the challenges of the following: (a) a longer living population; (b) increasing costs of health technologies – including drugs; (c) rising patient and public expectations.

ICPs then are clever instruments premised on evidence based medicine and practice and clinical guidelines within the overall trajectory of care, but they have also become the vehicle for implementing e-patient information systems with the involvement of I.T. specialists. An issue here is whether the IT element is implemented to support the clinically defined ICP, or, the care pathway is (re)designed to best fit the managerial requirements possibly embedded within the IT system? This is an issue that comes up in the case studies (Chapters 6-8) and directly addressed in the final chapter.

ICPs, share a crucial logic with that set out in the 1997 white paper: The New NHS, Modern and Dependable, for while that document did not specifically
refer to pathways its commitment to provide ‘integrated care’ (ibid: para. 1.3) and general aims are ‘strikingly similar’\(^{68}\) (p. 76), \(^{72}\). Computer-based ICPs within Primary Care received a substantial push with the publication in 2002 of the National Service Framework policies. Here we find the firm advice from the DoH that ‘Information handling for NSFs is much easier with good use of computers’\(^{73}\) (p.4) (b) ‘Systems set up for one NSF can be applied to others’\(^{73}\) (p.4) and (c) ‘the time is right to consider more innovative approaches to referral via integrated care pathways’\(^{73}\) (p.6). All of which is underpins the reality that ICPs are becoming (or already become) the dominant mode of NHS organisation and service delivery mode on which the current commissioning model is largely based, for the model has the flexibility to redesign and improve services\(^{74}\), \(^{118}\). One needs to be careful, however, in citing ICPs as panacea, for as some observers, including Goodwin, \(^6\), Peck, Freeman, Posaner\(^{75}\), have pointed out, ICP development within the UK, has been ‘problematic and effectiveness often unproven’. While, there is some evidence of benefits to be had pathways take time to become embedded in practice. A key reason is that they are ‘highly context-specific and not necessarily transferable between organisations’, conclusions they draw from the work of Bryson and Browning\(^{67}\); Campbell, Hotchkiss. Bradshaw, Porteous \(^76\); Peters, Baxter, Pollard \(^77\); Goodwin, \(^6\), Peck, Freeman, Posaner\(^{75}\) also point out that the ‘prescriptive nature of the approach’ can alienate the doctors who then revert to their ‘traditional ways of working’, to quote Young, Kennedy, Davidson, Rayment\(^{78}\). ICPs are unable to design out all the tensions, or ambivalences, which can exist between various occupational and professional groups. This includes not between professional and managerial groups, including, Information and Communications Technology (ICT) people in the design and implementation of IT support for the pathways.

What ICPs offer – in principle - is a system to re-engineer the NHS\(^{67}\) (pp. 75-76) from a function- based system to a process driven service. It is an inter-organisational arrangement - effectively a network model - that interconnects different specialisms, services and facilities via what is essentially an information system, one which activates clinical, management and patient\(^1\) interventions at particular junctures. Where the ICPs are linked to an electronic patient record (EPR) they become eICPs and Crump\(^{80}\) (p. 5) argues can become:

more than just a passive route map for guiding a particular intervention[s], [they] become..., in the words of the NHS Information Authority Guidelines (2000): ‘not simply a question of computerising existing practice ... [but] should be seen as a business process re-engineering tool’.

\(^1\) An example of patient involvement would include, ICPs with telehealth support where, for instance, a patient with chronic breathing problems (COPD) is living independently at home with the support of community nurses who inter-leave their visits to the patient’s home with virtual ones\(^{127}\) (p.342)
This tool, however, has not been as powerful as the NHS Information Authority may have hoped and certainly less than was intended to be delivered by the National Framework for Information Technology programme (NPfIT). The reasons related to the inability to establish on a national basis an integrated e-patient record\textsuperscript{13}, or even gain agreement over the contents of the Summary Care Records (SCR)\textsuperscript{7,8} (see also 2.1 above)

2.6 Understanding the links between e-Health, work-based tasks and integrated care: interdependencies and task couplings

The literature on e-Health described in earlier sections of this chapter has focused on either broad strategies for implementing e-Health systems (e.g., top-down vs. bottom-up implementations) or more detailed studies of the impact of information technology on the working practices of clinicians and health care workers. As section 5 shows, few studies, at least in the UK, have examined how electronic patient information is shared across organisational boundaries. A number of potential areas within organisational psychology which have the potential to ‘bridge’ the gaps between broad and more focused accounts of the impact of e-Health systems lies within the field of organisational psychology. Thompson’s\textsuperscript{3} model of task and technological interdependencies for example, puts forward three types of relationship which determine the nature of information sharing in organisations, namely:

1. *Pooled task interdependence*

Organisational units that use mediating technologies lead to pooled interdependence. Progress by one unit is independent of the progress of other units. The demand for coordination is minimal. Rules and standard procedures provide enough information to align activities. Examples of pooled task interdependence are University departments and factory day and night shifts;

2. *Sequential task interdependence*

Tasks are performed in a sequential order wherein the progress of a worker earlier in the process determines the progress of workers down the line. The demand for coordination to prevent slowdown is greater than for pooled task interdependence. Planning and scheduling is required to optimise capacity utilisation. An example of sequential task interdependence are factory production lines;

3. *Reciprocal task interdependence*

The scope of a task is too large for one unit. Units must work together simultaneously to produce the desired result. Information must flow
between the involved units during the execution of the task to harmonise their efforts. This relationship, the most complex of the three task interdependencies, requires mutual adjustment as a coordination mechanism. An example is project-based teamwork.

A similar construct which aims to probe deeper into the nature of information sharing within organisation is Charles Perrow’s work on the nature of ‘coupling’. Perrow defines coupling as the amount of slack, buffer or give between two items. Loosely coupled systems are characterized by decentralized operations, mission orders, ambiguous performance standards and flexible control mechanisms. Change has little effect upon loose organizations. These types of systems allow a wide variety of responses during emergency situations. If something goes wrong, there is time to correct the problem without catastrophic consequence. Processes do not flow in rigid sequence. Tightly coupled systems are highly centralized and rigid. Output is closely monitored within specified tolerances and subsystems are interdependent. Tightly controlled time schedules with little slack are predicted according to Perrow’s theory to be sensitive to delays.

Discussion of the role of task interdependencies and coupling in shaping the nature of electronic information sharing in health care pathways is taken up in later chapters of the report (Chapters 9 and 10). In addition, we partly use the ‘top-down’, ‘bottom-up’ and ‘middle-out’ distinctions to interpret our findings. Finally, work examining the impact of e-Health on working practices is used to illustrate some of the findings as they relate to the various examples of the impact of e-Health systems on the day-to-day work of health care staff (Chapter 10).
3 The Research Design and Methods

3.1 Introduction

The research was designed to explore, by longitudinal study the barriers/facilitators in the development of e-health systems, their implementation and the outcomes achieved when used across organisational boundaries. This is a challenging but important area of systems work and health and social care practice for it is rare that e-health systems are truly compatible across such boundaries. We carried out the research within the Local Health Communities of Northants and Walsall teaching Primary Care Trusts (PCTs). Our methods were designed to capture the emergent practices and improvisatory behaviour commonly associated with e-systems2, 14.

3.2 The research design

The project studied the processes and experience of information management and technology (IM&T) specialists and health professionals implementing and using IT supported care pathways (‘e-care pathways’) that crossed organisational boundaries. The research design was a longitudinal, qualitative, socio-technical systems (STS) and organisational research and evaluation. In design, the research draws on grounded theory, but of the kind that has emerged post-Glaser and Strauss82, in particular Charmaz83, 84, for as Bryant85 (pp. 7-8), 86 has pointed out, in relation to Charmaz’s interpretation of grounded theory and its application to systems research: [t]he value of GTM [grounded theory method] lies in its guidance for the conduct of research... In other words we need to pay attention to what they do, rather than what they say they do’. But, GTM has other virtues too, as Orlikowski86 (pp 325-326) points out, for it is ‘inductive, contextual and processual’ or put another way our research has been ‘a process of engagement with actors-in-contexts85 (p. 8). This also means it fits well with the action research approach we adopted, which is all about engagement with the users.

Originally, the research was intended to include systems that were top down designed within the National Programme for Information Technology (NPfIT), but that national programme was waning rapidly by the start of the project (see Chapter 2) so we adapted our selection of cases to better reflect the reality within the two PCTs.

We adopted a five-stage research process, that started with a broad overview and then progressively focused in on specific systems and pathways. In brief, the stages consisted of:

(1) Understanding the role of informatics in the two PCTs.

(2) Mapping nine care pathways to plot the systems and identify the user communities of existing electronic care record systems.
(3) Studying user experiences in six selected pathways through interviews of boundary-crossing roles for patient information sharing.

(4) Following in detail system (re)development in four pathways.

(5) Engaging in ‘action research’ activities to develop a framework for the ‘practice’ of developing IT systems to serve pathways.

3.3 Outline of research methods

The methods of investigation were as follows:

- mapping IT supported pathways through discussion with, and assistance of, Information Management and Technology (IM&T) and informatics managers and business change and clinical change management (‘hybrid’\(^2\)) staff and health professionals,
- observations of information management and care pathways meetings
- interviewing I.T. and health professionals,
- action research workshops and meetings

3.4 Fieldwork – meetings, observations and interviews

We were delayed by the demands of the LREC processes and even when we did gain clearance were frustrated by (a) not being able to interview persons working within other organisations within the local health community\(^3\) and b) not having clearance to view electronic patient information or records. The latter was less of a problem than the former, as we were able to see ‘dummy’ systems in operation. Nevertheless, our research would be even more robust if we had been able to interview staff as they accessed e-patient information. This would be in order to better understand the physical system and check our understanding of participants’ accounts. We progressed the research in the first 12 months by concentrating on mapping the e-health systems and pathways with the Northants IM&T and Walsall Informatics staff, which was possible within the

\(^2\) ‘Hybrids’ here refer to IM&T/Informatics staff coming from a background in the health professions. See Dent\(^1\) and also Ashburner, Ferlie, and Fitzgerald\(^122\); Fitzgerald, Lilley, Ferlie, Addicott, McGivern and Buchanan\(^123\); Buchanan, Addicott, Fitzgerald, Ferlie, and Baeza\(^124\).

\(^3\) The procedures to gain clearance to interview non PCT staff were slow. We could not identify who we needed to talk with until we had mapped the pathways, but then it took months to get clearance.
constraints of the ethics research governance. We also drew up a history of the main systems and that of the IM&T (Northants) and Informatics (Walsall) departments and their organisation and commenced a review of the research literature.

Once we had LREC clearance we moved onto carrying out interviews. We discussed IT and care pathways with 44 persons (20 in Northants and 24 in Walsall). Of these 35 interviews were audio recorded and transcribed (17 in Northants and 18 in Walsall) with the remaining 9 discussions (3 in Northants and 6 in Walsall) being noted and not recorded. This was the preference of the participant or the researchers. These meetings were between 40 minutes and 2 hours duration.

We also attended Intermediate Care pathway e-health systems development meetings at Northants and similar Frail Elderly Pathway (FEP) meetings at Walsall over several months. These were intended to progress the implementation of the pathways and to try and ensure effective I.T. support. In two cases (Retinopathy and Stroke) there were no development activities during the research period and with the help of informatics staff we constructed a systems development history. Fieldnotes were maintained throughout. Action research workshops and meetings were noted. A wide variety of documentary evidence was collected and analysed. Field data and transcriptions have been thematically analysed to map the experience of users and the process of design to the organisation-spanning properties of the healthcare pathways. All meetings and interviews were conducted in accordance with LREC research governance approval.

A variety of emergent factors led the research team to review and revise the detailed way in which research aims were to be accomplished and a brief history of these decision points is provided in appendix 4.

### 3.5 The Case Studies

We will here discuss the rationale for the selection of the two PCT and the six care pathways, for this study which comprises two sets of case studies, one embedded within the other. First, there are the two PCTs within their LHC (e.g. acute hospitals, social care, private care homes) – the organisational case studies. Second, there are the six e-care pathways – the care pathway case studies.

#### 3.5.1 Organisation case studies

The study was based on a comparative organisations case study of two PCTs in the Midlands (Northants and Walsall). These were selected because both were implementing and planning to introduce innovative e-health solutions and systems and could be characterised as being at the forefront of e-health developments within the NHS. Moreover, they were actively developing solutions to cross-boundary sharing of patient information. Two
of our team were members of these PCTs, one (Dr Andrew Thornett) a GP and an officer of the Professional Executive Committee (PEC) and the other (Mr Phil Hurd) a member of the senior management of the IM&T department. Their role in explaining policy, organisation and in facilitating access was crucial to the success of this project.

There are differences between the two LHCs which are relevant to the development of effective e-health systems. Northants and Walsall, are characterised by substantially different demographic and urban/rural mixes. The population of the county of Northants is estimated to be 678,300 in 2007\(^88\) while the Walsall figure is less than half that number, estimated at 255,400 for 2008\(^89\). Walsall, unlike Northants has a large multi-ethnic urban population which is also reflected among the health professionals, particularly the GPs. Northants is less obviously urban than Northants consisting of a number of old towns (e.g. Northampton, Wellingborough, Kettering), with burgeoning populations. There are many more single-handed practices in Walsall than Northants, partly it appears because of the cultural expectations of the British Asian doctors and their patients\(^90\). On the other hand, Northants is served by two acute hospitals (Northampton and Kettering) while Walsall only has one (The Manor). All these factors indicate different levels and types of organisational complexity that will impact on the design and implementation of e-health supported care pathways.

3.5.2 e-Patient information systems and care pathways: case studies.

The e-patient information systems selected were those integral to care pathways. Effectively, e-patient information systems within the NHS are integral components of care pathways. The cases selected enabled us to identify the processes whereby the sharing of e-Health records between PCTs and related agencies may have contributed to improved clinical care of patients (aim 1). Each e-health system case study examined how they were implemented, adopted and how usage evolved (aim 2)

Initially (Stage 1) we mapped out 9 pathways from which we then selected 6 of these for detailed study (see Chapter 5). With one exception, we did not seek to match up pathways from the two LHCs as the comparisons were in terms of task interdependencies\(^3,4\) not the specific health categories covered by the pathways.

Our selection criteria took examples that included the following:

- they were characterised by each of the three kinds of task interdependencies (sequential, pooled and reciprocal\(^3,4\) [see Chapter 5]),
- crossed a number of different types of organisational boundaries internal and external to the PCT
- from both Northants and Walsall PCTs.
As a result of these criteria, and in discussion with local healthcare informatics staff, we initially selected the nine pathways to ‘map’ and then six for closer study. These six pathways were chosen because they focused on the experience of healthcare workers using e-health systems and their organisational implications.

The care pathways selected were the following:

- 1/2. Unscheduled care (Northants and Walsall) – pooled;
- 3/4. Stroke (Walsall) and Diabetic Retinopathy (Northants) - sequential;
- 5/6. Intermediate Care (Northants) and Frail Elderly (Walsall) - reciprocal.

The task interdependencies approach has some limitations in that it only deals with the functional correspondences along the pathways. Moreover, care pathways will exhibit a mix of task interdependencies, although in the cases listed here one type was always dominant. Despite caveats the model was found to be a practical way of characterising the range of care pathways and effectively differentiating between the relatively simple to the more complex processes. It was also a good basis to distinguish between systems for the purpose of comparative analysis based on an socio-technical systems methodology.

### 3.6 Data Collection and Analysis

In this study data was collected and analysed for two purposes:

- To capture user experiences with e-health systems
- To map e-health systems design and implementation practices

The approach we took to sampling, structuring data collection and analysing data in respect of these two purposes was as follows.

#### 3.6.1 User Experiences

For each pathway case study we sought a sample of users that represented the different roles and agencies that contributed to delivering the service and who needed to access and contribute to electronic patient data. The objective was to capture the diversity of needs for information sharing. A semi-structured interview protocol was used that examined (a) the role and responsibilities of the user in the pathway, (b) the e-health system functions that provided access and enabled the user to contribute to patient records, (c) the mechanisms that facilitated access, (d) the
benefits obtained for the pathway and (e) barriers to usage and issues arising from the use of the e-health systems.

The analysis of data focused on relating each transcript to the role of the user in the pathway, i.e. we sought to place the user’s experiences in the relevant sociotechnical context. We did not attempt to aggregate data across the sample because we feared it would become de-contextualised and important lessons for the range of user requirements that e-health systems have to meet would be lost.

3.6.2 Systems Design Practice

The data collected about systems design practice was drawn from semi-structured interviews, attendance at design meetings and documentary analysis. The aim was to create a timeline of project developments from project initiation to implementation and subsequent use. It was also to document the different locations in which design decisions were taken, i.e. from boardroom policy debates to local meetings between informatics staff and users. The protocol for organising and analysing data was informed by the design capability maturity literature initiated by Paulk, Weber, Curtis and Chrissis at Carnegie-Mellon University. Their initial work was on the software development process but the framework was extended by Eason and Harker to include multi-agency, socio-technical developments of the kind examined in this research. This framework identifies the issues to be addressed at each stage of project development from system specification through implementation to evaluation and evolution. Data was gathered about each e-health system project to examine what practices were in place to address the issues at each development stage. Further detail on the maturity framework used is provided in chapter 9.

3.7 Action Research

According to Ramirez and Bartunek an action research cycle involves:

- Systematically collecting research data about an ongoing system
- Feeding these data back to the system and conducting a collaborative diagnosis of the data
- Taking action based on the diagnosis, and
- Evaluating the results of the action.

The first phase of this cycle was the collection of case study evidence reported in chapters 6, 7 and 8. In the final period we fed back the data and worked with staff in both of the Local Health Communities (LHC) to
jointly consider the implications of the results for their future e-health systems development. In the time available there was no systematic evaluation of the results of the action. However, in appendix 3, we reflect on the achievement of two related purposes of this action research cycle and thereby undertake our own evaluation. The two purposes were:

- To feed our results directly into the ongoing systems development ‘action’ and provide a relevant evidence base that local developers could use in their future decision-making.

- To feedback our results to the wider community of relevant stakeholders in each LHC and thereby check the validity of the results and potentially enrich the evidence base by capturing the views of other stakeholders.

In practice, because feedback was in some instances up to a year after data collection, the action research process also served a third purpose, that of up-dating the research.

### 3.8. Concluding comments

The research design was sufficiently robust and adaptable for us to cope with the non-implementation of major NPfIT systems and the delays caused by the LREC process. Our study of e-patient information systems within the two PCTs has been grounded on an *inductive, contextual and processual* approach that bridges the sociological and socio-technical systems approaches that inform this research.
4 The Local Health Communities

4.1 Local Health Communities

Primary Care Trusts commission healthcare from a variety of agencies to serve the needs of the population in the area they cover. Although healthcare can be provided by agencies outside of that area, in the two examples in this research, the majority of the care is delivered by agencies within the area. There is consequently a Local Health Economy consisting of all the local agencies that are commissioned by the PCT to provide healthcare for the local community. It is the flow of electronic patient information between these agencies to support the ‘seamless’ delivery of healthcare that is the subject of this research. This chapter describes the various agencies that provide healthcare in Walsall and in the Northamptonshire. It also describes the informatics services that provide the electronic patient systems that are in use and the main features of their strategies in delivering these systems.

Some agencies that contribute to the local health economy did not feature in this research and are not included in the descriptions below, for example, dental service and pharmacies. However, some non-NHS agencies also contribute to local healthcare although their services are not commissioned by the PCTs. The relation between health and social care is a particularly significant issue and the degree of electronic information sharing between healthcare agencies and Social Services has emerged as an important theme in this research. Consequently, where appropriate, we have extended the range of agencies that we have considered beyond the boundaries of those funded by the PCTs. For this reason, throughout this report, we have adopted the term Local Health Community (LHC) to describe the many agencies that need to work together to provide healthcare services for their population.

4.2 The Walsall Local Health Community

4.2.1 The Agencies Within the Community

The Metropolitan Borough of Walsall is a compact urban area in the West Midlands. In March 2011 the health needs of the Borough were served by a LHC that consisted of:
• NHS Walsall (previously Walsall Teaching Primary Care Trust), responsible for commissioning healthcare services for the population of Walsall

• Walsall Hospitals NHS Trust which, through the Manor Hospital, a District General Hospital in Walsall, is the provider of secondary care in the area. 88% of patient admissions are from the Walsall area

• Walsall Community Health which is the provider of a range of community services

• 67 GP practices (155 GPs) many of which are ‘single handed’, i.e. having only one General Practitioner.

All of these organisations operate within a common geographical area that is co-terminus with the local council and with providers of social care and education. The LHC maintains extensive contacts with the local council in order to agree and pursue a common strategy for the development of the community.

Other organisations contribute to the LHC although they do not share the same geographical boundaries:

• The Dudley and Walsall Mental Health Partnership Trust which provides mental health services for the two boroughs of Dudley and Walsall

• The West Midlands Ambulance Service which, in addition to the greater Birmingham area, also serves Worcester, Hereford, Staffordshire and Shropshire

The local LHC has undergone a number of organisational changes in recent years. In October 2008 the Dudley and Walsall Mental Health Partnership was formed as a trust by merging the mental health services of the two boroughs. Prior to this mental health in Walsall was part of the local health community and was served by the informatics service described below. After 2008, it received its informatics service from a different provider. In 2009, as part of the separation of the commissioning and providing functions of Primary Care Trusts, Walsall Community Health was formed as an ‘arms length’ provider of community services and the commissioning function became the responsibility of NHS Walsall. On the 1st April 2011 Walsall Hospitals NHS Trust was integrated with Walsall Community Health to form a health economy wide provider service entitled Walsall Healthcare NHS Trust. Other changes are envisaged in the future if the proposals in the Government White Paper ‘Liberating the NHS’ are implemented when the commissioning responsibilities of NHS Walsall would pass to GP led consortia.

4.2.2 Walsall Informatics Shared Service
Formally part of NHS Walsall, the Walsall Informatics Shared Service is now a joint service for NHS Walsall, Walsall Hospitals NHS Trust and Walsall Community Health Trust and the Dudley and Walsall Mental Health Trust. It is not responsible for the patient record systems of GPs although GPs are able to access some of the systems the Walsall Shared Informatics Service provides.

The strategic mission of the Walsall Informatics Shared Service is to provide integrated informatics systems across the Walsall Health Community to support joined-up healthcare for the people of the borough. It has close strategic links with information services in Walsall local government and education to foster integrated services where health and other services need to be co-ordinated. It was established as an Informatics Shared Service Directorate for Walsall and Wolverhampton in 2001 but, from 2005, the Wolverhampton shared component was dissolved and work has since focused on Walsall.

The service supports a wide range of information systems many of which relate to patient care. It has a rolling programme of system developments, many of them enhancing and developing existing systems, broadening access to a wider range of healthcare staff and integrating the exchange of data between systems.

Walsall is served by the CSC-led consortia delivering the applications of the National Programme for Information Technology (NPfIT). At the outset of this research project, Walsall had implemented some of the applications in the national programme but not others; ‘Choose and Book’ had been deployed across all GP practices, PACS had been implemented in the Hospital Trust and the Community Health Trust deployed iPM, a PAS system. There were expectations that the summary care record (SCR) and the detailed electronic care record system, Lorenzo, would be deployed during the time period of the research but this did not occur in either case.

The Informatics Service had been at the forefront of efforts within the NHS to provide widespread access to medical records across the local health economy for nearly a decade. From 2000 to 2003 Walsall was part of the national Electronic Record Development and Implementation Programme (ERDIP) and, as a result of this, in 2002 it implemented FUSION. This is a system that delivers access to detailed medical records across the Walsall Health Community but by a different strategy than that employed by Lorenzo or other detailed electronic care records in the NPfIT. Whereas they are based on replacing the array of current systems by a single database system that all parts of the health community can access, FUSION is a web-based portal that gives a user access to the records of a patient held on a number of systems. It is an example of a middleware application used to link existing systems. The user enters the patient number from the master patient index and can then see a window that contains a ‘dynamic patient record’, i.e. up-to-date details about the patient held on a variety of databases, e.g. ward information, path lab reports, discharge summaries etc. In the ERDIP project FUSION was developed initially to provide detailed
pathway support for stroke patients. Subsequently it has been broadened to cover many other health conditions and at the beginning of this research period it had 4,500 users including hospital staff, GPs, community health staff and some users in the social services.

As a concept and as a practical example of a different way of providing access to medical records, FUSION has attracted considerable attention. In March 2003 it was awarded first prize for ‘Best Technological Innovation’ at the Healthcare IT Conference in Harrogate and it was part of an international evaluation project undertaken by an Australian research team\textsuperscript{94} (HealthConnect Program Office 2003). It remains the central plank of the integration work of the Informatics Service and, as such, was a focus for the ‘crossing organisational boundaries’ work in this project.

4.3. Northamptonshire Local Health Community

4.3.1 The Agencies Within the Community

Northamptonshire is a county in the south midlands of England. In March 2011 the major health agencies that provided services co-terminus with the county boundaries were:

- Northamptonshire NHS PCT which was formed in 2006 by a merger of north and south Northamptonshire PCTs to provide a single commissioner of healthcare for the county.

- Northamptonshire Provider Services. In 2009 the commissioning and providing services of the PCT were separated and Northamptonshire Provider Services was created to provide 66 local community healthcare services ranging from district nurses and occupational therapy to hospice services and community hospitals.

- Two Hospital Trusts:
  - Northampton General Hospital Trust
  - Kettering General Hospital Foundation Trust

- 82 GP Practices. Most of the GP practices are members of Nene Commissioning a well-established GP consortium that works closely with Northamptonshire NHS PCT on the provision of healthcare in the county. It holds the contract to provide GP Out-of-Hours (OOH) in the county.

- Northamptonshire Healthcare NHS Foundation Trust which provides mental health services for the county.

The East Midlands Ambulance Service provides emergency, urgent care and patient transport services for the six counties of the East Midlands including Northamptonshire.
The NHS Healthcare agencies co-operate with Northamptonshire County Council in the provision of health and social care, Children’s Services etc and with the Borough Councils of the main towns in the county where their services are relevant.

Major changes in the organisation of healthcare in Northamptonshire took place in 2006 and 2009 and another change came into effect on 1st April 2011 when 80% of the services of Northamptonshire Provider Services joined the Northamptonshire Healthcare NHS Foundation Trust. The other 20% of the services became part of the local authority. If the proposals in ‘Liberating the NHS’ are implemented there will be further changes in the future when Northamptonshire NHS PCT would be disbanded and responsibility for commissioning passed to GP consortia.

4.3.2 Northamptonshire NHS Informatics Services

Before 2006 there were separate IM&T (Information Management and Technology) Services in the North and South PCTs and in each of the two Hospital Trusts. The two PCT IM&T services merged when a single PCT was formed but, when commissioning and providing services were split in 2009, separate informatics services were formed in Northamptonshire NHS and in Northamptonshire Provider Services. With the splitting of Provider Services in April 2011, the IM&T Service joined the Northamptonshire Healthcare NHS Foundation Trust. It was already the provider of informatics services to this Trust.

The goal of creating electronic patient information services that can cross organisational boundaries and support seamless care is a major part of the IT strategy of Northamptonshire NHS. The first theme of its IM&T strategy is ‘Integrating Information and Processes across Northamptonshire NHS’ and central to this is the need to ‘develop informatics for clinical care across the LHE’. The major technical means of achieving these aims has been the deployment of SystmOne. This is a clinical database system that has been widely deployed in primary care. It has been in use in Northamptonshire for some years and has been adopted by Commissioning for Health (CfH) as an accredited system within the NPfIT. In Northamptonshire it is in use within Northamptonshire Provider Services and a programme of encouraging GP practices to adopt it is being pursued as part of the IM&T Strategy. 50% of GP practices had adopted SystemOne by 2011. The GP Out-of-Hours (OOH) service in Northamptonshire makes use of the SystmOne Out-of-Hours module. The strategy within primary care, therefore, is to develop patient information sharing by encouraging the use of the same system across different organisational units.

Other parts of the Local Health Authority also have electronic patient information systems. The two general hospitals have their own systems and, following the NPfIT, expected to see the ‘roll-out’ of Lorenzo during the time period of this research. This did not occur. The mental health trust, Northamptonshire Healthcare NHS Foundation Trust, uses a system called ePEX.
In addition to its deployment of SystmOne, Northamptonshire also makes use of other NPfIT applications, it has deployed Choose and Book for GP use and PACs in the two hospital trusts. It had not deployed the Summary Care Record (SCR) by the end of this research period but had begun preparations for its use.

4.4 Discussion

4.4.1 The Organisational Context

The delivery of healthcare in these two LHCs is the responsibility of a number of different organisations and ‘seamless’ care will require close co-ordination between them. Healthcare pathways cross many different kinds of organisational boundaries, some of which might be regarded as major boundaries, e.g. between the NHS and non-NHS organisations such as Social Services and private suppliers of healthcare, and others which are notionally less problematic, e.g. between two services operating within an NHS Trust. In the table below the main boundaries are listed. Since the organisational units have a range of names, e.g. service, clinic, hospital etc, we will describe them all as ‘agencies’. Within any agency, healthcare may be undertaken within a specific work role, e.g. district nurse. In mapping how healthcare is undertaken and the boundaries that have to be crossed it may be appropriate to specify both the agencies and the healthcare roles that are involved (Table 4.1).

It is one thing to find a means of sharing information across an organisational boundary. It may be quite another to achieve sustainable sharing across boundaries when the organisational fabric of LHCs keeps changing. It is notable that, following new national policies, there have been several major changes in the organisational structure of healthcare in both LHCs in recent years and further changes seem inevitable. How these changes have affected plans to develop durable technical structures through which information can be shared will be examined in later chapters.

4.4.2 The Informatics Services

Both LHCs have significant well-established informatics departments that have been working for years to provide electronic patient information systems in each trust and also to develop opportunities to share information between the agencies. There are, however, differences in the organisation of the informatics services in the two LHCs. In Walsall there is a shared service that bridges most of the healthcare agencies in the community. In Northamptonshire the different Trusts have their own IM&T departments and these departments have moved as the different trusts merge or split. Again, how the base from which the informatics service is delivered affects the degree to which information sharing objectives are accomplished will be examined in later chapters.
<table>
<thead>
<tr>
<th>Organisational Boundary</th>
<th>Description/Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>NHS to non-NHS organisation</td>
<td>e.g. to Social Services for social care</td>
</tr>
<tr>
<td>NHS to non-NHS contractor</td>
<td>A contractor, e.g. a private care home, that has been commissioned to deliver a healthcare service</td>
</tr>
<tr>
<td>NHS Trust – NHS Trust</td>
<td>e.g. Primary to Acute Trust</td>
</tr>
<tr>
<td>NHS Trust – GP clinic</td>
<td>Each GP is a separate business and may or may not use a system compatible with that used by an NHS Trust</td>
</tr>
<tr>
<td>NHS services within a Trust</td>
<td>Each service, department or speciality may have its own protocols etc even if they all make use of a common electronic system</td>
</tr>
<tr>
<td>Different healthcare roles or specialities within an agency</td>
<td>Each healthcare role may have different information needs and different access to patient information</td>
</tr>
</tbody>
</table>

Table 4.1 Organisational Boundaries in Local Health Communities

4.4.3 The Provision of Electronic Patient Information

Each Trust in each of the LHCs already has an electronic patient information system of some kind and they have a range of computer applications specific to the healthcare work they do. Since the inception of the NPfIT they have also deployed some applications of the national programme, notably Choose and Book and PACS. By the end of this research period they had not deployed the SCR. The deployment of Lorenzo, as the detailed healthcare record system offered by CfH particularly for secondary care, has been delayed beyond our research period. However, in both LHCs there are significant developments to examine that provide ways of sharing detailed patient records across organizational boundaries. Furthermore, the two
LHCs have adopted different strategies which may have different implications for what can be shared by whom. In Northamptonshire, in the community provider trust and in some of the GP practices, SystmOne, now part of the national programme, is being deployed and makes it possible for those making use of it to share patient records. In Walsall each Trust keeps its own systems but, via the web-based portal FUSION, patient records held on some of these systems can be viewed by users in many parts of the LHC.
5. Mapping Current Healthcare Systems

5.1 Introduction

The first stage of the research was to examine how patients moved between agencies in the LHC in order to identify where integrated care was necessary and where e-health systems might usefully support this process. An initial scoping exercise was undertaken with the informatics staff in the LHCs to map the way the different healthcare agencies related to one another. This high level map was then used to identify a number of specific healthcare pathways within which particular agencies needed to co-operate to provide integrated care. This chapter introduces and gives an example of a mapping process that was created in order to display the links between the processes within each pathway, the agencies that needed to co-operate in the delivery of care and the e-health systems that supported the sharing of patient information.

5.2. The Local Health Community and Organisational Boundaries

Although the specific organisational arrangements were different in the healthcare communities, the overall functions performed were similar. Figure 5.1 is a simplified representation of the common underlying structure.

The first point of contact for the patient is usually the GP clinic in which they are registered and most scheduled appointments are made with their GP. There are, however, a number of other agencies to which the patient may turn for unscheduled care – GP Out of Hours, Walk in Centres, A&E, Ambulance Services and NHS Direct etc. From these initial contacts, patients may be referred to local Acute Hospitals who offer a wide range of specialist treatment in out-patient and in-patient services. On discharge from the Acute Trusts or by referral from GPs and others, the patient may receive care in the community. Walsall Community Health offer 73 specialist services and Northamptonshire Provider Services offer 66. Care may also be provided by a Mental Health Trust or other providers who may be charities or private companies. Social Services may also be involved as social care is provided for the patient. It is, of course, possible that patients may be referred for care outside the LHC, for example, to hospitals that offer a national service in a particular specialism, but the great majority of patient journeys take place within the local health community in which they are resident.
There are, therefore, a multitude of different services and organisations associated with each LHC and a typical patient journey may involve quite a number of them.

The overall task of caring for patients is sub-divided in a variety of ways in this structure and, if a patient is to be treated in a co-ordinated way, the sub-divisions create different kinds of task interdependencies between the agencies involved. We utilised a classification developed by Thompson\(^3\) to look for different kinds of task interdependencies and to explore their implications for information sharing. In figure 5.1 three different kinds of task interdependency are identified that have to be managed across organisational boundaries.

### 5.2.1 Pooled Interdependency in Unscheduled Care

When there is pooled interdependency in a shared task, different activities can be pursued independently but all engaged in the activity share a common resource pool. In the local health community the most obvious example of pooled interdependency is the provision of a number of front line healthcare services to which patients can turn – their GP, GP out-of-hours, Walk-in-Centres, A&E, NHS Direct, Accident and Emergency etc. Although each can deal with a patient independently they are all part of the NHS and should deliver care according to the same standards and procedures. It can be argued that they should also have access to the same electronic patient records in order to ensure they deliver good quality healthcare.

### 5.2.2 Sequential Interdependency in Handovers and Referrals

Sequential interdependence occurs when one agency completes its work on the task and passes it to another agency for them to undertake their work. Obviously the quality of information in these ‘handovers’ affects the degree to which the overall task can be effectively undertaken. In the LHCs it is very common for patients to be referred from one service to another, especially in the referral of patients by their GPs for specialist services in acute care and to all the services that community care offers.

### 5.2.3 Reciprocal Interdependency in Shared Community Care

Reciprocal interdependence is the essence of close teamwork, when different agencies have to co-ordinate their task activity with the work of other agencies in the same timeframe. There are many examples in healthcare where this kind of close teamwork is essential, for example, surgeons, anaesthetists, nurses and technicians working together in an operating theatre. However, in the LHC there are also many examples of multi-disciplinary, multi-agency teams coming together to provide healthcare for a patient at home where boundaries between agencies have
Figure 5.1: The Local Health Community

to be managed for effective joint working to occur. In these forms of ‘shared health and social care’ the ability to share patient information in real-time could well have an impact on the co-ordination of healthcare for a patient.

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5.3 Healthcare Pathways: Methodology for Sampling and Mapping

In order to explore the way in which electronic patient information systems are currently used to support healthcare that crosses organisational boundaries, we needed to look in more detail at particular situations where integrated care was necessary. Healthcare pathways constitute major routes by which patients move between agencies in the LHCs and we decided to focus on a sample of pathways that included the different kinds of task interdependencies described above. That raised questions of sampling, data collection and pathway mapping.

5.3.1 Sampling  Only a small number of pathways could be studied in detail and the priorities in selecting them were:-

- Examples that cross a number of different types of organisational boundary
- Examples that are characterised by each of the different kinds of task interdependency
- With one exception, we did not seek to select the same pathway in the two Local Health Communities because we are not attempting to make a direct comparison between them. It was more appropriate to get examples from across the range of pathways.
- Examples where e-health systems were being used and/or were under development

As a result of these criteria, and in discussion with local healthcare informatics staff, the following nine pathways were selected to ‘map’.

- As examples of pooled interdependency; unscheduled care in both Walsall and Northamptonshire
- As examples of pathways dominantly sequential in character; the Stroke Pathway in Walsall and Elective Hip Replacement, Multiple Sclerosis (MS) and Diabetic Retinopathy Screening in Northamptonshire
• As examples of pathways with strong elements of reciprocal interdependency; the Frail Elderly Pathway in Walsall and Intermediate Care and Palliative Care in Northamptonshire

5.3.2 Data Collection

In order to map the nine healthcare pathways we consulted informatics staff, process managers and clinical change facilitators and, where possible, held workshops to work through the process. We also collected process diagrams, organisational charts and system descriptions of the pathways. From these we constructed pathway descriptions using a standard template devised for the purpose. Lastly, we reviewed the pathway diagrams with the healthcare staff concerned to ensure there were no gross errors, for example, in the case of Palliative Care we interviewed a senior member of hospice staff.

5.3.3 Pathway Mapping

There are many pathway maps in the NHS but, this research, required a particular kind of map. Many of the existing maps were prescriptive and specified an intended or optimum healthcare pathway. Our informants told us, often with great emphasis, that healthcare was emergent, very dependent on the condition of the patient, and actual pathways were very varied and were often at variance with the prescribed route. For an information system to be useful it has to support healthcare in all its forms and we were therefore concerned to map the reality of practice. Many of the pathway maps also gave more emphasis to one aspect of the healthcare service than others; there were, for example, process maps that told us little about the organisations and agencies that delivered the process or information systems diagrams that told us little about the healthcare process. This research is about mapping the couplings between agencies that undertake healthcare and the process of healthcare and the couplings between the technical information systems and the healthcare agencies. Any maps, therefore, had to be sociotechnical representations of all three elements and the relationships between them.

With these requirements in mind the template constructed for pathway maps:-

• depicted the major activities in the pathway and the relations between them

• identified the agencies (and where possible the healthcare roles within the agencies) that undertook each of the major activities

• listed the electronic patient information systems available to each of the agencies that could be used to support each of the activities and where these systems made it possible to share information across agencies.
since sharing of information has traditionally been accomplished by non-electronic means, we added other major forms of communication that were in use.

Healthcare delivery is complex and it would have been easy to create large and complicated maps that went into great detail and tried to represent every kind of contingency. To avoid this we constructed top level maps (with a pragmatic criterion that it should be possible to present each on an A4 page) that show how the healthcare process, in all its forms, is contained, i.e. the major activities to be undertaken and the agencies responsible for handling whatever exigencies may arise. Where necessary to understand what happens across a particular boundary we also mapped parts of the pathway in a greater degree of detail.

In total we mapped nine pathways. One of these pathways, elective hip replacement, is presented below as an illustration of the mapping process.

### 5.4 An Example of a Pathway Map: Elective Hip Replacement

The main elements in this map are (i) the healthcare activities and the interdependencies between them, (ii) the agencies, organisations and work roles that undertake the healthcare work and (iii) the electronic patient information systems that support them in their work.

#### 5.4.1 The Interdependencies in the Pathway

The Hip Replacement pathway is primarily a sequential process with a number of ‘handover’ points as the nature of patient care changes. At these points there is a need for an administrative process, e.g. bookings, and the transmission of demographic information, along with specific and current clinical information about the medical condition of the patient and requests for specific treatments. There is, however, some sharing of care between agencies during some of the major activities producing a need for teamwork to deal with reciprocal interdependencies.

#### 5.4.2 The Organisations, Agencies and Work Roles Involved.

The process begins with the GP and, if the patient does not reach the criteria for hip replacement, a referral may be made to a Pain Clinic, a service offered by Northamptonshire Providers who provide a range of community based services. This constitutes a sequential interdependence (a handover). When the GP considers the patient has reached the criteria for hip replacement, a referral is made to the Clinical Assessment Service, (another community based service) where doctors make an assessment.
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<tbody>
<tr>
<td></td>
<td>Patient to GP. Does meet criteria for hip replacement or Does not meet criteria – refer to physiotherapist or pain clinic</td>
<td>Patient attends for diagnosis</td>
<td>Pre-admission Surgery (hip replacement)</td>
<td>Admit to community rehabilitation</td>
<td>Support for discharge process</td>
<td>Patient discharged from Intermediate Care Team</td>
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<td></td>
<td>Linked Pathways</td>
<td></td>
<td>In-reach discharge</td>
<td>Social care referral</td>
<td>Social care package in place</td>
<td>Social Care</td>
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<td>Pain clinic</td>
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<td>Out-reach discharge</td>
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<th>Community Rehab Team</th>
<th>Inter-mediate Care Team</th>
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<th>Sequential</th>
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<th>External Sequential, Internal Reciprocal</th>
<th>Sequential</th>
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<tr>
<th>Communications</th>
<th>Internal – paper referral</th>
<th>External – Choose &amp; Book to Pain Clinic or Assessment Service</th>
<th>Choose &amp; Book correspondence to patient</th>
<th>Paper medical notes sent</th>
<th>Discharge summary sent</th>
<th>SystmOne record shared</th>
<th>Discharge summary sent</th>
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<th>IT Systems sharing possible</th>
<th>GP alternatives: SystmOne PACS</th>
<th>SystmOne PACS</th>
<th>SystmOne PACS</th>
<th>SystmOne</th>
<th>SystmOne</th>
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<td>Vision EMIS Anglia ICE</td>
<td>Anglia ICE</td>
<td>Acute Trust alternatives: iPM ICIS Lorenzo ELMS ePEX CareFirst</td>
<td>CareFirst</td>
<td>CareFirst</td>
<td>CareFirst</td>
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Figure 5.2 Elective Hip Replacement in Northamptonshire
and, if necessary, help the patient choose a hospital for the operation. There is then a referral to a secondary health trust hospital (if it is in the local health community it will be Kettering or Northampton General Hospitals) where the surgery is preceded by an administrative process and pre-operative clinical work. After the surgery and immediate recovery care, a discharge process is begun by the hospital outreach team. There will be a degree of reciprocal interdependence at this stage within the hospital as they work to both treat the patient and prepare for discharge. The patient may be transferred to a Community Rehabilitation Team at a Community Hospital for a further period of recovery. At this stage Social Care may become involved to develop a health and social care plan for the patient’s return home. Healthcare in the Community Hospital is in the hands of local clinical staff but the planning of future care requires integrated work by clinical and social care staff. There are some elements of sequential interdependence here along with some reciprocal interdependencies. When the patient goes home, the Intermediate Care Team are responsible for their health until such time as the patient is fit enough to return to the care of the GP. Throughout this period the Intermediate Care Team will need to liaise with Social Care to provide an integrated care package.

5.4.3 Information Sharing

Although each agency has an electronic patient information system, much of the sequential processing between agencies is done through the transmission of paper documents. Where the agencies have a common electronic information system, there is the possibility that handovers will be supported by electronic sharing of information. SystmOne is being used within the provider services and in some GP practices. If, for example, the GP is using SystmOne for patient records, the services that are part of Northamptonshire Providers (the pain clinic, the clinical assessment service, the community hospital and the intermediate care service) will all, with the permission of the GP, be able to access the GP patient’s record and add to it as they provide their service to the patient. In this scenario only the Hospital and Social Care do not have access to the GP records. If the GP uses EMIS or another system (or does not give permission to share the patient’s record), a SystmOne record will be created in community services as the patient moves through the pathway. Similarly, the hospital will create its own electronic record (and possibly add it to any record the hospital has as a result of previous admissions of the patient). There could, as a result, be three different detailed electronic patient records with no opportunity for data interchange. Some of the referrals are made using specific computer applications, e.g. Choose and Book to make a hospital appointment or PACS may be used to share access to X-ray images.

In summary there are many handovers in this pathway and, unless SystmOne is a shared system, it is likely that patient information will be collected in different electronic patient information systems and that communications between agencies will be in paper form.
5.5 Selecting pathways for further study

Of the nine pathways mapped, six were selected for the next stage of research in which the experience of using e-health systems is explored with the staff delivering care in the pathway. The selection was made by choosing (1) three pathways in each LHC, (2) one in each LHC that was an example of pooled, sequential and reciprocal forms of task interdependency. This led to the sample in figure 5.3.

<table>
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<tr>
<th>Interdependency</th>
<th>Walsall</th>
<th>Northamptonshire</th>
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<td>Unscheduled Care</td>
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<td><em>Chapter 6</em></td>
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<td>The Stroke Pathway</td>
<td>Diabetic Retinopathy Screening</td>
<td>Elective Hip Replacement</td>
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<td><em>Chapter 7</em></td>
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<td>The MS Pathway</td>
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<td></td>
<td><em>Appendix 1</em></td>
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<td>Reciprocal</td>
<td>The Frail Elderly Pathway</td>
<td>Intermediate Care</td>
<td>Palliative Care</td>
</tr>
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<td></td>
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Figure 5.3

The Sample of Healthcare Pathways

Maps of the two remaining pathways (palliative care and the MS pathway) are provided in Appendix 1.

5.6 Conclusions

This mapping of the electronic patient information system support in nine healthcare pathways suggests that a complex situation currently exists. Many electronic systems exist to support the different agencies involved in the pathways but only occasionally is it possible for them to share the information they hold. Who actually needs to share information and what they need to share is very much a property of the characteristics of each pathway. It is necessary to ’drill down’ to particular agencies in particular
pathways to ask what kind of patient information they need and whether the current electronic information provisions for them are enabling them to work effectively with their colleagues in the pathway. The six cases presented in the next three chapters seek to answer this question.
6 Pooled Interdependencies in Unscheduled Care

6.1 Shared Access to Patient Information

There are circumstances when many healthcare agencies need access to patient information and it will need to be ‘pooled’ for many people to use. An example is unscheduled care in which a patient may visit a variety of healthcare agencies that, unlike the patient’s GP practice, have no prior knowledge of them. The information these agencies may be able to obtain from patient records held by others may thus be of great value. Providing such information involves the creation of a ‘many-to-many’ information system, i.e. information about patients held, for example, in GP practices needs to be made available for the use of many, for example, A&E, Ambulance Services, GP out-of-hours services, Walk-in Centres etc.

At the beginning of this project it was intended that both local health communities (LHCs) would ‘roll-out’ the Summary Care Record (SCR) system of the NPfIT during the course of the project. The SCR system is intended to up-load a summary of each patient record from GP records to a database. The summary includes medication, allergies and adverse reactions and is then to be made available to healthcare staff in unscheduled care settings. In the event, delays in the deployment of the SCR meant that it was not rolled-out in the two LHCs during the project. At the end of the project in April 2011 GP practices in both LHCs were notifying their patients about the implementation of the SCR during 2011 in order that patients could opt-out of having their records up-loaded to the system if they so wished.

Although the SCR was not deployed, electronic patient information from a variety of sources is available to healthcare staff in unscheduled care agencies in the two LHCs and, in this chapter, we examine what is available, what advantages it brings and what kinds of problems and issues it leads to.

6.2 The Walsall Unscheduled Care Pathway

6.2.1 History

Walsall has an A&E Department at the Manor Hospital and located next door is the WALDOC (Walsall Doctors on Call) Centre where a GP is available to see patients. Out of hours, the A&E Department and WALDOC become an Urgent Care Centre. Visiting patients are directed by reception either to A&E or to an out-of-hours doctor in the WALDOC centre. There is
a separate Walk-In Centre in Walsall and also a GP Out-of-Hours Service (OOH). Each NHS agency has its own electronic records for patients but the main shared system is the FUSION portal which provides all these agencies with access to the patient records held in the Manor Hospital system. At the time of the study FUSION did not provide access to any information held on GP record systems. However, it is planned that later in 2011 the information that would have been in the SCR will be uploaded from GP records and made available through the FUSION portal. GPs providing out-of-hours services use the Adastra system to record patient episodes, make referrals and report back to patients’ GPs. If a patient has used the out-of-hours service on a previous occasion, Adastra will hold a record on the patient that may also be of value to the clinician.

6.2.2 Information Sources Discussions with informatics staff led to the formulation of the pathway described in figure 6.1 below. Four interviews were undertaken with GPs, two with experience of out-of-hours consultations. Shadowing and interviews were undertaken with two members of GP practice staff and interviews were undertaken with two medical staff who were able to report A&E experience of unscheduled care. Two meetings were held with the Local Medical Committee during which discussions of unscheduled care were undertaken with up of 40 GPs on each occasion.

6.2.3. Mapping the Pathway

This process exhibits pooled interdependency between the many places where unscheduled care might take place and the many places, especially GP practices, where patient records might be held. The ‘pooled’ phase is followed by sequential interdependency as reports are passed to GP practices and others. More detailed accounts of the organisations and agencies involved and of the e-health systems that serve them and given in the section below that reports the experience of use of e-health systems by many of the agencies involved.

6.2.4 Experience of Use

Experience of use is reported from two perspectives. First, the conduct of unscheduled care in A&E and by the out-of-hours (OOH) GP service and, second, the subsequent reporting of these episodes to the patient’s GP.

6.2.4.1 Unscheduled care settings

FUSION is the only source of electronic patient information for most unscheduled care clinicians (OOH GPs may also find a patient record in Adastra). Whether a record exists in FUSION depends on whether the patient has had previous hospital visits and the record could well be quite old. However, clinicians could cite examples where it had been useful. They reported that, particularly in the case of ‘frequent flyers’, it may well be worth looking at the electronic record in FUSION. OOH respondents also reported examples where, if a patient had previously used the OOH, the
<table>
<thead>
<tr>
<th>Pathway</th>
<th>1.1 Patient call A&amp;E</th>
<th>1.2 Patient call Out-of-hours</th>
<th>1.3 Patient call Walk-in Centres</th>
<th>1.4 NHS Direct</th>
<th>2.1 Patient Follow-up in GP Clinic</th>
<th>2.2 Patient Follow-up in Community Care</th>
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<tbody>
<tr>
<td></td>
<td>Assess, Treat and Refer</td>
<td>Route, Assess, Treat and Refer</td>
<td>Assess, Treat and Refer</td>
<td>Assess, Advise Route, Refer</td>
<td>Up-date records &amp; follow up as necessary</td>
<td>Up-date records &amp; follow up as necessary</td>
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<td>Linked Pathways</td>
<td>Hospital Admission</td>
<td>OOH, A&amp;E</td>
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</tr>
<tr>
<td>Roles and Agencies</td>
<td>A&amp;E staff: Nurses, Doctors, Admin staff</td>
<td>Call Centre staff</td>
<td>Walk-in Centre staff: Nurses, Doctors</td>
<td>Admin staff Nurse call centre staff</td>
<td>GP Clinic admin staff</td>
<td>Community matron/nurses, admin staff</td>
</tr>
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<td>Pooled, Many to Many, Internal sequential</td>
<td>Pooled, Many to Many</td>
<td>Pooled, Many to Many</td>
<td>Sequential, Many to Few</td>
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<td>Telephone</td>
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<td>IT Systems Information access possible</td>
<td>FUSION Clinical alert STAR PAS</td>
<td>FUSION Adastra EMIS</td>
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**Figure 6.1**

The Unscheduled Care Pathway System at Walsall

Adastra record was helpful to the GP particularly in reducing the amount of history taking that was necessary.

We asked respondents in what ways the current provision of information was helpful and, if relevant information was not available, in what circumstances the lack of access mattered in treating the patient. These questions drew a variety of responses. For some clinicians that have been used to managing with what the patient could tell them, the cost of creating...
and using shared electronic records seemed to outweigh their usefulness. But others were keen to point to circumstances where they really needed access to patient records:

*The elderly person who comes in and is confused. Those with complex conditions, and those that... visiting someone from...perhaps from abroad. ... Without knowing their past history it can be very difficult...*

OOH GP

A&E can be presented with special difficulties because the patient may be very ill. One casualty member of staff reported that in most cases they could get the information they needed by talking to the patient and from electronic patient information

*...you are only really talking about people who can't communicate in English, or can't communicate verbally because they are unconscious.....*

Clinician in A&E

Another A&E member of staff reported how useful the FUSION system could be when the patient had a recent medical history because it contained a recent history of all the test results, PACS images etc.

But whilst the information currently available could be useful, interviewees identified many circumstances where it was not adequate and where access to up-to-date GP records was the only route that would have been useful. One A&E clinician recounted a case in which a patient was admitted as an emergency and, although he had recently had blood tests done at a different hospital, they could not get the results quickly.

*We didn't have them, and as a result we did have an adverse effect on the outcome of this patient.*

A&E Clinician

This A&E clinician stressed the need for summary information to be available quickly because of the 4-hour target A&E had to work under:

*We need quick access to their past history, medications, allergies etc., Some of it we can get through our own systems via FUSION but for a new patient,... we need access to GP records*

A&E Clinician

An OOH GP reported a rather different value such access could have. He had a patient who had worked out that there was no communication between OOH and her own GP and got both of them to prescribe inhalants. In this case, an electronic record would work to prevent patients ‘playing the system’.
Most respondents could identify a minority of circumstances in which access to electronic patient records would be useful – in most cases, however, they used their experience to obtain the information they needed from the patients. The electronic resources they had available at the moment, through FUSION and Adastra, gave useful information on occasions but it was fairly ‘hit and miss’ and a reliable route to GP records would be much more widely useful. However, one GP sounded a cautionary note about access to greater volumes of electronic patient data. Suppose you did not have time to check it all and there was an adverse outcome for a patient that might have been prevented had you searched everything available. Could the clinician be deemed to have failed in his/her duty because significant information was available to them and they did not use it?

### 6.2.4.2 Reports from unscheduled care received by GPs.

OOH doctors summarise patient encounters in Adastra for transmission to the patient’s GP. Reports from other unscheduled care agencies such as A&E are recorded on other systems and are also sent to the GP. In addition to accounts from unscheduled care, information about patients also arrives from other sources; discharge summaries from hospitals, reports from consultants from out-patient clinics, test results etc. They are nearly all produced in electronic media but in only a few cases can they be sent directly to the GP in a form that can go directly into the patient’s record. They most often arrive as email attachments, by fax or in the post and are added to the collection of other letters being received for other reasons from other sources.

The GPs reported favourably on electronic communications because they speeded up the rate at which they got information. This was particularly true for the information they could get via FUSION, e.g. electronic discharge summaries. Getting information quickly could be important if action needed to be taken and they did need it before the patient came into the practice. Getting the information electronically was also welcomed because it might help cut down the volume of paper processing that had to go on in each practice. However, getting information in electronic form often made it a more complicated process rather than reducing the load:

> On a daily basis we go into the Out-of-Hours module of EMIS and print off all the letters for our patients that have been seen Out-of-Hours. They are filed into the patient record and then the letters are passed to the doctor, so the doctor can just see if there is anything that he needs to follow up.

**GP Practice Administrator**

The GPs and their practice staff reported that it was a major clerical exercise to go through all the incoming material each day and ensure proper actions were taken and the patient’s records up-dated appropriately. Strategies in practices varied but in general a process was
in place in which clerical staff examined the letters for ‘patient data’ to enter into the patient’s records. They only added what was significant in order that the record did not become clogged with transient material. The clerks annotated the original letters and organized them for the GP and passed them on for action etc. A GP or senior administrator would check any coding, e.g. diagnosis, in the information or insert codings themselves. At the end of the process paper records are normally scanned into the system to be attached to the patients’ records before the original paper record is destroyed.

There were several aspects to this process that respondents reported as problematic. One was the sheer amount of time and effort it required from GPs and administrative staff and the costs involved. One GP reported that printing ink was a major cost for his practice and that scanning documents took up most of the time of one member of staff. Another concern was the variable quality of the information received and the time in some cases that it took to arrive. Information from A&E was singled out as particularly slow and limited in its content.

A major concern was that information could now arrive in a number of different ways that needed different treatment. At the most integrated electronic end of the spectrum blood test results arrived by Path Link and, after checking, could go straight into the patient’s record. Adastra OOH reports arrived electronically as letters and Electronic Discharge Summaries and other information could be accessed on FUSION. Access via FUSION was valued because it gave the quickest access to information; you could often see blood tests there before they arrived by Path Link. However, although you could print out the record on FUSION, you could not easily transfer the information to your own system in an electronic form.

Every morning, our receptionist will look at FUSION to see if any of our patients is admitted to hospital, or anybody is discharged, and if there is a discharge summary - so we can read the discharge summary straight away now. But we cannot put it directly into the records of our IT system, and that means manually we have to cut and paste it.

GP

Reports from other sources arrived by fax or as email attachments and there were still a lot of cases where it arrived as letters in the post. In some practices new paper inputs are scanned straight into patient notes but in one practice the strategy is to print everything out whatever form it came in, extract data and pass it to doctors, i.e. even if it arrived electronically it was printed out. As one GP explained this provides a single safe way of proceeding - it is a way of avoiding missing some inputs because they come in a different form from other inputs. There is some fear in GP practices that unless a ‘fail safe’ procedure of this kind is followed, new patient information may be missed because it arrived in a different form from most other information. Another advantage is that it
puts all the information into a form the GP can work through, annotate and pass back to administrators for action. In some cases, when the information has been directly attached to an electronic record, the GP has to enter each patient’s notes to read the new material which is both laborious and open to new information about patients being missed.

*Because of all the combination of letters and non-letters we get, my staff print all the non-letters... That’s the problem with two systems, you end up resorting to the lowest common denominator. And the PCT actually encourage this – someone visited us as part of a QOF Review and they were quite happy with printed letters being looked at by doctors ... basically they said you either have to have the doctors review them, or you don’t have the doctors review them – it’s got to be consistent. You can’t have two processes.*

GP

The issue of GPs reviewing the new material was particularly significant when it came to the Read codes used to describe the healthcare issue. In some cases senior practice administrators undertook this work but some found it quite difficult:

*It is very important that certain things are added correctly, and it’s all based on Read codes. So you could put a diagnosis in and say ‘essential hypertension’ and it brings up a whole picking list, and you have got to make sure that you choose the right Read code.*

GP Practice Administrator

Several GPs drew attention to consultant’s letters from outpatient clinics and said they could be slow in arriving, written in ways that were not particularly helpful for primary care and may include coding that could cause problems.

*When the data comes in the coding needs to be meaningful. We need to look carefully at what exactly the code is. It might be about ‘a pain in the calf‘ but it might not be DVT. But somebody might write DVT or possible DVT and they can be coding errors. The hospital might have a different perspective, not knowing the entire picture of the patient but that will be coded. We need to change these codings before they get into our records.*

GP on getting outpatient letters from consultants

The issue of getting the coding right was important to ensure the patient was given the right treatment and that, in the long term, the record did not leave a history that could mislead future healthcare workers treating the patient. However, it could also have important implications for the QOF (Quality Outcomes Framework) which provided financial benefits and benefits for the practice in terms of its achievement against a wide variety of targets. Inaccurate codings could have a negative effective in a variety of ways. They could for example lead to a direct loss of income. In a quality system the coding of a particular diagnosis might invoke the
requirement for a specific intervention and the practice might be penalised if there was no evidence they had provided such a follow up.

The GPs were obviously getting value from the electronic delivery of patient information but the irony of the current situation is that the data originates in electronic systems and, if it is important for clinical outcomes, needs to be placed in other electronic systems in GP practices. However, the process in between can be very messy and depends on good practice and organisation and can involve translation into paper forms. At best it involves practice staff in a lot of ‘paperwork’ and, at worse, it could lose information important for patient outcomes. One GP reported that there are document management systems that could put everything in an electronic form and allow the process of summarizing, reviewing, annotating and coding to be managed electronically by GPs and practice staff but, he said, it was too expensive for small practices to contemplate.

6.3 Unscheduled Care in Northamptonshire

6.3.1 History

Northamptonshire has A&E Departments in Northampton and in Kettering and two minor injury centres (the M1aMI (Minor Illnesses and Minor Injuries) Walk-in Centre in Northampton and the Corby Minor Injuries Unit). NeneDoc, a consortium of Northamptonshire GPs, bid for and won a contract to deliver OOH services to most of the county for 5 years starting in 2009. One condition of the contract was that they use the OOH module of SystmOne. NHS Northamptonshire planned to roll-out the SCR later in 2011 and a process of consulting patients about opt-outs had begun.

6.3.2 The Sample

Discussions with informatics staff led to the pathway mapping presented in figure 6.2 below. The experience of using the system was obtained from five GPs, two members of GP practice staff, a representative of one of the A&E Departments and a clinician with experience of a walk-in service.

6.3.3 Mapping the Pathway

The overall process of providing unscheduled care is similar to that in Walsall as are the roles of staff providing the service. The provision of different electronic systems means that, at a detailed operational level, there are many differences between the two LHCs.

The use of SystmOne in some settings whilst others continue to use other systems means that the pattern of access for unscheduled care agencies is varied as are the mechanisms for informing GPs of the results of these
episodes. There are three main e-health system settings associated with OOH unscheduled care:

a. **OOH using SystmOne OOH and GP Practice using SystmOne GP**: In this case the OOH practitioner can access the patient’s GP SystmOne record and the notes prepared after the consultation in SystmOne can be transferred directly to the GPs patient record with an alert to indicate that an addition has been made to the record.

b. **OOH using SystmOne OOH and GP Practice using EMIS LV**: Here the OOH service cannot access the patient’s record. After the consultation the OOH service can send an electronic message (a Data Transformation Service - DTS) from SystmOne to EMIS LV. It is displayed in an inbox with other DTS information, e.g Path Link blood test results. After review, practice staff can add it electronically to the GP patient record.

c. **OOH using SystmOne OOH and GP Practice using EMIS PCS or INPS VISION**: In this context the OOH service cannot access the patient’s record and no electronic transfer is possible between SystmOne and the GP systems. The OOH report is sent as a fax message or letter as are reports from A&E or other unscheduled care settings that do not use SystmOne. The GP practice may then scan it as an attachment to the electronic record.

6.4 The Experience of the System

Experience of using these electronic systems in unscheduled care is reviewed for the three settings above and is examined at two different stages in the process; accessing records in unscheduled care and receiving reports in GP practices.

6.4.1 Accessing and using electronic patient records

6.4.1.1 Where electronic access to the GP records is possible.

When the GP practice uses SystmOne the OOH service can get fuller access to a patient’s record than any other part of the OOH service. To access the record they need the consent of the practice and of the patient and it was widely reported by unscheduled care staff that consent, particularly by patients, was readily given.

There were some different accounts of the experience of getting access to the records and how useful it was in the patient encounter. One OOH GP who had been using SystmOne for over five years in his own practice was very positive about the experience.

...then its game on...you have got medications, you don’t have to talk to them about previous medical history and drugs ...it is immensely useful
for the minority with complex medical problems and psychiatric problems

GP in a SystmOne practice using SystmOne OOH

Even so, he reckoned that it was only valuable in about 20% of his OOH patient encounters. Another GP agreed that access to the full record would be most valuable for complex cases but in his OOH service he could hardly remember a case where the record would have been helpful.

The downside of using SystmOne was that the OOH module was described as ‘clunky’ to use and there was a danger of missing patients. And a mobile solution, to be used ‘on the road’ just never worked. The result of this is that:

we are currently printing out ..a list for the doctors to go on visits... they write their notes on the printout and come back and enter them in the system.. we are probably losing 10-15% efficiency from visiting doctors

GP using SystmOne OOH
### Figure 6.2

**The Unscheduled Care Pathway in Northamptonshire**

One GP said that his performance dipped massively for a couple of months when he first started using the module and another had become so infuriated by it that he had ceased offering himself for OOH duties.

*It increased my frustration...it was just one extra hassle. When I looked I couldn’t find my way around and I couldn’t find anything useful anyway*

GP from EMIS practice using SystmOne OOH
This OOH GP used EMIS in his own practice and he was unfamiliar with the structure of SystmOne records. He claimed he was spending up to 50% of his time in an OOH episode working with the computer rather than with the patient.

6.4.1.2 Where unscheduled care does not have access to patient’s medical records.

When the patient’s GP was not a SystmOne user OOH practitioners had to rely on information in the OOH SystmOne module. SystmOne retained the record of every encounter a patient had with OOH and a patient who was a frequent user of the service would have a substantial record available in the system. One GP said that this could be very helpful and most certainly saved a lot of time because history taking was not then necessary.

A&E did not use the SystmOne module and a representative reported that they only had access to the patient records in their own system which might be useful if the patient had had a recent hospital admission. She did not feel access to GP records would make much difference because ‘doctors are pretty malleable and make use of whatever information they can get’. The main difficulty was unconscious patients where you could not establish their identity; in this case electronic records would be of no help because you did not know the record you needed. In these circumstances A&E staff used a fail safe approach to treatment because they did not know about medication or allergies.

6.4.2 Receiving information in the GP practices.

Ideally the information from the unscheduled care encounter needs to reach the GP practice the following morning. From the reports of GPs and their practice staff the experience of receiving and processing information from unscheduled care episodes varies with the three settings

6.4.2.1 Where the practice uses neither SystmOne nor EMIS LV

The information arrives as a free text letter, fax or email attachment. Practices vary in their procedures for dealing with such information but there is a common basic process – data is extracted by administrative staff for entry to the patient record and the letters are annotated and organised for GPs to review. After GPs have reviewed each letter for action, e.g. calling patients in, the letter is scanned and added to the patient record, and codes are assigned to the encounter and entered into the patient record. A number of examples were given of coding mistakes that were made in the past that had negative consequences. One GP reported that the codes in the letters, often based on a single consultation, were frequently wrong and junior staff in the practice might simply copy them.

The GPs and practice staff reported that mis-coded information put into clinical records could have two kinds of effects. First, the patient could be called-in or referred for inappropriate follow-up procedures. Secondly it could introduce errors into the QOF statistics of the practice and thereby upset
performance records. As a result, coding or re-coding was normally done by a GP or a senior practice administrator.

The GPs said that reports from OOH GPs usually arrived the following day and could be actioned quickly. However, reports from A&E usually came in batches every fortnight and could arrive long after the patient had come into the practice. A more serious issue was the quality of these reports. They were often very brief and non-specific, e.g. they would say the patient attended with ‘a limb problem’. As one GP put it they are such rubbish that there would be no point making them electronic to speed the process up.

6.4.2.2. Where the practice is EMIS LV

When SystmOne is used in the OOH service and the patient’s GP practice uses EMIS LV it is possible the report is sent by DTS. This ensures it arrives quickly at the GP’s practice. The practice receives a long list of DTS messages for patients (including all blood tests) each day and they have to go into each patient’s record to read the message. As one GP noted, not having the message immediately to hand, encourages staff to wait until the patient makes an appointment before reading the new messages in the patient’s file. In some cases this could mean that a need for the practice to be pro-active is missed.

An administrator highlighted the issue that some unscheduled care reports came in the form of letters, others as email attachments and others went straight as electronic attachments to the patient record. She recognised there was a danger that the different routes might lead to different actions and she was not sure they had established internal processes for each route to ensure nothing was missed.

6.4.2.3. Where the practice is SystmOne.

When SystmOne is used in both the OOH service and the patient’s GP Practice it becomes possible to send the OOH account straight to the practice in a form of an automatic addition to the patient record. The GPs and practice staff who had experienced this process were unanimous in their grave concern about it. They had three concerns. First, that the codes that had been used, particularly for diagnosis, might be wrong. Second, that all of the details of the episode were entered into the record rather than the summary of important points. As a result of the volume of material being entered, it became difficult to extract the important issues from a patient’s record. Third, the material that was entered without being processed by practice staff could have a negative effect on the QOF returns of the practice. At the heart of these comments was a view that this process took control of the patient’s records away from their GP.

When it comes to pass that information is entered into my system, Read codes and all, and given that I am responsible for ... any information in my patient’s records, I ought to be in charge of it, I don’t want somebody else to be adding codes or whatever to the system

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Project 08/1803/226
As another GP put it ‘I wouldn’t trust somebody who wasn’t working in my practice to put in codes’.

Reports from Walk-in Centres were even more of a problem. One practice administrator said that the nurses added every telephone call to the patient’s record so that it became completely overloaded with trivia.

One GP commented on the difference between a free text letter reporting an unscheduled care episode and the structured report received from SystmOne. He commented that clinicians sending letters usually expressed their own doubts about diagnoses, with lots of ‘it might be’ statements. But in SystmOne they had to select items from menus and it was difficult to communicate any doubts and caveats.

The question of what the practice could do to stop externally coded information getting into their records drew conflicting views. In one practice the GPs were struggling to find a way of regaining control over their records. However, in another a GP reported that they had ‘disabled’ the input of OOH reports directly into their record.

The policy of encouraging the adoption of SystmOne by GP practices across the county was commented on by several GPs. For some it was a sensible move in the direction of being able to share information but for others it was an unwanted example of top-down pressure. EMIS, for example, was regarded as easier to use than SystmOne and had more useful functionality for a GP practice.

### 6.5 Discussion

#### 6.5.1 The ‘state of the art’ of electronic information systems serving unscheduled care.

Although the SCR was not available, there was, across the two cases, a wide range in the degree of access to electronic patient information in unscheduled care settings. It ranged from none at all for some patient encounters through the provision of FUSION records in Walsall to the full access to GP records in some examples in Northamptonshire. It is likely, therefore, that in many situations staff in unscheduled care settings will have access to some form of electronic patient record if the patient is registered in the local health community.

Clinical staff have been used to managing without access to records in unscheduled care settings and on many occasions they do not see the need for it. There are, however, some circumstances in which they have found it useful or would have found it useful had the information been available. This conclusion is similar to that of Greenhalgh, Stramer, Bratan, Byrne,
Russell, Hinder et al who conducted an evaluation of the pilot sites using the Summary Care Record. They found that clinical staff accessed the record for 22% of the unscheduled care episodes when it was available and that the general view was that it was useful when access to important information by normal means was not possible.

Whether the electronic patient information that is actually available is helpful in unscheduled care is another matter. In Walsall, at present what is available is the record from previous hospital visits via FUSION and from previous OOH visits via Adastra. At Northants it is the record via SystmOne and, where SystmOne is a shared system, access to the full GP patient record. The SCR provides access to a different sub-set of patient information than any of these systems, specifically medication, allergies and adverse reactions. From the evidence here there is no doubt that the SCR sub-set of information is of great importance but some of the interviewees wanted to understand the full context and needed access to the full record when a patient presented with complex symptoms. In other settings, the need was to be able to access very recent information such as a recent set of blood test results. Another gain from having access to very recent information is that it reduces the need for history taking. It is obviously difficult to specify what information a clinician will require when, by definition, the patient can present with a very wide variety of needs.

In the SCR evaluation there were examples of problems in getting the permission of the holders of the record and of the patient to access records. No problems of this kind were reported in this case. This may be because the rules for access are less stringent than they are for the SCR, that the sample here is quite small or because, in most cases, the person requesting access was known and trusted and access was freely given.

Another issue these results raise is that access to a wide range of patient information in unscheduled care settings brings with it a new set of problems. There is only so much information that the clinician can digest in a limited amount of time and, for one of the interviewees, access to a full patient record structured in an unfamiliar way became a problem too great to overcome. Is open access to the records held by others the solution or is it necessary to look at filtering and structuring records so that they are suitable for use in unscheduled care settings, especially in pressurised settings such as A&E?

6.5.2 GP Practice administration of incoming information

The records that flow from unscheduled care episodes to the GPs become part of a bigger set of reports reaching practices about patient encounters elsewhere in the health service. The scale of these reports and particularly the variety of forms in which they can appear in the practice obviously creates a clerical headache for practice staff. It is a problem that raises issues of efficiency; a great deal of time and money seems to be spent moving back and forth between electronic and paper forms via, for example, printing and scanning. There are also issues of patient care and
safety because it is easy for patient reports to be hidden, to be late or to be lost. An electronic solution could be seen as the ideal solution to these problems; if all the information arrived in an electronic form that could be easily placed in the records of the patients, much of the complex ‘paperwork’ processing may be substantially reduced. Many GPs are looking forward to this day but at the moment there are a number of factors that mean this ‘paperless world’ is a long way off for most practices. First, the different forms in which the information arrives complicates the process. Second, the information needs validating before it can be placed in the patient records. Third, the work process by which different members of practice staff, check, filter and annotate the incoming information would need to become electronic rather than paper-based. There may be electronic document management systems that would help a practice keep information that arrives in an electronic form in that form and to convert paper reports to electronic documents. They would, however, also have to be systems that supported, in an easy-to-use and fail-safe manner, the complex process that practices follow to extract data from records, annotate them for action, organise them for urgency and code or recode entries for their own records.

Another obvious solution to the clerical burden of processing letters is to pre-structure the inputs at source so that they can be entered directly into the patient’s record. The fact that additions have been made to the record could be signalled to practice staff and they would not have to engage in any processing of the material. As the interviews show this is a solution that brings great concerns to GPs and their staff. It is a process that, first, means that they have to look at each individual record to see what is new. Second, and most important, it means that structured and coded material may enter the record that is not wanted by the practice staff – it may be far more than is necessary and may be deemed to be wrong or mis-leading. The problem is that the practice staff in this scenario have lost control of what they consider to be ‘their’ records and there is obviously a concern to re-assert control for the good of the patients and for the performance measures that are important in GP practices. This concern does not seem to extend to other forms of data that flow into the patient’s records. Blood test results also get added automatically to patient records but this system is generally regarded as excellent – perhaps because they are the results of tests requested by the practice and the results come in a structured form which is well institutionalised and widely accepted. The issue of how to enable local staff to review and amend information that reaches them before it is accepted into the record is obviously one deserving of close attention.

6.5.3 Conclusion

Substantial progress is being made in using electronic systems to both speed up the communication of patient information and to enable greater amounts of it to be shared (and that further progress is likely to be made in the near future). These gains are not unappreciated by most clinicians. However, the metaphor of creating a motorway bypass around a city seems
apt. The speed and efficiency of the motorway can be wasted if it produces bottlenecks at either end where it joins the existing road network. In this case at the unscheduled care end and at the GP practice end, there are serious issues about how to manage the new ways of receiving patient information especially in circumstances where all the old ways are simultaneously present for other purposes. Finding good practices and good systems to support them at both ends seems to be an important goal if the benefits of electronic patient information crossing boundaries are to be fully realised.
7 Sequential Interdependencies in the Stroke Pathway and in Diabetic Retinopathy Screening

7.1 Introduction

This chapter reports two cases of pathways that are dominantly composed of sequential task interdependencies. The main characteristic of the pathways is the handover of responsibility for healthcare from one agency to another, one of the most common characteristic of healthcare pathways in the NHS. The two cases are the Stroke Pathway in Walsall and Diabetic Retinopathy Screening in Northamptonshire.

Each case begins with a pathway map to demonstrate the task interdependencies to show the extent to which electronic sharing of patient information is currently possible. This is followed by data on the experiences of the healthcare staff that occupy key boundary-spanning roles in the pathway. A new section in each of the cases is an account of the way the e-health systems have been designed. In each of these cases we studied the history of the design process and/or engaged with the staff who were designing new systems during the course of this research.

7.2 The Stroke Pathway at Walsall

7.2.1 History

In 2001 the National Service Framework (NSF) for Older People set out health service targets for stroke patients and these were made more comprehensive in 2007 in the 'National Stroke Strategy' which listed 20 'quality markers' defining good quality care at every stage of the patient’s journey. Since then guidance has continued to be updated, for example, in the Act FAST Campaign that highlights the steps to be taken when a patient shows early signs of a stroke. Walsall has responded to national policies on strokes by making process and organisational changes over a period of years. In the same timeframe it has also implemented e-health systems to support the stroke pathway.

7.2.2 Information Sources

Research access was possible to most of the agencies in the Stroke Pathway but we did not have access to the Ambulance Service or to Social Services. Experience of use of the system (7.3 below) was reported by a member of
A&E staff, two members of nursing staff in the Hospital Stroke Unit, two members of the Community Stroke Unit and three GPs. The mapping of the system was assisted by two members of staff from the informatics business change facilitation team. The account of the design history of the stroke pathway (section 7.5 below) was informed by documentary analysis, interviews with three members of staff involved in the earlier phases of development and three members of staff involved in current developments.

7.2.3 The Stroke Pathway

The first part of this pathway is a time critical series of sequential interdependencies. Paramedics diagnose a suspected stroke and get the patient to hospital where A&E staff organise a CT scan and administer the clot-breaking drug, Alteplase when appropriate. Thereafter, the general pattern is treatment and rehabilitation within the hospital stroke unit followed by further rehabilitation in a community hospital or at home. The nature and length of the rehabilitation process will be dependent on the severity of the stroke and the particular functions that it has impaired. The varied nature of the impact of the stroke and the unpredictable course it may follow mean that many forms of treatment may be necessary simultaneously both in the early critical stage and the later rehabilitation phases. The underlying sequential nature of the process is therefore overlaid by many reciprocal interdependencies and iterative loops. A series of reviews take place for up to three years after the stroke.

FUSION includes a stroke register that contains the records of all patients being treated for a stroke. It provides a relatively joined-up way in which healthcare staff in the Acute Trust and Community Services can share electronic records about patients. Healthcare staff input data about the patient on a number of other systems: the STAR PAS system in the Hospital, iPM in Community Services and in GP practices on their own systems. It is not currently possible to access either iPM or the GP systems via FUSION. The ambulance service does not have access to FUSION and GPs, although they can use FUSION, do not have access to the Stroke Register. When the patient is discharged from the hospital an electronic discharge summary is sent via FUSION to the GP of the patient. There is an embedded Social Worker in the Stroke Unit in the Hospital who has access to the Stroke Register and to the social service system PARIS.

7.3 Experience of Use

The experience of the use of this system by the healthcare workers in the pathway is presented below for each stage of the pathway sequence.

7.3.1 Ambulance Services and A&E

A&E staff report that the Ambulance Service do not have access to electronic patient records but they doubt they would be useful to them in
**Figure 7.1**

**The Stroke Pathway at Walsall**

Dealing with the onset of a stroke, A&E have a general deadline of 4 hours to process each patient but the target for a suspected stroke victim is to get them to the hospital stroke unit, CT scanned and treated as appropriate within 30 to 60 minutes. A&E staff use an electronic whiteboard system to monitor and progress the patients who are in A&E and this provides access...
to previous hospital information about the patient if it is available. A&E staff report they have little time in the case of suspected strokes for detailed investigation of the patients’ past medical history; their priority is to diagnose the stroke and move the patient on for investigation and treatment.

7.3.2 The Hospital Stroke Unit

In 1997, in response to the Department of Health’s National Stroke Strategy, the Manor Hospital created a 28 bed dedicated stroke unit as part of its own stroke strategy. Patient’s admitted to the ward are investigated and treated and thereafter a rehabilitation programme is initiated to deal with whatever forms of incapacity have been caused by the stroke. Although they are admitted to a Stroke Unit, patients are not immediately placed on the Stroke Register. Instead their treatment is logged on the Star PAS system in the Hospital and on paper records kept by the patient’s bedside. One of the Stroke Unit nurses reported that, the patient was entered into the Stroke Register at the time of discharge information from other systems into the Stroke Register. The Stroke Register was not therefore an aid in patient treatment whilst they were in the Unit. The nurse gave the following reasons for delaying the creation of the Stroke Register entry until discharge:

1. Some patients come onto the ward and were found not be suffering from a stroke.

2. The template in the register requires an exact classification of the kind of stroke the patient has suffered. It is not possible to be this exact early in the treatment process.

3. Each stage of the early care of the patient has strict time deadlines and the performance achieved has to be recorded in the Stroke Register. Quite often the overall time from admission to A&E to the CT scan and treatment was within the deadline but some of the component times within the process may not be. Putting in the times at a later date allowed some adjustments to be made.

The Stroke Register record when compiled includes reports from medical and therapy specialists and also a social care report from the Social Worker who creates a social record in the Social Services system PARIS but also has access to FUSION and can complete a section of the Stroke Register. Also at the time of discharge medical staff complete an electronic discharge summary FUSION which becomes instantly available to the GP of the patient.

A nurse on the Stroke Unit said there was a lot of double entry of data involved in the present arrangements and that there were plans to pilot the use of mobile devices for use by the bedside of the patient which would reduce this need.
7.3.3 Integrated Stroke Services

On discharge from hospital the Integrated Stroke Services unit of the Community Trust may take responsibility for the rehabilitation of the patient. The Service includes specialists in the different kinds of rehabilitation that might be required and can call on other more specialist expertise when needed. 90% of their patients come from the Stroke Unit of the Manor Hospital and, before discharge, staff from the service visit the ward, meet the patient and attend multi-disciplinary team meetings to assess the specific needs of the patient. On discharge a nurse is appointed as the key worker for the patient and a team of relevant specialists appointed. One of the key performance indicators (kpis) in stroke care is early supported discharge so that facilitating discharge is an important management objective for the service. Once the patient is in the community the team meet weekly to review the progress and revise the care plan if necessary. A nurse within the service reported that there is no designated social worker in the community unit which makes joint health and social care more difficult.

At discharge, community staff have access to both the Stroke Register and the electronic discharge summaries held on FUSION. They described the quality and usefulness of this information as variable, reflecting who had entered it in the hospital. They were particularly concerned about the information given about the rehabilitation the patient had received in the hospital and what it meant for the care plan they should establish in the community.

They did not see the Stroke Register as a working tool to help team members care for the patient. It contained a template for Community Care that was completed by staff in the service but this was more about managing the service and knowing whether you were meeting targets.

The way the Stroke Register is set up is primarily around data management. We hope maybe at some stage later we can get something that may help the staff.

Community Stroke Nurse

The front line staff who visit the patients manage care by the using SAP (Single Assessment Process), a set of agreed, paper-based documents that all healthcare workers visiting the patient complete on every visit. It is left in the patient’s home and provides an up-to-date account of the care the patient is receiving that everyone can consult. The members of the team bring back to the office a carbonated copy of their account of each visit and which they enter into the Community Services System, iPM. Several respondents pointed out that this process involves a lot of repetitive data entry. A particular problem, especially for part-time staff, is that they have two days to return to the office to enter the information into iPM.
There were plans to run a pilot with District Nurses of an electronic version of SAP in which staff visiting a patient can use a mobile device to enter their account of the visit (see chapter 8). The staff of the Integrated Stroke Service were watching this development with interest and hope.

### 7.3.4 Monitoring the Condition of the Patient

When a patient is discharged from hospital their medical care becomes the responsibility of their GP although, for stroke patients, the national strategy requires that reviews of the patient are made at regular intervals (3 month, 6 months etc). The Stroke Register was regarded as helpful in monitoring because it provided the complete history needed when reviews were undertaken.

The GPs did not have access to the Stroke Register but they welcomed the electronic discharge summary it provided fast notification. As in other settings, the GPs commented that the discharge summaries were of variable quality; some lengthy and detailed and very helpful whilst others are cursory and can miss important details about, for example, the patient’s medication. It was likely they would have access to the Stroke Register in the future when it became possible to operate role based access controls on access to FUSION by GP practice staff. At present access from practices was barred because any member of practice staff could access all the information held and many were not permitted to view clinical information.

GPs commented on access to information about community work with patients. There were a lot of examples, for example, physiotherapy, where you referred a patient to a service and just let them get on with their job, and this was the case with the rehabilitation work done by Integrated Stroke Services. If a medical problem related to the stroke or another condition came up, the patient would ask for a home visit or come into the surgery. There was a broader problem relating to Community Services: it was hard at times for GPs to know what they were or were not doing for a patient.

### 7.4 The System Development Process

The development of e-health systems to support stroke care has been a continuous process at Walsall over the past decade. It has been closely associated with developments in the care pathway, organisational changes in the agencies involved and detailed development of associated working practices. Although healthcare workers in the stroke pathway use a number of e-health systems, it is the facilities available via the FUSION system that provide opportunities to share information across organisational boundaries. There is access to both the general information resources FUSION provides and the dedicated facilities developed to support the stroke pathway. To provide an account of these developments the section below gives an account of the system developments in FUSION implemented in the last decade and those that are currently being planned and in a subsequent
section describes the design process and the roles played by various stakeholders in the process.

7.4.1 The Development of e-Health Systems to Support Stroke Care

FUSION was a major innovation implemented as part of the ERDIP programme in 2002. The initial plan was to provide access to a limited range of applications held on other systems and to create detailed records for two disease management pathways (CHD and Stroke). As a result FUSION is not only a portal but also contains its own database applications; it is better regarded as a ‘hybrid’ system. Since 2002 there has been a steady growth in the breadth of applications on FUSION, listed, year by year, in figure 7.2. Some of these developments are specific to the stroke pathway but there are others that, whilst more generally applicable, also provide useful resources for healthcare workers in the stroke pathway.

In 2004 the first application in FUSION specific to the stroke pathway was the implementation of a stroke disease management pathway, i.e. there was no specific intention to supply clinical information to front line staff. Further templates were added to form the Stroke Register in 2009 and in 2010 this was extended to cover community services and clinical reviews in the stroke follow up. At each stage the aim was to provide aggregated reports against the growing number of kpi targets for performance in the stroke pathway.

In the evolution of FUSION a number of other applications have provided access to information of specific relevance to the stroke pathway. Providing access to PACS in 2006 meant that FUSION could be used to access the results of scans and the development of the Whiteboard in 2008 meant that the progress of patients through A&E could be monitored. In 2008 Electronic Discharge Summaries were implemented and in 2009 the results of scans for TIAs could also be accessed. In 2010 changes to the role based access model meant that was possible to give more access to clinical information to those healthcare workers qualified to access it.

In 2011 there will be further developments in FUSION that will affect the stroke pathway. A contract to provide stroke services to a nearby trust means kpis will have to be revised because the other trust uses an additional set. Other developments include the piloting of eSAP mobile devices by district nurses. Informatics staff reported that there are between 20 and 30 developments being undertaken in FUSION, some large and some small, at any one time and that, in order to preserve version control, they are released in batches four times a year.

7.4.2 The Design Process

7.4.2.1 The Origins of FUSION

The impetus for the creation of FUSION in 2002 came from clinical drivers and from a desire to pursue a particular route to share electronic patient
information. As part of the ERDIP programme Walsall informatics staff committed themselves to testing a different approach to the ‘common database system’ approach being promoted elsewhere in the NHS. This was the portal approach that enables different services to retain their own systems but for their data to be accessed through a common portal. In addition to these technology drivers, the major objective was to fulfil the clinical requirements of the NSF (National Service Framework) in relation to the two pathways that were supported that included stroke. Clinically-led teams, drawn from the relevant health agencies in the local health community, designed pathways for the management of each disease and, with the help of informatics staff, specified the information requirements to support these pathways that FUSION needed to deliver. The fact that the informatics service was a shared service within the local health community meant that the specification represented all relevant interests across the pathways. These information requirements were used by local informatics staff to work with suppliers on the detailed design of the technical system.

<table>
<thead>
<tr>
<th>Year</th>
<th>FUSION developments</th>
</tr>
</thead>
<tbody>
<tr>
<td>2002</td>
<td>Initial Dynamic Patient Screen view, Demographics, Inpatient and Outpatient details, A&amp;E details, MPI Search, Ward List and Outpatient List.</td>
</tr>
<tr>
<td>2003</td>
<td>CHD disease management pathway (DMP) implementation of Heartcare, congestive cardiac failure and in-patient heart failure templates</td>
</tr>
<tr>
<td>2004</td>
<td><strong>Stroke disease management pathway implementation</strong></td>
</tr>
<tr>
<td>2005</td>
<td>Full Results Integration and implementation of community cardiac nurses templates in DMP</td>
</tr>
<tr>
<td>2006</td>
<td><strong>Picture Archiving Communication System (PACS) integration</strong></td>
</tr>
<tr>
<td>2007</td>
<td>Technical refresh and cardiac rehabilitation and diabetes templates in DMP</td>
</tr>
</tbody>
</table>
| 2008 | **Development of A&E Whiteboard.**  
**Development of Electronic Discharge Summary (EDS)**  
Endoscopy, bronchoscopy, cancer waiting times and palliative care templates in DMP |
| 2009 | Child Protection alerting system for A&E and Paediatric Assessment Unit. **Identification and notification of Imaging abnormal results plus transient ischaemic attacks (TIA), podiatry, stroke register** and sleep apnoea templates in DMP |
| 2010 | Endoscopy system integration, **advanced role based access model (RBAC)**, community neuro rehabilitation team (CNRT) alerts, **stroke follow-up**, pre-assessment and breast care templates in DMP |

**Figure 7.2**

**Developments in FUSION (2002-2010)**

*(Developments most relevant to the stroke pathway in bold)*
When FUSION was implemented it created considerable national and international interest. PA Consulting\textsuperscript{126} who were commissioned to evaluate the ERDIP programme concluded that FUSION was yielding considerable benefits for Walsall:

\textit{Using the FUSION system.... to support the broader health-community in Walsall would appear to have resulted in some cost savings, and a broad range of other clinical benefits. Parallel Clinical and IT process redesign has been an important part of this process and together this should translate into health gains.}

The project was also evaluated by an Australian research team making an international comparison of approaches to the development of electronic health records. They concluded that among the lessons to be learned from the success of FUSION were:

1. \textit{Ensuring that development is driven by clinicians and}

2. \textit{Structuring implementation around key clinical focus groups then extending the rollout to the total consumer population}

\textsuperscript{94}Health Connect Program Office

\subsection*{7.4.2.2 Design Principles and Processes}

The IT facilities that support the stroke pathway are largely, but not wholly, the result of the evolution of FUSION. From its beginnings in 2002 FUSION has evolved to be the major vehicle by which patient information is shared across the healthcare agencies in the Local Health Community. The principles by which it was originally designed have been sustained in subsequent developments and they have been further refined in relation to how developments are initiated, how projects are governed, the way projects are managed and the detailed processes at each stage of development.

Nearly all developments are initiated by clinical requirements but they come from different directions. The process was described by one member of informatics staff as top down and bottom up. The Walsall LHE Informatics Plan 2009-2010 to 2011-2012\textsuperscript{121} describes the top down process, i.e. the major national objectives that Walsall will be pursuing and how these are translated into informatics work streams, for example, how the implementation of the national Stroke Strategy leads to the design of templates in FUSION. A manager in the Informatics Service expressed the strategy of starting from clinical objectives rather than technical ones as follows:

\textit{It is always our ... practice ...to be business driven ... the technology is just a work stream within that. Prior to this period we put technology solutions in and then tried to encourage people to use them. That never worked properly. So now rather than starting from a}
technology and trying to knock it into the organisation, we very much start from the organisational need and the clinical need.

Informatics Service Manager

The top down approach has primarily been concerned with major clinical priorities and the creation of clinical pathways to meet these priorities. The pathways often lead to new forms of organisation and new relations between the agencies and work roles contributing to the pathway. In this approach the informatics needed to support the new pathway is one of a number of parallel ‘work streams’ needed to implement an integrated solution.

The bottom up strategy is represented in the Informatics Plan as ‘the continued development of FUSION’, recognising that there would be several new releases each year, some being part of major initiatives but most being local, small scale developments responding to customer requests.

A lot of it comes from clinicians who say to us, ‘it would be great if your system could do this’ and then we just say ‘well it probably can’. For example one of the consultants said to me ‘why can’t we have a formal handover document between doctors when they handover.... So in Fusion we are developing a handover system for them.

Informatics Project Manager

The informatics policy for the LHE is set by an IT sub-board of the main board that includes representatives of all the local health agencies, clinical and informatics staff. Projects within the plan then become the responsibility of local information executive groups. Where a major project crosses organisational boundaries it becomes the responsibility for a specific pan-organisation group, for example, the eSAP project is the responsibility of the Joint Adult Information Board. Within the Informatics Service technical delivery is the responsibility of a project manager but the way the new facilities relate to parallel changes in clinical care pathways and organisational changes is co-ordinated by a business change section of the Informatics Service. This section is staffed by people with a clinical background and its establishment was a major departure for the Informatics Service.

It was implementation of iPM in the Community that was the catalyst for us to look at how we were going to reshape our informatics directorate and to have a team of business change facilitators and we certainly did learn a lot from that. There was lots of documentation, lots of change management models available. We completely refined them and Walsall‘ised them to make them meaningful to our end users

Informatics Service Manager

Several Informatics Service staff commented on the process of working with end users to establish the broader context of service changes in order to specify the informatics service that would be necessary. They also reported that, because many of them were ‘hybrids’ with a clinical background, they
could ‘talk the language of the users’ and could cross the cultural barriers that had existed between healthcare staff and informatics specialists.

Project managers responsible specifically for the IT strand of projects reported that, for the more major top down technical developments, they followed the project management processes of the PRINCE 2 methodology. However, working with the user community on the parallel activities that went with the development of the technical facilities, was outside the scope of the normal IT project management methodology.

The way in which the bottom up and relatively minor changes in FUSION were undertaken did not involve such systematic processes but did involve close engagement with users and a number of formal stages, for example, getting clinical agreement that the development had priority.

One of the senior staff in the Informatics Service commented that the decision to go for a portal approach had paid huge dividends in the way it supported evolution. They were able to add new links to the portal and new facilities in FUSION almost endlessly as and when the users decided they wanted them or it became necessary as a result of major new developments.

FUSION.... is just the visual front end. The systems that support it, the data, the repositories and data gathering systems... sit below it, and so you can constantly plug a new one in and change it, because of the model. We have come on a long journey because it started as a relatively small deployment, and obviously now it is significant, it is the key system for the health economy - there are 3,000 users on it daily.

Informatics Service Manager

7.5. Discussion

Developing Stroke Pathways has been a national priority for a long period and in that time Walsall have responded by developing their own pathway, making associated organisational changes affecting a number of healthcare agencies and creating informatics services to support the pathway. The process has been an evolutionary one because of changes in top down requirements and because the user community have requested new facilities. The information facilities that cross-organisational boundaries are based on FUSION in terms of the dedicated Stroke Register and a number of more general facilities, such as the Electronic Discharge Summaries. The portal approach has made possible relatively seamless change and growth in the informatics support given to the stroke pathway.

A lot of progress has been made in this time and as a result the Stroke Register contains a clinical account of the progress of the patient from the beginning of their stroke through to the rehabilitation and review procedures after discharge from hospital. Although this integrated e-health
record has been achieved it has been of benefit for some purposes but not others. The Stroke Register in FUSION has been developed in response to requirements to manage stroke patients in relation to the ‘markers’ or kpis set out in the NSF. The top down development of FUSION was driven by clinical needs but it was clinical needs for pathway management as set out in the NSF. As a result the Stroke Register was initially a management tool and it has largely remained so; the current developments to serve the needs of another trust are again directed at the monitoring and management of new kpis. Given this driver, it is not surprising that the primary users of the stroke pathway are service managers, particularly those in the acute and community trust, for whom the aggregated data provides evidence of the quality and timeliness of the service against the many kpis and this identifies where actions, be they organisational, resource deployment or training, are required. However, the register has not been designed to provide many front line staff with the information they need to care for their patients. In this sequential process there are many significant ‘handovers’ where information about the patient may be important and it seems at the moment as though this information, if it is available, is provided by other mechanisms. It is, as Berg, Langenberg, C., Berg and Kwakkernaat31 have noted in the context of an e-health system being implemented in a Dutch hospital, a case of secondary users, i.e. managers, getting priority over primary users, i.e. the front line healthcare staff.

7.6 Diabetic Retinopathy Screening in Northamptonshire

7.6.1 History

Diabetic Retinopathy Screening is one of a number of services providing proactive care, i.e. identifying patients at risk of a particular negative health outcome and intervening early. The Department of Health announced a drive to give emphasis to proactive care in the NHS in 1994120 and there are now national screening programmes for a number of health areas. The UK National Screening Committee has established pathways, standards and kpis for a number of screening programmes including diabetic retinopathy. The English National Screening Programme for Diabetic Retinopathy (ENSPDR) provides guidance for diabetic retinopathy screening. One of the complications of diabetes is damage to the retina which can lead to blindness. If an abnormality is identified early laser treatment can be effective in stopping the retinal deterioration. The current programme has a number of kpis including the screening of all diabetics (from the age of 12 to the very old) every 12 months, screening within 3 months for newly diagnosed diabetics, reporting the results of screening within 3 weeks and undertaking treatment where a sight-threatening abnormality is found within 4 weeks98.

Northamptonshire has an established diabetic retinopathy screening service
that uses a dedicated electronic patient information system (OptoMize) to support the entire pathway from selection for screening to treatment for an abnormality. It is a sequential interdependency pathway that involves a number of health care agencies including GP practices, the Diabetic Retinopathy Screening Service (a community service) and Ophthalmologists in the two Acute Trusts in Northamptonshire

7.6.2 Information Sources

Meetings with informatics staff and clinical change facilitators, together with document analysis, led to the development of the pathway described in section 7.6.3. The history of systems design and the process of design was also reported by members of the informatics team and the clinical change facilitator and was supplemented by document analysis. Experience of use was described by two GPs and a practice administrator with special responsibility for information systems. The experience of the Retinopathy Screening Service was described by a failsafe officer and a screener/grader.
7.6.3 The Pathway

<table>
<thead>
<tr>
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<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Identification of diabetic patients on GP records who need screening</td>
<td>Letters to patients to arrange a date for screening</td>
<td>Screening unit takes photographic images</td>
<td>Images checked for abnormalities</td>
<td>Follow up and treat cases with abnormalities</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Follow-up letters when no response</td>
<td>Re-arrange for non-attendees etc</td>
<td>Re-arrange for un-assessable images</td>
<td>Set dates for future screening for all other patients</td>
</tr>
</tbody>
</table>

**Linked Pathways**
- Hospital Admission

**Roles and Agencies**

<table>
<thead>
<tr>
<th>Pathway</th>
<th>GP</th>
<th>Retinal Screening Admin Team</th>
<th>Healthcare Assistants and Screeners</th>
<th>Graders and Secondary Graders</th>
<th>Ophthalmologists</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Pathway</th>
<th>Retinal Screening Admin Team</th>
<th>Failsafe Officer</th>
<th>Retinal Screening Admin Team</th>
<th>Failsafe Officer</th>
<th>Retinal Screening Admin Team</th>
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<table>
<thead>
<tr>
<th>Pathway</th>
<th>Fail Safe Officer</th>
<th>Retinal Screening Admin Team</th>
</tr>
</thead>
</table>

**Interdependencies**

- Pooled: many to one data capture
- Sequential with iteration to previous stage
- Sequential with iteration to previous two stages
- Sequential referral

**Communications**

- Lists to GPs to check
- Appointment letters to patients
- Call centre for booking appointments
- Re-appointment letters to patients
- Referral letter or e-mail. Results reported to GP. Re-appointment letters to patients
- Letters to patients and GPs

**IT Systems**

<table>
<thead>
<tr>
<th>Pathway</th>
<th>OptoMize Quest Browser</th>
<th>OptoMize Quest Browser</th>
<th>OptoMize</th>
<th>OptoMize</th>
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<tr>
<th>Pathway</th>
<th>OptoMize Quest Browser</th>
<th>OptoMize Quest Browser</th>
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<thead>
<tr>
<th>Pathway</th>
<th>Acute Trust System iPM, ICIS, Lorenzo Local GPs SystmOne EMIS Vision</th>
</tr>
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**Figure 7.3**

The Diabetic Retinopathy Screening Pathway
The pathway aims to screen diabetic patients for retinopathy once every 12 months. The basic sequence, managed by the Retinopathy Screening Service, is i) identify people with diabetes, ii) make an appointment, iii) screen, iv) grade, v) follow-up and treat those with abnormalities. However, the actual process is more complex because the ideal process can fail at any point and the whole or part of the sequence has to be repeated (missing a person with diabetes, not making an appointment, missing the appointment, unreadable images etc). The reverse arrows in table 7.3 are indicative of these iterative loops. The pathway in Northamptonshire deals with over 30,000 patients every year spread across all the GP practices and, throughout the year, there are patients at every stage of the process.

Information about diabetic patients is held on the electronic record systems of GP practices (SystmOne, EMIS, Vision) and the Retinopathy Screening Service need access to the relevant files to create a list for screening. Maintaining an up-to-date list is a constant challenge because the numbers of diabetics keep increasing. The list is entered into OptoMize by the Retinopathy Screening Team and the system has functions to generate letters to patients to make appointments (and reminder letters 4 weeks later etc). Once screening has been undertaken, the images are also uploaded into OptoMize where they can be viewed by graders and secondary graders. Once a patient has been referred to the Acute Trust, details of diagnosis and care are entered in the local patient administrative system (e.g. iPM, ICIS, Lorenzo) although Ophthalmologists can review the images on OptoMize. The Failsafe Officer uses OptoMize to monitor the patient’s progress. Whenever results become available they are sent by email or in paper form to the GP practice for entry to their own systems with information about the next requirement for screening. For a patient with retinopathy abnormalities there could then be three electronic patient records: the GP system, the Acute Trust system and the retinopathy service OptoMize system. Although there are some limited opportunities for other agencies to view data on OptoMize, there are no facilities for the interchange of images or administrative information between these systems.

### 7.6.4 Systems Design History

The Diabetic Retinopathy Screening service has experienced a considerable number of changes in the period from 2008 to 2011. Interviews with respondents took place during 2010 and 2011 and they reported experiences at different stages of the development of their service. As a consequence, the systems design history is reported in this section before the experience of using the system is presented in 7.6.5. An account of the process of systems design is provided in 7.6.6.

On behalf of the English National Screening Programme for Diabetic Retinopathy, Garvican and O’Leary summarize the challenge of providing this screening programme:

> All screening programmes are complex, involving several different
health professional groups, a challenging patient pathway, and thousands of individuals to be invited each year. Diabetic retinopathy screening is even more complicated because in no other national screening programme do patients have to be identified on the basis of a pre-existing condition, nor are people offered year-on-year screening from the age of 12 until they die...Tracking patients within the acute trust may therefore have to be carried out over an extended period.

The pathway for screening in Northamptonshire conveys this complexity. The basic process, if a patient has an abnormality and needs treatment, involves twelve separate processes, seven of which involve the patient directly, the others being administrative and the processing of retinal images. However, the variety of circumstances that are handled and the need for iterations when, for example, patients do not attend for screening, lead to a wide range of variations in the basic process.

Before 2008 the PCTs in North and South Northamptonshire operated two separate diabetic retinopathy screening services. In the South a mobile screening service visited each GP practice whilst in the North there were fixed sites that patients attended for screening. At that time the Retinopathy Screening Service sent each practice a printout of all the patients screened in the last visit and asked them to update it before the practice sent out invitations to screening. Two different computer systems were in use; Orion in the North and an earlier version of OptoMize in the South. The numbers being screened in the North and the South by this method were well short of the national target.

When the two PCTs were merged in 2008 a decision was taken to run a single Diabetic Retinopathy Screening Service and to standardize on one computer system, OptoMize, in both the south and north of the county. The merger of the two databases was only partially successful and the screening records of a number of people with diabetes were 'lost in the ether'.

The service continued to operate 'blind', not knowing it had this problem. .....Then it was halted and an IT project manager was recruited in November 2009 to lead a review and 'restart' the service

Informatics staff member

At this time, the North and South were continuing with their previous screening practices, i.e. mobile screening was being undertaken on a six monthly basis in the south of the county. A National Retinopathy Screening Programme had been announced which specified that newly diagnosed diabetics had to be screened within three-months and the six-month gaps between mobile visits to a practice meant this target could be missed. The 'restart' was undertaken quickly in parallel with an organisational change that located all the Retinopathy Screening Service staff in one place and created eight fixed sites around the county where screening could take place. This change meant that, rather than a fixed time when all the
patients from one practice were screened, patients could be screened any time in accordance with the priority they needed to be given.

It was decided to make a ‘clean’ start with the database, i.e. to re-create it by extracting the data anew from the GP practices. This was done by contracting a company to use ‘middleware’ software called QuestBrowser to extract from the GP electronic records details of patients coded as having diabetes. This extraction was undertaken remotely in January 2010. Because there could be changes before the list was used to issue screening requests, GP were asked to notify the Screening Service of any newly diagnosed patients, any who had moved in or out of the practice etc.

GP practices were notified of the new list and they found many omissions, commissions and errors. Since the problems went beyond clerical errors, a clinical change facilitator from the informatics department was ‘embedded’ with the Retinopathy Screening Team in November 2010. The aim was to actively ‘manage’ the process of inviting patients for screening and to influence the planned Version 2 of OptoMize so that it better supported each stage the process. The numbers on the Retinopathy Screening Team have trebled and there has been detailed re-design of many aspects of the process.

7.6.5 The Experience of Use

7.6.5.1 A GP Practice Perspective on Diabetic Retinopathy Screening

Some of the respondents remembered when screening began as an initiative in GP practices and when fundraising events were held to raise money for mobile vans. At that stage GPs set their own criteria for who needed screening and patients came to their own practices for screening.

As the National Programme became established and the Diabetic Retinopathy Screening Service became a centralised service, the GPs role became one of notifying them about who needed screening. There was recognition that the records kept centrally were not accurate but the problems created when the Quest Browser process of extracting data from the GP records was introduced were reported with considerable feeling. One GP administrator commented on the process by which Quest Browser was installed and what happened as a result.

*I’ve got Retinal Screening on the phone saying ‘this patient’s not diabetic’ – I never said that they were. They’ve picked up all those that have gestational diabetes and put them down as being on the register. But obviously they’re not – they wouldn’t need retinal screening, they’ve only got diabetes whilst they’re pregnant.*

GP Administrator

Many of the GPs and practice staff found that the data about their patients with diabetes extracted by Quest Browser was incorrect or incomplete. Patients could be called for screening who did not need it and there were
many not on the list who should be, for example, newly diagnosed diabetics and those who had recently transferred into the practice. The GP list was constantly changing and in the time between the automatic extraction of data and its reporting to the practices many changes could have occurred. The pathway design specified that, after the automatic extraction, GPs would notify the Retinopathy Screening Service of each change as it occurred in order to maximise the time available for screening. However, Practices tended to do returns to Retinopathy in batches. They were concerned not only that the correct patients got screened but also that screening could be done in time for them to meet their annual QOF targets. As a result the batch report tended to coincide with the time period when QOF returns had to be made and late notification meant the patients needed screening quickly. The result was that the Retinopathy Screening Service had a surge of requests for screening just before the end of the 'QOF returns’ year.

7.6.5.2 The Retinopathy Screening Service Perspective

The Retinopathy Screening Service has four sections. There is an administrative team that makes appointments for a scan and a team of healthcare assistants and screeners who go to the various centres around the county and run the clinics at which the retinal images are collected. Back at the main location there is viewing equipment that enables graders to assess the images. In most cases the screeners are also graders. Finally, there are three Fail-safe Officers who are responsible for tracking patients through the entire process and making sure they move from one category to another, i.e. from having been sent a request to arrange an appointment to having booked an appointment to having had images collected etc.

The OptoMize system is fundamental to the work of the Retinopathy Screening Service because it is designed to cover all aspects of the service. Firstly, it is the database of patients with diabetes they have to screen and it contains the templates for the different kinds of letters they send to patients. Secondly, it enables patients to be tracked at every stage of their journey through the retinopathy pathway by assigning them to different ‘queues’ as they are screened, images are processed etc. Thirdly, the system ‘flags up’ when patients are getting near a time when they need to be moved into another category. Fourthly, it contains the clinical details of the patients including the retinal images that are to be graded and assessed. The ability of the system to meet the needs of the Screening Service staff at every stage of the screening process is therefore vital to the success of the service. The experience of the service can be reviewed for each stage of the process as identified in figure 7.3.

a. Selecting patients for screening Following the ‘restart’ the Diabetic Retinopathy Screening Service found that the ‘clean’ database had many errors and they were especially troubled by the fact that there were patients who needed screening they knew nothing about.
In the database we had patients who had moved out of area or were now deceased that the surgeries hadn’t told us about and close on 2,000 patients that the surgeries had never told us about. Quite often GP surgeries were not telling us when they had a patient that was diagnosed with diabetes, and some were not telling us when a patient had died or a patient had moved out of area.

Member of the Restart Team

When the change facilitator was ‘embedded’ with the Retinopathy Service she worked with the retinopathy staff, the GP practices, a member of the PCT Commissioners and the OptoMize team to look for improved working practices. This process led to some changes in the pathway and to some changes in the new version of OptoMize. One of the consequences of the changes made was that the Failsafe Officers developed more of an ongoing dialogue with practices about patients who needed screening. For the Failsafe Officers it has meant much more manual entry to a system that was intended to be mostly automatic, as it is necessary to add and delete patients and move them between categories. At the time of the interviews the new processes of validating the database with 3-monthly uses of Quest Browser were just bedding-in but there was optimism that they were getting on top of the job.

b. Booking appointments for screening

The admin team are responsible for sending letters, generated by OptoMize, to patients to ask them to contact the service to arrange a screening appointment. If they do not respond they are sent two reminders. OptoMize helps manage this by flagging when relevant time periods have passed and action is required. When the patient does not respond other measures have to be considered and consulting the GP practice may well prove to be the most effective way of approaching the patient, because the local diabetic nurse is more likely to be successful than a direct approach from Retinopathy.

The Failsafe Officers were concerned to hit the kpi targets for the patients being screened and non-respondents were a particular difficulty. If patients did not respond or, when contacted, said they did not want to be screened, the Failsafe Officers needed to get proof that the service was not necessary or wanted by the patient. Once proof was obtained they could be excluded from the returns.

If they are registered blind, for example, we would go back to Ophthalmology or the GP and try and get a certificate of visual impairment... The biggest thing is getting that proof.

Failsafe Officer

Another problem for the Failsafe Officers is the boundary of the county. If patients move outside of the county but are still with their GP they will be in the retinopathy screening catchment area although the patients may think otherwise. They may also wish to go for screening to a site outside...
the county. Working out the best course for such patients can involve liaison with other retinopathy screening services and GPs.

Reviewing the different circumstances that have to be dealt with led in the re-design process to a need to change some of the standard letters to patients held in OptoMize. Getting them modified was not a straightforward process.

*If we wanted a line deleted from a letter...we have to wait for OptoMize to remove it from the letter. They have to upload the modification to the server and then we can start using it. ...So they are the annoying bits....*

Clinical Change Facilitator

c. Screening and Grading

The main change for the patients in the south of the county is that rather than attending a mobile screening session near their GP practice they now have to go to a fixed site that might be further away which can be difficult for elderly or infirm patients. The process of screening involves having drops placed in the eyes and patients are advised not to drive. In the view of the screening team these factors contribute to the difficulties of achieving high attendance levels.

When patients attend, the healthcare assistant updates their record in OptoMize or starts a new record for new patients. The Retinopathy Screening Service receive very little information from GPs so they need to do their own history taking in relation to diabetes and eye problems. The healthcare assistant also puts in eye drops before the screeners take four photographs, two of each eye. These images are stored in OptoMize with the patient’s record. Subsequently, back at the headquarters of the Retinopathy Screening Service, graders review the images. Some of the clinics have 'live' connections with the OptoMize server and new records and images can be put on the system immediately. However, at some clinics, staff have to store the new records on laptops and upload them to OptoMize when they return to base. This can cause problems:

*When we work remotely and cannot upload data directly, there is a risk factor to getting it accurately transferred when we are back. There are problems with data transfer. Also it creates a delay - when we work remotely, it will be a least a day before a grader can see an anomaly that needs urgent attention*

Screener/Grader

The graders are in many cases also the screeners who captured the images and the grading process has several levels. There are regular multidisciplinary meetings at the Retinopathy Screening offices which screeners, graders and ophthalmologists attend to review difficult cases and to improve their collective expertise in assessing screened images.

There can be several outcomes to this process that may lead to the
Failsafe Officers having to intervene. If the patient did not attend for their appointment or the images were not of sufficient quality for the grading to be made, the patients will need to be contacted and another appointment made.

The majority of patients are found to be free of abnormalities. In some cases there are minor abnormalities that do not require referral to Ophthalmology. More serious cases go into two pathways. Those needing non-urgent treatment are referred using OptoMize to the relevant Acute Trust Ophthalmology Department and there is a 13-week target for treatment. Urgent cases, where sight-threatening abnormalities have been identified, have a 2-week target and the Failsafe Officers deal with them separately.

The urgent referrals things that are sight-threatening, come into Failsafe and I email each Acute with them. I check the next day to make sure they have been accepted. If they haven't then I get onto the Ophthalmologist and say 'you haven't done it, do it now quickly'.

Failsafe Officer

d. Treatment

Most of the referrals for treatment are to the Ophthalmology Departments of the two Acute Trusts in Kettering and Northampton. The Ophthalmologists make their own assessments of the images and decide whether to call the patient for further diagnosis and treatment. The Ophthalmologists in the county have access to OptoMize and can view the patient’s details and their images on the system. However, when they make an appointment for the patient they use their own Acute Trust System and thereafter, the Ophthalmologists use that to record subsequent treatment. Failsafe Officers are responsible for tracking patients who are referred to ensure they get appointments and receive treatment and there may be 1,000 patients in this process at any one time.

Fulfilling these responsibilities is largely a manual process because the information needed is not in OptoMize. The Ophthalmologists can enter details of appointments made with referred patients and of treatment outcomes into OptoMize but because there are few computers that can access in OptoMize in the hospital, in most cases they send Failsafe Officers a form with the details.

The Failsafe Officer summarized the job as one big on-going detective hunt – continually trying to find ways of checking whether patients were in the right place and were being progressed through the system. Sometimes they could do this directly by using OptoMize but often it was a case of checking other systems and of communicating with other healthcare agencies. They had been given access to the appointments system of one of the hospitals and this helped but much of the time was spent ringing people to see what had happened to particular patients.

The process led to much manual entry into Optomize – entering details of
patients and moving them from one queue to another. The Failsafe Officer thought it might be possible to get OptoMize to do more searching and reporting for them, e.g. listing patients in various queues. The reports, at present, told them what targets they were hitting but did not help them manage the patient load more effectively.

But the Failsafe Officer concluded they were still a young service and they had made a lot of progress.

*The job is developing as we go along really and so is the system. The only way we can see what we need is to be doing it and then we can ask 'can the system help us with this?'

Failsafe Officer

### 7.6.6 The Design Process

In the early stages of the development of the Diabetic Retinopathy Screening Service different strands of the system were developed separately. When the North and South of the County merged there was an organisational design exercise to merge the service into one team and undertake the screening in a number of fixed sites. In a separate exercise technical work was undertaken to integrate the databases from the North and the South. When this was unsuccessful the whole service was paused. The National Programme had issued guidance and targets for the performance of the service and the pause was an opportunity to re-design the pathway.

When the restart was begun, it was again regarded as a technical task to use Quest Browser to obtain a new and ‘clean’ database from all the GP practices in the County. The Clinical Change Facilitator commented on this stage of the design process.

*The first time around when most of these changes were happening, it was IT ... it wasn’t even IT internally to us - it was a company coming in to give Retinopathy a new system.*

Clinical Change Facilitator

This process did not yield an accurate database because of the rate of change in the diabetic population and problems of coding etc. It led the IT team in conjunction with the staff of the Retinopathy Screening Service to take a different approach. They concluded that, whilst the detailed operational practices of the delivery of the pathway were being worked out, especially the increasing role of Failsafe Officers, there was a need for IT staff to work very closely with the operational staff so that clinical involvement in the development of technical systems could be greater. A crucial part of this change of approach was the embedding of a Clinical Change Facilitator – a hybrid - with the Screening Team.
This time around we have had clinical involvement in it, and there is a lot more questioning of what they needed from the technical system to do the job

Clinical Change Facilitator

But there were limitations to the changes local IT staff could make to OptoMize which has been designed to meet the requirements laid down by the National Diabetic Screening Programme. They could not change the national data set and major changes would involve a contract review with the suppliers. There were, however, quite a number of ‘tweaks’ possible to customise the existing system to local needs, such as, changing the flags so warnings came up earlier.

Although there was a belief that version 2 of OptoMize would support the operation of the Screening Programme more effectively than version 1 there was a realisation that there was more to be done, for example, to help the Failsafe Officers move all patients through the process and sharing information more effectively at the boundaries of the system.

7.7 Discussion

The diabetic retinopathy screening pathway has a dedicated technical infrastructure that provides much of what is needed for an integrated service. It is technical support to implement the guidance and kpis of the National Programme for Retinopathy Screening. However, the rapidly changing nature of the diabetic population and the many different circumstances that can arise during the screening process mean that the overall sociotechnical system delivering the pathway has to be resilient and responsive. The use of a technical solution Quest Browser to extract information from GP records has been useful but has to be backed up by an on-going dialogue between the GP Practices and the Screening Service. Similarly, OptoMize may signal how to move most patients through its various ‘queues’ in the screening process but there are many patients who fall through the cracks. In these circumstances it is up to the healthcare professionals to spot the needs and take corrective action. It is noteworthy that the role of the Failsafe Officers has become more prominent and the ability of OptoMize to support their detective work is crucial to the success of the service. Their role has strong echoes of the ‘progress chasers’ in manufacturing plants that ‘oiled the wheels’ of automated production systems.

The design process for the Screening Service has had an evolutionary character with different facets of the service in focus at different times. Initially the merger of the two PCTs in the county meant there was a focus on organisational change. Then the promulgation of the National Screening Programme meant there was a focus on designing the service to meet the targets of the programme. Separately there were technical efforts first to merge two databases and, when that was not successful, to restart the service with a clean database by using QuestBrowser to extract data from...
the GP records. These rather separate ventures seem to have served to set up a basic structure for the pathway that, when put into operational practice, revealed the many areas where patients were likely to ‘slip through the net’. At this point a design approach was used that focused on the operational delivery of the service and, by using clinical change facilitators to ensure close clinical engagement with technical developments, issues of service design (to meet the requirements of the National Screening Programme), the detailing of work roles and responsibilities in the screening service and the refinement of the technical systems supporting the process were addressed in an integrated manner, albeit within the constraints of the existing policies and technical system.

7.8 Commentary: eHealth Support for Sequential Interdependency Pathways

Both of the pathways reported in this chapter are dominated by sequential interdependencies, by a series of handovers that sometimes have to cross major organisational boundaries. In theory the information sharing need is to ensure that specific information about patients passes effectively between the particular front line agencies and workroles involved in each handover. The task for the designers of information systems should then become one of producing systems that can support each handover. But in practice the emphasis in the top down developments has been designing a system to enable the management of the pathway against kpis derived from national frameworks. This has left much work to be done at a local level to create a system that can assist frontline handover tasks. And the two cases demonstrate that these handovers can be anything but simple – there can be many variations, there can be misunderstandings about what the receiving party needs to know, there can be failures to communicate, issues about common understandings of ‘codings’, failures in trust etc.

In neither case is the process of developing the pathway complete or the technical systems to support it fully in place. In both cases the biggest hurdles to overcome are at boundary crossing points. In Walsall, getting the stroke register to provide operational support to the stroke rehabilitation service in the community is a major goal. In Northamptonshire it remains to be seen whether the Quest Browser approach has made a major contribution to the issue of collecting data from GPs and finding ways of tracking patients through the Acute Hospitals remains an issue. Given the turbulence in the NHS world it seems likely that there will always be a need to keep some design capacity in hand and some flexibility in the technical systems to cope with an ongoing challenge of change in pathways of these kinds.
8 Reciprocal Interdependencies in Intermediate Care and the Frail Elderly Pathway

8.1. Introduction

In many healthcare circumstances the patient needs the attention of different healthcare workers and healthcare agencies at the same time and there will be reciprocal task interdependencies to manage. This chapter explores two pathways in which reciprocal interdependency is the dominant characteristic. The focus in both cases is the Intermediate Care Team (ICT) which occupies a boundary-spanning role between Acute and Community care. Many patients when discharged from hospital need intensive care for a period of time before they can resume more independent living. This is the role played by the Intermediate Care Team. It is significant for the study of e-health information crossing organisational boundaries for three reasons:

1. Intermediate care involves many disciplines that share the care of the patient in the time frame after they leave hospital and relate to Social Services for ‘shared health and social care’.

2. Patient care is often provided in their homes and this means that health and social workers have to be mobile with all the consequences this brings for sharing information.

3. It is a national objective to provide more support for patients in the community rather than treat them in hospital that is more costly and can be detrimental to the patient’s wellbeing. As a result there are many developments taking place in care pathways at present that are changing the role of the Intermediate Care Team.

This chapter first examines Intermediate Care at Northamptonshire where developments throughout the research period meant that we could observe an e-health system development team during systems development. This is followed by an examination of Intermediate Care in Walsall where we followed the progress of a development team creating e-health systems to support a new Frail Elderly Pathway (FEP).
8.2. The Intermediate Care Pathway in Northamptonshire

8.2.1 History and Organisation

The current countywide Intermediate Care Service was formed from separate services in the North and South of the county when the PCTs merged. Although it operates as one service, there are teams and facilities located in the north and the south of the county as well as four smaller specialist centres. As part of the county IT initiative, the Intermediate Care Service adopted SystmOne as its electronic patient information system in 2006.

8.2.2 Information Sources

The pathway was constructed with the help of the clinical change facilitation team of the IM&T Department and analysis of documentation that represented different parts of the pathway. The experience of use was informed by discussions with clinical staff from the north and south branches of the intermediate care services. Three members of the change facilitation team who had experience of working in intermediate care had recently undertaken a shadowing exercise in the Intermediate Care Teams to evaluate the use of the current e-health system and interviews with them on this exercise were also undertaken. The design process was described in four interviews with IM&T staff, the analysis of documents and attendance at three meetings of the ‘refresh’ design team. Attendance at the design meetings also gave the opportunity to be part of less formal discussions before and after the formal sessions.

8.2.3 The Intermediate Care Pathway

The first part of this pathway is a time-critical referral: a sequential interdependency. Once admitted to the pathway, a care plan is established which may involve the shared health and social care of the patient by a range of nursing, medical, therapy and other carers in a complex, rapidly changing pattern of reciprocal interdependency. The target is for patients to be given intense community support for as short a time as possible (one to six weeks) and thereafter another assessment process leads to discharge from the pathway to healthcare provided by their GP and local district nurses and social care provided by social services and others.

SystmOne has been in use in ICT for several years. When patients enter the pathway a SystmOne record is created which can be shared, with the permission of the patient and the team, with other community staff who care for the patient and with GPs whose practices make use of SystmOne. Similarly if the patient has been treated previously by other community services or by their GP there will be an existing SystmOne record that can be accessed with permission by the ICT. Information about the patient from...
### Pathway

<table>
<thead>
<tr>
<th>1.1. Patient discharged needing intermediate care</th>
<th>1.2 Patient referred needing intermediate care</th>
<th>2. Care Assessment</th>
<th>3. Multi Disciplinary Care Provision (one to six weeks)</th>
<th>4. Assessment for Discharge</th>
<th>5. Discharge</th>
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</thead>
<tbody>
<tr>
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<td>Other referrals</td>
<td>Assessment for IC</td>
<td>Develop care &amp; rehabilitation plan</td>
<td>Assess for discharge</td>
<td>Handover</td>
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<tr>
<td></td>
<td></td>
<td>No</td>
<td>Deliver care</td>
<td>Social care planning</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Yes</td>
<td>Review progress of care</td>
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**Linked Pathways**

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<th>Social &amp; GP Care</th>
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</table>

**Roles & Agencies**

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<th>Referral from A&amp;E, GP, Community hospital, social services or other</th>
<th>ICT Admin (triage) ICT Assessment nurse</th>
<th>ICT Team: Nurses, OT, Physio, Rehab. Assistants, Podiatrist, Dieticians, Psychiatric nurse,</th>
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</thead>
<tbody>
<tr>
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<td></td>
<td>GP Medical Consultant Speech Therapist Care Manager Care Homes</td>
<td>Assessment Nurse</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Social Services</td>
<td>Social Services</td>
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**Inter-dependencies**

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<th>Internal Real-time reciprocal few-to-known few</th>
<th>Internal Real-time reciprocal few-to-known few</th>
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**Communications**

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<td>Referral letter</td>
<td>Referral letter</td>
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</tbody>
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**IT Systems Sharing possible**

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<th>SystmOne (with patient permission &amp; share)</th>
<th>SystmOne (with patient permission &amp; share)</th>
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<tbody>
<tr>
<td>EMIS etc</td>
<td>SystmOne with patient permission &amp; share</td>
<td>SystmOne with patient permission &amp; share</td>
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<tr>
<td>EMIS etc</td>
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<td>EMIS etc</td>
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<td>CareFirst</td>
<td>CareFirst</td>
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</table>

**Figure 8.1**

The Intermediate Care Pathway in Northamptonshire
the referrer is usually provided by telephone, fax or secure e-mail. When GPs are using EMIS, Social Services are using their system (CareFirst) and private providers are using their own systems, there is no provision for information to be shared in an electronic form.

8.2.4 Experience of Use

8.2.4.1 Care Assessment

The referral of a patient to the ICT is usually by telephone to the administrative office. If it concerns a hospital in-patient the ICT have 48 hours to make an assessment of whether IC is suitable for the patient. If the call is from the community (from a wide variety of sources) assessment needs to be within 3 hours. The administrative staff undertake a triage process to gather sufficient information for an assessment nurse to make a clinical decision and also check whether a SystmOne record already exists for the patient. If a record exists it can be of assistance to the Assessment Nurse and to the formulation of a suitable care plan. In order to access a SystmOne record the staff need the permission of the patient and of the holder of the record ‘to share’. The staff reported that patients were usually only too pleased to give permission. The holders of the record, whether they were other Community Services or GP practices were also co-operative but it could take time to get their response by which time decisions usually would have had to be made.

So I can send a request to a District Nurse saying ‘we have got Mrs Bloggs on our books now, can you share the record with us? …but if they are all out district nursing and there is nobody sat there……..

ICT Nurse

Meeting the deadline for the three-hour assessment can often be a challenge. If the patient is seen at home it will be necessary to get all the information from the admin staff, make the assessment and then return to base in order to record that the patient has been admitted to the service and agree the care plan. The difficulties of working in this way have stimulated discussions about ‘mobile working’, i.e. the use of laptops etc, to provide a means of accessing and updating records whilst away from the office. This issue is discussed further below.

8.2.4.2 Shared Care in the Pathway

Once a patient is accepted by the ICT a care plan is prepared and rapidly implemented. Depending on the circumstances of the patient, it may involve different kinds of nursing care, visits by therapists (occupational, physiotherapists, psychological etc) and liaison with a social care manager. In complex medical cases a consultant, resident part-time in ICT, may also
be involved. If the patient is at home, the enactment of the care plan will involve visits by all those involved. Details of all such visits are recorded in SystmOne which necessitates a considerable volume of data entry. One of the major concerns of staff is that they are required to also enter the data in SAP (Single Assessment Process) which is an agreed document structure in which health and social workers record their visits to the patient and leave a copy with the patient so that anyone visiting can see what service they have been receiving. It is a process designed to help co-ordinate the care of the patient. A copy of the paper document is taken back to base and entered into SystmOne. The requirement to record everything several times was regarded as a very inefficient use of time. Another form of duplication that the staff found irritating was ‘regurge’. This is when they visit a patient several times to repeat an intervention, for example, dressing a wound, and afterwards had to enter exactly the same information as before into SystmOne.

Ways around duplication were being discussed and there had already been some trials of the use of laptops but they had not been successful. A trial of laptops by District Nurses was actually in progress but there were connectivity problems, cost-benefit issues about justifying their distribution and issues of weight. One nurse said ‘we will need a trolley to carry everything’. What staff did report from the pilot work with the laptops was that patients tended to be very positive about seeing them in use; they could see their record and who was caring for them and this seemed to give a sense of confidence and security.

The team caring for a patient attempted to have regular multi-disciplinary meetings to co-ordinate care but getting together was often difficult. One hope was that having a shared record on SystmOne would help people co-ordinate their activities. However, what had become apparent was that nearly all the disciplines involved recorded information in SystmOne in different ways and this made it hard to share the information. These differences had arisen because SystmOne has customisable templates and, in the setting up of the system for different services and disciplines, different templates had been designed and implemented.

_We had got to the point where people were saying there are 5,000 different care plans in there and we all talk of there being 6 different ways of recording blood pressure results._

IM&T Manager

One of the big challenges for the ICT is the turnover of patients and the scheduling and re-scheduling of staff to provide their care. Up to 150 patients were being cared for at any one time. The current staff allocation process involves a paper diary and a ‘whereabouts sheet’. Allocation of duties was usually done at an early morning meeting before staff went out on patient visits. One of the ICT nurses reported that last minute changes
to allocations were very frequent and that it was very difficult to protect supervision, training and meeting attendance because of late call outs.

ICT management wanted SystmOne to include a workload module which could be used for scheduling future work but investigations by IM&T had shown that records were incomplete which would make caseload assessments unreliable.

*Before the scheduler can work we have to have a system that reflects reality.*

IM&T Manager

The general issue of using SystmOne to generate reports to help manage the ICT was raised by the managers. There were a number of kpis for the service and it was difficult to get statistics on them from SystmOne. The basic measures used in the construction of reports were the number of patients on the pathway and the number of visits to patients per member of staff. The managers felt there was a need to ensure patient records were up-to-date, e.g. the records were changed when a patient left the pathway, to standardise the reporting of activities in SystmOne, and in particular to agree the codes to be used in order that informative management reports could be generated.

8.2.4.3 Discharge from the Pathway

At the end of the pathway a further assessment was made and the patient discharged usually to their GP and local services such as district nursing. The social care plan for the patient may also need amending. A letter would be sent to the patient’s GP. If the patient’s GP practice was a SystmOne user and sharing had been agreed, a joint record would now exist that contained both the GP records and the records of the care delivered by ICT. One of the Clinical Change Facilitators commented on the GP view of this situation.

*GPs are quite happy to share. Their complaint is mainly the amount of information that then goes in the record, because you see all the nursing care, and they don’t necessarily want to see every little bit*

Clinical Change Facilitator

8.2.5 The Design Process

8.2.5.1 The ‘refresh’ project

In order to promote the use of SystmOne, IM&T had developed a network of SystmOne ‘clinical champions’ who were based in the services already using the system. The clinical change facilitation team met the champions regularly who provided feedback on the use of the system and made many suggestions for improvements to the system. One of the clinical change
facilitators described the state of their office as these requests accumulated.

So we have got – we call it our’ wallpaper’ in our office – a lot of flipcharts which make sure we keep sight of all the wants and needs that have come in.

Clinical Change Facilitator

The clinical change facilitators contrasted the bottom up process of dealing with these requests with the top down ones which came via the commissioners. The process of reviewing bottom up suggestions was partly about getting support for them from other stakeholders, partly about the resources involved, partly about technical feasibility and partly about not compromising the safety and integrity of the system. Information governance staff of the PCT reviewed the impact of any proposal for change for risks to safety and integrity. The issue of what could be changed locally from a technical perspective was often problematic because SystmOne only permitted certain kinds of changes to be made. More fundamental changes had to be ‘escalated’ and could take a long time.

As a result of reviewing requests by community stakeholders, the IM&T department had established an internal project to deal with a number of them in an integrated change programme called the ‘refresh project’ whose main aim was to reduce the 5,000 templates currently used across the 22 community services to about 100. The aim was to standardise the templates for commonly used assessments and care plans to simplify data input, avoid needless replication and help information sharing. Alongside the standardisation objective was the objective of moving forward with mobile working by identifying key workers who would most benefit from laptops and setting up trials for them.

The project was planned for 8 months (April – December 2010) in three phases. It would begin with District Nurses but then extend to the 22 services using SystmOne. The project team used some of the processes within PRINCE2 to manage and document the project but considered that the full methodology would be too ‘heavy’ for a small project of this kind. The three phases of the project were:

Phase one - an assessment of the ‘as is’ processes in use in SystmOne for the assessments and care plans in the services. Clinical change facilitators shadowed the clinical staff of the services and logged the various care plans in use.

Phase two - configuring new templates and testing them with users. It was also the phase in which new reports could be designed to map onto the needs of kpi’s and a new mobile working trial was planned. The team were beginning phase two at the time of the interviews and gave
us the opportunity to observe design meetings held in this phase (see section 8.2.4.2 below).

**Phase three** - the training and trial phase including ‘go live’ with the new templates.

### 8.2.5.2 Meetings of the ICT Refresh Team

Monthly meetings of the ICT refresh project design team were held in the summer of 2010. The first, attended by three members of the clinical change facilitator team, discussed progress in formulating templates for three assessment and care plans in intermediate care. Nurses wanting alternatives within templates but managers wanted only one version of the template to better serve the collection of data against kpis. It had been agreed that the nurses doing the assessment of patients referred to ICT were in most need of mobile working and the team considered how to deploy ‘tough’ laptops to them for a trial period.

The second meeting of the team led to a major change of direction of the project. It was attended by two ICT service development managers. Originally the meeting was called to review the kpi targets for ICT services and what they meant for reports generated by SystmOne. However, the service development managers reported that ICT had made a successful business case to the commissioners within the national QIPP (Quality, Innovation, Productivity and Prevention) initiative to develop ICT so that it could play a more substantial role in avoiding admissions to hospital and managing care in the community especially for elderly patients. This development meant there was new urgency to deliver the SystmOne changes and also changed priorities. Staff numbers in ICT would be expanded, as would the number of beds, and the pathway for care was being re-designed. The commissioners wanted the new pathway ready for winter so plans needed to be in place by end of September.

The service delivery managers asked that the changes in templates for ICT be implemented in September rather than December and that ICT now receive the full attention of the design team. The change facilitators agreed to delay developments for other services and ‘Wheelchairs and Falls were dropped’. The service development managers also said that templates should be standardised for ICT alone without reference to other services and that ensuring data was collected in the form that enabled reporting against the new kpis for the service had to be a priority. One of the clinical change facilitators reflected after the meeting that the focus on supporting individual clinicians seemed to have been lost in favour of managing the new pathway. Other teams were working on pathway redesign and on organisational changes, e.g. on creating a single point of referral into the service and a much greater role for administrative staff. The service development managers also asked that the trial of laptops for
mobile working be replaced by an exploration of the locations where ICT staff could ‘drop in’ and use computer facilities to access SystmOne.

Subsequent to the meeting, the refresh project changed its scope and timescale to give the ICT project priority and rapid progress was made in developing the two specific templates that were required: for admission avoidance and to facilitate early discharge respectively. At the third monthly meeting the team were joined by an ICT nurse with responsibility for team facilitation and a community matron. One of the items on the agenda was ‘training the trainer’ for the adoption of the new templates because the training of all ICT staff was scheduled for the middle of September. However, the main issues debated were the implications for SystmOne of a revised kpi reducing the target length of stay of patients on the pathway from 14 days to 5-7 days. The implication for the service managers was that they had to be very resource efficient and they wished to put electronic scheduling back on the agenda.

Thereafter, it was planned to hold weekly meetings in order to make the rapid progress necessary for delivery in September.

8.2.5.3 Reflections on the Refresh project

Interviewed in December when the refresh project was due to finish, one of the clinical change facilitators reported that after a 3 month period in which there was a real impetus to the project and everything was done to develop SystmOne facilities to serve the new ICT pathway, the momentum had been lost and various aspects of the project remained ‘in the air’. The regular meetings had been discontinued mainly because ICT were too busy with other planning to attend. Implementation also tailed off because the peer trainers who were going to train their colleagues could not be trained. Nevertheless template configurations had been completed and were ‘signed off’ by the users. There were however, a lot of loose ends to tidy up and the consequences of the new pathway for SystmOne had not been properly explored.

During this period the nature of the new pathway had become clearer. Called CECS (Community Elderly Care Service), it was similar to the normal ICT service except that it was for over 75 years olds. The aim was not only to get early discharge of elderly patients from hospital but to do more to prevent unnecessary admissions to hospital. As a consequence, the front-end referral process would have to be more streamlined. Another aim was to take a larger number of patients and to move them through the intensive care process as quickly as possible. CECS would use SystmOne as its electronic e-health system and it would need to generate reports to inform progress on kpis. It was planned that a ‘virtual ward’ would be established in SystmOne: a list of all the patients currently on the pathway with up-to-the minute accounts of their condition and the care they were receiving. Such information, if available to all the team
members looking after a patient, would be the equivalent of the SAP information held on paper records at the patient’s home.

The clinical change facilitator said that, knowing these changes were afoot, there seemed no point in pressing on with the tidying up exercise because there would be requests for major changes in SystmOne in the pipeline. She said that IM&T were not involved in putting together the business case for CECS and that, although there were obviously implications for computer support, they still did not know what they were.

However, there was a meeting planned for the CECS project manager to brief them on what was needed.

**8.2.6 Discussion**

Although this case began as a study of e-health systems serving the ICT pathway it became a study of e-health systems to support a new pathway to provide community care for the elderly. In Walsall the ‘shared health and social care’ case was also of an ICT involved in the development of a Frail Elderly Pathway but Walsall had already implemented what Northamptonshire were planning. Since the two cases involve a similar ambition, the evidence from two cases will be considered after the Walsall case has been described.

**8.3. The Frail Elderly Pathway at Walsall**

**8.3.1 History and Organisation**

Walsall Community Services has an ICT providing a similar service to that provided in Northamptonshire. Like the service in Northamptonshire it is also at the centre of efforts to care for more patients in the community rather than in hospital. There is a strategic ambition, as in Northamptonshire, to develop services that will keep the frail elderly, especially those who tend to be ‘frequent flyers’ in A&E, out of hospital whenever possible by providing intensive care in the community. Unlike Northamptonshire, Walsall had implemented a frail elderly pathway (FEP) approximately a year before we undertook research in the ICT. The pathway was supported by iPM, an e-health system supplied as part of the NPfIT, and, at the time of the research, developments were underway in iPM and in FUSION to provide an e-health service to better co-ordinate the shared care being offered to the frail elderly on the pathway.
8.3.2 Information Sources

The pathway map was constructed with the help of the business change facilitation team of the IM&T Department and analysis of documentation that represented different parts of the pathway and plans for its development. Experience of use was informed by discussions with a member of the senior staff of community services and three members of the ICT. These interviews also addressed the design process and further information about this process was obtained from interviews with three members of the IM&T. Detailed information about the on-going design process was obtained by attendance at 15 design team meetings over a ten-month period. The observations were supplemented by access to a wide range of project documentation.

8.3.3. The Frail Elderly Pathway

The pathway has similar phases to the ICT pathway in Northamptonshire but is limited to the frail elderly and already includes assessments to avoid admitting the patient to hospital (1.1). At the time of the research approximately 100 patients were on the FEP at any one time. However, the full technical support structure that was planned for the pathway was still under development. As a result the experience of use (reported below) is based on the IT support that was already in place. At this time the Rapid Assessment Team had access to records of patients held in FUSION which will exist for those with previous episodes of hospital admission. The ICT team keep their own records on iPM and had access to iPM records throughout community services. They did not have access to GP records. An iPM record was established for any patient entering the pathway and could be shared, with permission, by other users of iPM. Access did not extend to other specialists, e.g. to GPs, private providers or to Social Services (except social workers embedded within the ICT). SAP, the record held in patients’ homes, is shared by all providing patient care.

When the improved technical system is implemented there will be specialist facilities added particularly to FUSION. The plan is to create a ‘virtual ward’ in FUSION and monitoring of the patient may include telehealth facilities in the patient’s own home. The plans include the introduction of an electronic version of SAP (eSAP) so that the current paper record can be replaced by direct entry at the patient’s home to an electronic record. Discussions were also taking place to examine the possibilities of data sharing between FUSION and Paris, the system used by social workers.
8.3.4 The Experience of Use

8.3.4.1 Discharge, Referrals and Rapid Assessment

The FEP started in April 2010 with the appointment of two co-ordinators, one based in ICT and the other in the hospital trust. Its initial thrust was to bring patients onto the pathway through nurse-led discharge procedures. The hospital based co-ordinator and other nurses worked in A&E and the assessment ward as part of the triage process to assess patients who were suitable for the pathway and did not need to be admitted to the hospital. This process overlapped with the role of the community matrons. Each community matron was assigned to an area of the borough and had the task of working with GP practices, district nurses etc, to identify patients at risk of admission to hospital and to intervene and set up alternative care plans wherever possible. Community Matrons went into the hospital regularly to intercept ‘their’ patients when they arrived in A&E and to try and arrange early discharge when they had been admitted. Most of the patients they dealt with fitted the category of ‘frail elderly’ but not all. When the FEP was established the community matrons worked with the co-ordinators to synchronise their discharge efforts with FEP. In many instances the co-ordinators identified ‘the referral’ and asked...
Figure 8.2 The Frail Elderly Pathway at Walsall

[( ) indicates e-health systems under development]
one of the senior nurses in the ICT or one of the community matrons to make an assessment. One of the community matrons was now spending a substantial amount of her time with the Frail Elderly team and she gave an example of how it worked:

_The hospital FEP co-ordinator rang me to say that a lady presented in A&E yesterday and the co-ordinator thought she might be suitable for FEP. So tomorrow I will go and see her to assess whether we could manage to stabilise her at home._

Community Matron

When a referral was made the nurse making the assessment also had access to electronic information about the patient.

_I had a new referral this morning for frail elderly and the first thing I did was to check on FUSION to see what other clinical staff were involved and what her last lot of bloods were._

ICT Nurse

Often the patients are ‘frequent flyers’ at the hospital and as a result FUSION will contain a great deal of information about them. As one of the interviewees put it ‘You have got all the jigsaw puzzle pieces together’. The staff had no direct access to GP records but GP staff were fairly quick to respond by fax.

_We would all die without the fax_  

ICT Nurse

The community matrons also had another facility to help them respond quickly. A&E staff were familiar with the matron’s caseload of ‘frequent flyer’ patients and sent them a FUSION Alert whenever one of these patients re-presented and it was often the case that a community matron could attend and find a way of avoiding hospital admissions.

In December 2010 a rapid response team was established to reach patients before they went to hospital. The service was available from 8.30 am to 10.00 pm, 7 days a week. The staff said that, at the point of referral, because of the need to respond in hours, they were very reliant on the information the referrer could give about the patient because they had to make an instant response and often did not have time to consult FUSION or get faxes from GPs. Once an initial assessment had been made and the patient admitted to FEP, the assessment nurse set up the SAP documentation in the patient’s home. This consisted of an ‘overview and contacts list’ behind which every nurse, therapist, carer etc who became part of the team could add their specialist record. Carbon copies of the SAP documents completed by members of the team were taken back to the office to be put on the patient’s iPM record.
For the co-ordinator of the FEP the creation of the rapid response team was making co-ordination more difficult for three reasons; more patients were coming into FEP for a short period of time, they had to move very fast in the rapid response phase and there was now a bigger team to co-ordinate. Many patients were admitted as a result of falls at home and they may stay on the pathway for a relatively short time. The team had previously had morning meetings but now people were beginning to feel they were not coping.

_We are getting comments like ‘I am frightened of missing something’ because of the complexity of who else you have to co-ordinate with and the speed you have to do it.....You know, somebody might miss their IV antibiotics for a couple of visits because we thought the district nurses were doing the next doses_  

ICT Nurse

There were calls for an electronic whiteboard like in A&E and a strong feeling that, as the FEP caseload got bigger, the more they would need a ‘virtual ward’ where they could find all the new data about their patients.

### 8.3.4.2 Providing Support for the Frail Elderly

The care of the frail elderly within the pathway could continue for up to seven weeks perhaps with a changing team delivering care as the patient’s condition changed. As a result of the implementation of the FEP, and the gradual ramping up of the numbers on it, the changes were putting pressure on the existing ways of co-ordinating care within the team and with other agencies. The usual ways of getting information and co-ordinating care; SAP paper-based records, team meetings, using the telephone, getting faxes from GPs etc, all took time and getting back to the office to put data into iPM was a strain. The hope of many was mobile working so they could access patient data and input their reports ‘on the road’. There were plans for e-SAP but there were doubts about its achievement.

_We have had plans to move to eSAP for seven years and the fact that we have got nowhere tells you something about how difficult it is._  

ICT Nurse

Some of the interviewees had used a laptop on their rounds and they found it very useful not only to access patient records and make their reports but to send and receive emails. Some of the interviewees recognised the advantages of a laptop but also worried about the weight and the need to carry a printer in order to leave copies with the patient. And some recognised that the current ‘workarounds’ by which they got information and made reports whilst on the move could be fairly effective.
Don’t get me wrong, - having a laptop would be very beneficial. But we do learn how to manage. I can get on FUSION on any computer in any clinic and I can do my emails. So you learn your way around...you know which doctors surgeries you can go into and say ‘can I access FUSION?’

ICT Nurse

Unfortunately, you could not access iPM remotely and several staff felt that real progress needed iPM and FUSION to be able to ‘talk to one another’.

One of the important areas where they needed to share information was with the care managers from social services. The main documentary way of sharing information was through SAP which was only fully available when you were with the patient. Two social workers were embedded with the ICT and when, for example, they had a multi-disciplinary meeting they could look at their Paris records for a patient whilst healthcare staff looked at the iPM records. Together they could build up a picture of the patient. But for many of the patients, responsibility for social care rested with local care managers and it was harder to share patient information with them. Another expressed need therefore was to be able to access Paris records via FUSION. Some limited progress in this direction was reported. The social workers in ICT had been given limited access to FUSION and the ICT FEP co-ordinator was now able to use the social workers’ computers to access to Paris records.

The interviewees also expressed views about the possible use of telehealth equipment in the care of FEP patients. They were familiar with this equipment because social services already deployed telecare equipment for patients with long-term conditions. The feeling was that the healthcare staff could manage the patients who were in the acute phase of the pathway better if telehealth equipment could be installed. These patients were often quite unstable and it took a lot of attention and frequent visits to take good care of them. If equipment could be installed so that anybody in the patient’s home could report results like blood pressure on a regular basis to a control centre it would be very helpful. They would then be alerted if a patient’s condition deteriorated and could take rapid action. In general the view was that they were coping with existing e-health and manual systems while the FEP programme was in its infancy but they foresaw great problems as the numbers grew. They had hopes that better e-health systems would help them cope better with the growing populations of sick, elderly people scattered across the borough.
8.3.4.3 Managing the Frail Elderly Pathway

As a new venture of considerable significance to the LHE the FEP had been under scrutiny ever since its inception. One of the first information technology requirements was to establish two separate monthly reporting processes, one for the nurse-led discharge process and the other for rapid responses to community referrals. Initially there was no way of drawing this information from iPM records so the leaders of each service had to create a standalone database. It took a lot of time each month but, as one of the interviewees said, ‘since funding depended upon it, we had to do it’. Several of the interviewees were concerned about managing expectations of the pathway. They knew it was helping to prevent hospital admissions but they thought it might only serve to slow the inevitable rate of increase of elderly patients being admitted to hospital as the population of elderly people in the borough grew.

8.3.5 The Design Process

8.3.5.1 The History of the Frail Elderly Pathway

The Business Case for the Frail Elderly Pathway cited a projected 40% increase in the elderly who are over 85 in Walsall in the period 2007 to 2018. This ‘demographic timebomb’ was recognised by all of the agencies in Walsall involved in the care of the elderly and they came together under the banner of ‘champions of the elderly’ to consider how to respond. They created a ‘Dragon’s Den’ form of competition in which they invited ideas on possible ways forward and these were evaluated by a team of experts on the elderly. The ICT, whose caseload was already 50% frail elderly and the social services division that dealt with social care for the elderly were seen as key elements in a future pan-agency strategy. In December 2009 a Business Plan, supported by all the relevant agencies, was presented to the NHS Commissioners to form the FEP. The major objectives were to intervene when or before elderly people go into crisis and, wherever possible, to provide intense periods of acute care for patients in their own homes. The cost justification for the pathway was the savings that would be made by reducing the numbers of elderly patients requiring hospital treatment. One of the major cost items was for the development of new e-health systems regarded as essential if a distributed healthcare system was to be well co-ordinated across the many disciplines and agencies involved. According to the Business Case there were the following requirements for e-health developments:

- **Able to record patient details and current care**
- **Enable health and social care professionals to view existing records throughout the health and social care economy in Walsall**
Both hardware and software needed for use at the patient’s home and staff to use the IT systems

A systems that will enable the ‘bed’ management of patients in the systems

Incorporated the use of tele-care and monitoring equipment

To be able to record data, so that clinical and other audits may be conducted

FEP Business Case (December 2009:12)

The business case was accepted with the expectation that the FEP would start on 1st April 2010 but no implementation plan had been put in place. In this vacuum Community Services set up a group to plan the changes to the ICT and this enabled two co-ordinators to be appointed and for the pathway to start taking patients in April. It soon became apparent that the pathway would have implications for many other agencies and representatives of these agencies, which included the Acute Trust, the Commissioners, the Ambulance Service and Social Services, joined the group so that it rapidly became an inter-agency venture. As several of the interviewees reported ‘it had a cast of thousands’, and whilst there were very good discussions, actions tended to be left to a small number of individuals. So a number of sub-groups were formed to deal with different workstreams:

Workstream 1: Step Down (nurse-led discharge from hospital)

Workstream 2: Averting a crisis (the rapid response process)

Workstream 3: Proactive Management (caring for the patient on the pathway)

Workstream 4: Communications (ensuring all relevant agencies are engaged in the design process and informed of its progress).

All of these workstreams were chaired by members of ICT but had a membership from a range of agencies.

In addition to these workstream groups, the range of e-health developments that were required by the FEP meant informatics design boards were also needed. Two were formed, one for the overall needs of the pathway and the other specifically to develop eSAP. In the period September 2010 to June 2011 the research team had the opportunity to observe three meetings of the overall steering committee and six of each of the two informatics design boards. The work of these meetings is summarised below and a longer account is provided in appendix three.
The steering committee meetings for the implementation of the FEP were well attended by representatives of the many agencies involved; the ‘cast of thousands’. The meetings addressed four main issues: (1) getting agreement on an implementation plan for the pathway, (2) dealing with the implications of the pathway for agencies such as the Ambulance Service, (3) clarifying what the commissioners expected from the pathway and how this would be represented in kpi’s and (4) setting up the boards that would pursue e-health systems developments for the pathway.

The six meetings of the e-SAP Informatics Board had the goal of running a trial of e-SAP within six months. This required a means of sharing data between iPM and FUSION and a means of capturing data electronically in patient’s homes (a ‘digipen’). The informatics service was struggling with the need, as a ‘back room service’ to cut their resources by 35% and were unable to do the necessary programming with the result that at the end of this period, no e-SAP trial had been planned.

The six meetings observed of the Frail Elderly Informatics Board considered the other e-health developments needed by the pathway; the creation of a ‘virtual ward’, arrangements for Paris/FUSION access, the issuing of laptops to healthcare workers, the possibility of installing telehealth equipments in patient’s homes and the collecting and reporting of information against kpis for the pathway. At the end of this period the virtual ward was available in trial form and laptop and telehealth equipment had been earmarked for the pathway. Social Services staff attended the meetings and progress had been made in providing some ICT staff with access to Paris. The operational definition of kpis was contentious because it was difficult to define exactly what contribution the pathway could make to keeping elderly patients out of hospital. Progress was being made slowly and the user community expressed considerable frustration (1) because informatics had limited resources it could commit and (b), because of the wide range of boards they had to refer back to because the Informatics Board had little authority to make decisions. However, the users remained convinced these were necessary developments for the success of the pathway and were determined to continue their efforts.

8.4 Discussion

The implementation of the FEP in Walsall is based on the existing ICT service just as the Community Elderly Care Service (CESC) is in Northamptonshire. Both LHCs are responding to a national strategy that is shifting more healthcare from hospitals to community care and particularly focusing on caring for the frail elderly in their own homes wherever possible. There is wide recognition in the UK and overseas that achieving integrated care in the community raises major policy and operational challenges and the development of the FEP in Walsall shows...
just what kind of challenges it presents for process design, organisational change and technical development. If well co-ordinated shared health and social care is to be achieved many agencies and many disciplines need to be involved in the pathway design. Overlap and intersection with many other pathways means the ramifications of the new pathway are considerable. In addition caring for patients in their own homes who might be quite ill and unstable poses challenges for the speed and quality with which healthcare can be delivered. In Northamptonshire they are setting out with a similar ambition to Walsall, and both LHCs regard the delivery of more sophisticated e-health systems as a vital ingredient to the achievement of an effective service.

In both developments top down and bottom up drivers are in evidence. In Northamptonshire the ‘refresh’ project was an internal exercise to respond to user requests to help them share information more effectively. It was replaced by the top down CESC project funded by the commissioners. The initial aim for improved e-health support for CESC was to help managers achieve the new kpis for the service and local aims, for example, the provision of laptops for front line staff, were quickly abandoned.

In Walsall a wide range of e-health systems developments were planned for the Frail Elderly and many of them, for example, e-SAP, laptops, telehealth terminals and the ‘virtual ward’, were planned to make it easier for front line staff to co-ordinate their work with patients when they were away from base. Nevertheless there was still top down pressure to establish information systems to demonstrate whether kpis for the new pathway were being met and these were the first developments implemented. In Walsall the polices and the implementation plans were both multi-agency and multi-strand but it was proving difficult to hold the strands of development together as implementation proceeded and as a result other e-health developments were slow and frustrating for the user community. The difficulties are partly related by the need for development groups to refer back to the many boards in different agencies that had to approve plans and partly because of the many technical challenges faced by informatics staff in relating different databases, linking them to new equipment and customising the systems that have in place. Their resources were being cut at this time which added to their difficulties.

The Walsall case in particular shows the variety of e-health systems that have a role in delivering this service. It also shows the great challenges of multi-agency co-operation that the delivery of this pathway presents and the need to satisfy top down requirements whilst at the same time leaving room for developments to address the requirements of frontline staff.
Part 3: Analysis, Discussion and Conclusions

9. E-Health Systems Development in Practice

9.1 Introduction: top down and bottom up Design Processes

A key objective of this research project was to examine how e-health systems are being developed and implemented. We had anticipated that this process would be heavily influenced by the top down delivery of major IT systems as part of the NPfIT and that there would be a dynamic to examine between top down deployments and local bottom up developments. In the event neither Lorenzo nor the SCR were deployed in the two LHCs although some NPfIT systems were already in place in the Trusts e.g. SystmOne, IPM, PACS and Choose and Book.

This has meant that the examination of the impact of new top down IT developments on local design processes could not proceed as planned. However, in examining the forces shaping e-health system developments we found another set of national policies that influenced local development in a top down way. These were the national policies that shaped the healthcare pathways in LHCs that thereby influenced local e-health systems development.

In this chapter we explore the forces at work shaping the e-health systems that are developed considering a variety of top down influences as well as the influences from within each LHC. We draw on the evidence presented in chapter 4 that described the strategy adopted in each LHC for the development of e-health systems and the evidence in chapters 7 and 8 that described four examples of the operational delivery of e-health systems. The aim of this chapter is first to review the overall strategy for e-health systems development in each LHC and subsequently to examine the mechanisms and structures in the local design processes that deliver cross-organisational e-health systems.

9.2 Strategic Approaches to e-Health Systems Developments.

Historically in the NHS separate e-health systems have been adopted by each healthcare agency. The result is a ‘sil’ effect that makes it difficult to share electronic patient information across the boundaries to other agencies which is necessary for the achievement of integrated care in pathways. The
strategic solution to this problem adopted in Northamptonshire is to encourage the adoption of a common system (SystmOne) by as many agencies as possible and it is now used widely in community services and by about 50% of GP practices. This is the strategy promulgated in the NPfIT. In Walsall, by contrast, a portal approach (FUSION) was adopted that meant each agency kept its own system but the records of each could be viewed in a patient specific ‘window’. Using this approach Walsall could also deploy the systems provided within the NPfIT but could make them widely available through FUSION, i.e. PACS and, to some extent iPM records, can be viewed through FUSION.

The advantages and disadvantages of these two approaches can be debated from many angles but, on the evidence of this research, they have particular implications for the support of healthcare pathways. In five of the case studies the main technical solution to supporting the pathway in question was to use the principal general-purpose e-health system that was already in place, Thus SystmOne served the intermediate care service and unscheduled care in Northamptonshire and FUSION provided the interface for the stroke pathway, unscheduled care and the frail elderly pathway in Walsall. The exception was the diabetic retinopathy screening pathway for which a dedicated screening system (OptoMize) was employed.

FUSION and SystmOne are therefore being used as general-purpose systems: as an IT infrastructure to serve the needs of many different agencies, disciplines and pathways. If a system is to be used in this way it has to be sufficiently flexible to be adapted to many, emergent needs. Both FUSION and SystmOne are flexible systems that can be locally customized to serve particular needs and, although there are issues about the extent of flexibility (discussed below), there is evidence that both systems have the potential to serve many masters.

But the differences in the two strategic approaches had other implications for the support of a pathway. The advantage of the common system approach is that the agencies and disciplines that have the system can share a common patient record. Thus in Northamptonshire the GP practices, Community Services and unscheduled care services such as out-of-hours and walk-in centres that have SystmOne can work in a closely-coupled way, viewing and adding to a single patient record. Although this has been a long espoused aim of many healthcare informatics professionals it is not without implications for the user community and these are explored later. However, in none of the cases was SystmOne available to all of the agencies and disciplines involved in a pathway and this led to a two-tier effect in which, while some agencies are able to share a common patient record, other agencies that use different systems have to share information by other, perhaps non-electronic, means. Where there is no sharing of electronic information across the boundary, information sharing is at best slower and in many cases does not happen with the result, for example, that clinical
staff repeat history taking, more tests get undertaken etc. The two-tier effect has meant that progress in supporting a pathway can be dependent on whether agencies are willing to adopt SystmOne with the result that there is, for example, relatively little transfer of electronic patient data between community services and the two acute trusts in the county.

The use of the portal approach in Walsall has meant that the agencies in the pathway have been able to keep their own electronic systems but have been able to view electronic patient information on the systems of other agencies in the pathway and have been able to make their information available to other agencies. As a result there is a large and growing population of FUSION users in the acute trust, the community trust, in GP practices and, to a limited extent, in Social Services. The limitation at present is that, whilst they can all access hospital records, it is proving a technical challenge to provide access to the community records on iPM and to the social services system Paris. GP records remain out of reach although there are plans to provide a FUSION version of the SCR.

FUSION is providing a flexible service to which new users can be easily added and links can be made to new systems. It is, however, a service that is evolving in response to emergent needs and the degree of technical challenge. As a result, whilst it gives many people access to patient records, it may or may not provide users with access to the information they need to play their part in the delivery of a specific pathway service.

Another way in which FUSION differs from SystmOne is that it does not enable users to share a commonly owned single record of the patient. Instead it provides access to a common record in which each part is separately owned. The implications of this way of sharing information are discussed in chapter 10.

9.3 Maturity Models of Systems Development

The ways in which the e-health systems have been developed to serve the needs of the pathways described in chapters 7 and 8 are complex; they engage many stakeholders in many agencies, involve issues that go well beyond technical system design and extend over considerable periods of time. Some parts of these processes appear to be well-structured and orderly whilst others parts appear chaotic; a result of developers responding to unfamiliar and emergent problems. In order to make a systematic review of these processes we have employed a version of the capability maturity model (CMM)\textsuperscript{102} approach pioneered by Carnegie-Mellon University. The CMM has a long history and is used to evaluate and benchmark the maturity of organisational and business processes involved in information systems development. The maturity model provides a systematic framework for carrying out benchmarking and performance improvement and includes a series of descriptions of business performance for discrete business
elements. The descriptions are ordered into levels of capability from 'not able to do it' through to 'continuously improving' (Figure 9.1).

<table>
<thead>
<tr>
<th>Level</th>
<th>Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level 1 - Initial (Chaotic)</td>
<td>It is characteristic of processes at this level that they are (typically) undocumented and in a state of dynamic change, tending to be driven in an ad hoc, uncontrolled and reactive manner by users or events. This provides a chaotic or unstable environment for the processes.</td>
</tr>
<tr>
<td>Level 2 - Repeatable</td>
<td>It is characteristic of processes at this level that some processes are repeatable, possibly with consistent results. Process discipline is unlikely to be rigorous, but where it exists it may help to ensure that existing processes are maintained during times of stress.</td>
</tr>
<tr>
<td>Level 3 - Defined</td>
<td>It is characteristic of processes at this level that some processes are repeatable, possibly with consistent results. Process discipline is unlikely to be rigorous, but where it exists it may help to ensure that existing processes are maintained during times of stress.</td>
</tr>
<tr>
<td>Level 4 - Managed</td>
<td>It is characteristic of processes at this level that, using process metrics, management can effectively control the AS-IS process (e.g., for software development). In particular, management can identify ways to adjust and adapt the process to particular projects without measurable losses of quality or deviations from specifications. Process Capability is established from this level.</td>
</tr>
<tr>
<td>Level 5 - Optimizing</td>
<td>It is a characteristic of processes at this level that the focus is on continually improving process performance through both incremental and innovative technological changes/improvements.</td>
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Table 9.1: Capability Maturity Model

Maturity Models can be applied to an organisation, a business unit or a team to provide a road map for performance improvement. The first step plots the current capability to achieve. Assessing the current level of maturity typically involves answering carefully worded questions. The assessments
can be done internally (self-assessment) or externally, by an independent facilitator and may be scored. The second step plans out what needs to be improved. This uses the descriptions for higher levels of maturity to provide the focus for planning performance improvements. To move from one maturity level to another requires actions to be taken that make the organisation more robust, flexible and measurable. Maturity Models have been used for a number of purposes including: helping to visualise how to deliver business benefits in incremental steps; developing and embedding a seamless ‘strategy to delivery’ within an organisation.

The capability maturity approach has been applied in areas other than software development. It has, for example, been used to examine maturity in user-centred design and usability design\textsuperscript{103, 104}. One of the present authors (Eason) has also used it in the context of integrated socio-technical systems design, i.e. where the design process has to address process, organisational and technical system change at the same time. A capability maturity framework was developed for this purpose and applied in an action research approach to systems development in several government departments\textsuperscript{105}. It has since been used in other settings, including local authorities\textsuperscript{106}. This framework covers many of the issues that have emerged in the case studies of design processes in this research and provides a means by which to review these processes. The original framework employed 15 assessment dimensions. Section 9.4 below outlines a reduced version that utilizes ten dimensions. We have used this framework to examine the maturity of the design processes in the two LHCs.

9.4 A Framework for Integrated Systems Development in Healthcare

Five major objectives need to be achieved if the purpose is to develop an integrated system that serves several agencies. They can be further subdivided into ten component objectives as listed in figure 9.1 below.

The first objective is to establish a project of sufficient breadth to achieve integrated development and to create a governance structure for the project that can deliver the vision. A sub-objective is to set up a project not restricted to technical system development but covering also changes taking place in the work process and in the organisation. Integrated design involves holding together changes in all three of these spheres.

The second objective is to articulate the requirements of all the relevant stakeholders and convert them into a system specification (requirements engineering in the IT industry). The first sub-objective is to collect the requirements of the different stakeholders and, given there may be
conflicting requirements, there will be a second sub-objective to manage the requirements to specify a coherent system.

Designing a system to meet the specification involves three sub-objectives: selecting technical systems to meet the requirements; customizing them to meet local needs and engaging in ‘associated’ design processes which might include process design; organisational change and the development of new working practices.

<table>
<thead>
<tr>
<th>Major Objective</th>
<th>Component Objectives</th>
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<tbody>
<tr>
<td>Integrated Development</td>
<td>1. Project Scope, Vision and Governance</td>
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<td></td>
<td>2. Process, Organisation and Technical System Integration</td>
</tr>
<tr>
<td>Requirements Specification</td>
<td>3. Collecting User Requirements</td>
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<td></td>
<td>4. Managing Requirements</td>
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<tr>
<td>Design</td>
<td>5. Technical System Specification and Contracts</td>
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<td>6. Technical System Design</td>
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<td></td>
<td>7. Associated Design Processes</td>
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<tr>
<td>Implementation</td>
<td>8. Change Management</td>
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<tr>
<td>Adoption and Evolution</td>
<td>9. Evaluation</td>
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<td></td>
<td>10. Evolution</td>
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Figure 9.2 A Maturity Framework for Integrated Systems Development

Before, and when the new system is ready to ‘go live’, a change management process is necessary to ensure the user community is equipped and ready to work in a different way. When there are also associated process or organisational changes, there may be a wider change process to manage and it may be necessary to conduct trials etc before full ‘roll out’.

Once a new e-health system is operational the objectives will be to see that it is adopted and that it evolves to meet emergent needs. This requires evaluation processes and further customization as new requirements are identified.
9.5 The Processes and Mechanisms in place for Integrated Systems Development in Northamptonshire and Walsall.

Using the ‘lens’ of this framework we reviewed the approaches to e-health systems development in the two LHCs. Although there are considerable differences in strategy and practice there are also many similarities. Since the framework is being applied post-hoc we have not attempted a formal maturity assessment but have instead highlighted where there are well-institutionalised practices in place and where there are gaps or ad hoc processes.

9.5.1 Project Scope, Vision and Governance Structures.

In reviewing the four design process cases in chapters 7 and 8 we asked how they started, what the original scope was for the project, what kind of vision there was for the end product and how the project was governed and managed. A broad distinction can be made between the big vision for the project, e.g. introducing a new Frail Elderly Pathway (FEP) or a new centralized Diabetic Retinopathy Scanning Service and smaller scale projects such as the ‘refresh’ and ‘restart’ projects. The former are integrated systems developments often driven by national initiatives that have received additional funding. The latter are more likely to be scoped as developments of existing e-health systems defined as internal projects that receive no extra funding. We have labelled these top down and bottom up developments. In most instances the top down projects come before the bottom up ones but in the intermediate care case in Northamptonshire the internal ‘refresh’ project was underway before the top down CECS project intervened to send the informatics work in a different direction.

The top down projects that are big in scope were all initiated as a response to national imperatives. In the case of Diabetic Retinopathy Screening a key driver was a national framework for the delivery of this kind of screening linked to the organisational objective of creating a county-wide centralized service. Both the CECS and the FEP cases are responses to a national strategy to care for more of the frail elderly in the community and the Stroke Pathway at Walsall was a response to a national strategy for Stroke Care. In all these cases a dominant concern was to construct a process involving all the relevant agencies to achieve national performance targets and the scope of the project included process and organisational changes. In only one case, the Stroke Pathway in Walsall, was the creation of an e-health system (FUSION) one of the original drivers for the project. However, in all cases the vision for the project included an enhanced role for e-health systems. In all of these cases the scope of the projects and the vision for the planned outcomes involved multiple agencies, process redesign, organisational change and technical system development. Although it can only be inferred from the data, it is tempting to conjecture...
that the concept of a healthcare pathway has helped to provide a multi-agency vision of the common objective.

The internal projects tended to be much more restricted in their scope, focused on technical system changes and limited to one or two agencies. They did, however, because they were based on changing an existing working system, deal with technical changes, process redesign and organisational issues in an integrated manner, albeit within a more limited arena.

The governance of the top down projects involved most or all of the agencies that contributed to the pathway at least in the initial stages. There was a conscious effort in Walsall, for example, to bring all the agencies together to discuss a future strategy for the care of the elderly before the FEP project was launched. And in all of the cases the vision for the project coalesced in the form of a business case to be put to the commissioners to obtain the resources to undertake the development work. We did not investigate this part of the overall process but it seems likely that, where agencies such as Social Services who are not part of the NHS are involved in these projects, they may have sought separate resources for the project.

Whilst there is evidence for a broad based consensus for the policy-making stage of the big projects, the operational delivery of these developments was much more fragmented. It appears to have been very difficult for these projects to sustain an integrated delivery in which all the agencies and disciplines were involved in the process and in which process redesign, organisational changes and technical developments were kept together. There are, for example, no examples of an over-arching steering committee with membership from all agencies, guiding the project through all of its stages. It seems more likely that separate agencies and separate bodies within agencies take their part of the agenda and try to pursue it. In the Retinopathy case for example, the organisational changes appear to have taken place independently of the adoption of OptoMize. In the CECS case process and organisational changes also took place before e-health developments were considered. In the FEP case a deliberate attempt was made in the implementation plan to hold the different strands of the project together but the result was that the e-health developments lagged behind the other changes. Some of the difficulties of holding together a complex, multi-strand project can be gleaned from the FEP example where the creation of a body to engage with all the agencies through the implementation phase led to a ‘cast of thousands’ and what some concluded was a good talking shop but very poor at producing action. Other difficulties arise from the instability of organisational arrangements for the delivery of health and social care; during the course of this research there were re-organisations in the Trusts in the LHC and at the end of the research a further wave of changes were taking place. It can take some years to create a mature form of integrated care within a healthcare pathway and
organisational turbulence makes it more difficult to keep a stable framework in place.

There are some islands of maturity in the processes that these agencies regularly undertake; where new pathways and new e-health systems are required, for example, the processes of formulating business cases for review by commissioners is well established. There is also a degree of maturity in the way the different agencies in Walsall work together to formulate strategic plans for the borough. In a compact geographical area where agencies have co-terminus boundaries there has emerged over a period of years well-founded practices of working together on common concerns. The problems for both LHCs, however, is the immaturity of the practices of working together over the period of time necessary to deliver all the integrated care mechanisms necessary within a new health and social care pathway.

9.5.2 The Collection and Management of Requirements

To progress from a broad vision to an operational system detailed requirements for the new system have to be articulated and agreed. This is a requirement for the overall pathway and it is a requirement for any e-health systems that are to support it. There are many stakeholders involved in the commissioning, management and delivery of care in a pathway and there will inevitably be a degree of conflict in the stakeholder population. How, in these circumstances are the requirements for e-health systems being gathered and how are they managed in order to provide a specification for the system to be created?

There are significant differences between the requirements engineering process in the top down projects and the bottom up local projects. In the top down projects the driving force is the establishment of new or revised pathways to fulfill national objectives and they are approved in terms of their ability to deliver systems that meet key national performance targets and standards. These policy objectives are then translated into operational requirements as the local pathway is designed and staff resources are deployed to service it. The requirement for e-health system support follows the same pattern; an e-health system is specified that can collect information about the care being delivered in the pathway and provide reports to monitor whether kpis are being met. In this process there are also elements of controlling and standardizing the way the care is being delivered. As this process of establishing requirements proceeds it is accompanied by the operational specification of another set of national requirements; information governance policies that specify how access to patient records is controlled and monitored.

These two sets of requirements are privileged in top down design to the extent that there is little evidence that the specific needs of operational healthcare staff to share information across organisational boundaries is
systematically reviewed in these projects. Although there may be opportunities for operational stakeholders to attend meetings as these systems are developed, there is no evidence in the case studies of empirical studies being undertaken to establish their specific requirements for e-health systems. In the requirements engineering literature there are many examples of systematic ways of studying operational requirements, including forms of task analysis, ethnographic studies and scenario evaluation exercises. The consequence of not considering operational needs is that the first generation of systems to support pathways are often experienced by operational staff as systems to collect information from them in structured ways. The systems either provide little help for their healthcare work or provide access to information that is not the information they need.

By contrast the local bottom up projects often seem to result from requests from operational staff for changes in the e-health systems so that they can be more useful in the day-to-day delivery of care. These projects occur after an e-health system has been in service and users have had an opportunity to judge what they provide and what they do not provide. Typically there is some mechanism, for example, a local user champion, by which needs for change can be registered with the IM&T Department and a process is then undertaken to determine whether there is support for the change and whether it can be achieved in technical and financial terms. The clinical change facilitator team may then, for example, make a detailed study of the user requirements by shadowing users or by embedding a member of their staff with the users for a period of time. As a result, for example, FUSION includes new ‘releases’ on a regular basis to meet emergent user needs and the ‘refresh’ project in Northamptonshire re-designs templates to enable community services staff to better work together.

The mature parts of the requirements engineering process appear to be the way in which policy requirements are transformed into pathway design and thence into the design of the e-health system for the purposes of pathway management. The immature part of the top down approach is that it makes little use of the mechanisms used elsewhere for capturing the requirements of the staff who deliver healthcare and, as a result, once the system is in place, a process begins whereby local staff make requests and changes are made in the system. There is some evidence that in both LHCs there is an increasingly mature process for collecting and processing these requests but it is noteworthy that these processes occur out of step with the main top down developments.

9.5.3 System Design

In the top down projects the design phase may involve quite disparate activities, for example, the detailed design of new pathway processes and organisation and job design to define the roles staff will play in the new pathway. The e-health strand of design, in most cases, was separate and to
some extent considered after these strands of development. In the design of CECS, for example, e-health development came after the re-organisation of intermediate care and in FEP the new pathway was in operation long before serious attention was paid to the e-health support that it needed.

The maturity framework presented in table 9.2 recognises that there will be both technical design processes and associated design processes. In the examples in the two LHCs it is the ‘associated changes’ in the pathway process and the organisation that is driving the technical design.

The overall technical strategy in both LHCs is to establish a technology infrastructure on which the specific e-health services for a pathway can be constructed, i.e. using FUSION or SystmOne. In practice in the top down cases this has been the pattern for the Stroke pathway development and CECS. In the case of Retinopathy Scanning a different stand-alone system (OptoMize) was used (and mechanisms for getting information from SystmOne and other systems had to be found). In the Frail Elderly case the plan is to use a combination of iPM and FUSION as the basis for e-health support but with additional elements such a lap-tops and telehealth equipment and the ability to share data with the social services system, Paris. The pattern is to use a central platform and build on it through ‘middleware’ to provide inter-operable services. This means that, for these new developments, the need to procure new systems was limited to middleware, laptops and telehealth equipment. Making use of a pre-existing system has of course the potential disadvantage that it may not be able to accommodate the needs of the new development.

A long-standing issue in technical systems development has been the extent and effectiveness of user engagement in the design process. In the cases we examined, once a sub-part of the overall project was defined as an e-health development, the project management methodology PRINCE2 was deployed in both LHCs. This is a mature, well-documented set of procedures that manages a project through every stage and includes, for example, mechanisms for enabling users to ‘sign off’ the outcome of every stage. The methodology is also used in relation to bottom up projects although in a ‘light’ form as befits a small-scale project. A significant feature of the technical design process in both top down and bottom up projects is the role played by clinical facilitators or ‘hybrids’ who act as the intermediaries between the user community and the technical informatics staff. They play many roles; translating user needs into a form informatics staff can act on, explaining technical issues to users, training users etc. There is a long tradition of developing ‘hybrids’ in the NHS and it appears well-institutionalised in both LHCs. Whilst the role is well established, it is not so clear how one is trained to be a hybrid; as many of them reported ‘you learn on the job.’ Although the hybrid role is in place and the project management methodology that is adopted establishes formal user roles in the design process, there remains evidence, as presented in Appendix 3,
that the users often feel uncomfortable in the design process; that they do not understand what is being asked of them, their requirements are not really listened to etc.

In some respects, once a technical project has been established, it is governed by a mature set of processes many of which are in place to manage the relations between informatics staff and the user community. And yet in the big projects it does not lead to the initial systems meeting the needs of operational staff. This may well be because the scope for design is quite limited at this stage as may be the resources and time before deployment. The scope for technical innovation may also be limited by the need to use a technical infrastructure that was defined before the project was initiated. Together these factors may make it difficult for technical staff to respond to emergent requirements from users as they begin to understand the system that is about to be delivered. It seems more likely that the main role of user representatives will be to prepare their colleagues to receive the system rather than to challenge design decisions.

9.5.4 Implementation

Many of the procedures often labelled ‘change management’ are in place for the ‘go live’ stages of top down projects in both LHCs. In addition to the technical processes associated with equipment deployment and system testing, these include processes for establishing ‘user readiness’ to receive the system such as user registration and training. They also include the establishment of user champions to act as both explainers and motivators to their colleagues. All of these processes are well established and the clinical facilitators play a prominent role in the process, for example, in training the users or ‘training the trainers’.

These processes get the users ready to receive the new system but they do not deal with emergent problems, e.g. when there are unpredicted consequences of using the system for working practice. There are many implementation processes documented in the literature that are recommended as precursors to full roll out to identify and deal with such issues, i.e. scenario evaluation, testing the system in trials and pilots and conducting formative evaluations. In the cases we examined there is some evidence of the use of trials for component parts of systems, e.g. trials of laptops. There is also evidence that when timescales get squeezed, and there is pressure to implement the system, trials get abandoned or curtailed, e.g. trials of digipens and laptops. A trial, of course, may well reveal issues that need attending to before full ‘roll out’ and it may therefore be another cause of delay in the project and it may be cancelled for this reason.

The result of this approach to implementation is that systems get installed, i.e. they are in place and working, but they do not necessarily get adopted
widely by the user community, e.g. whenever users encounter implications of using a technical system that are problematic for their working practice they avoid using the system facilities that cause the problem or they find a ‘workaround’. Thus, a fax is requested rather than attempt electronic sharing, registering a patient in the stroke register is delayed until discharge from the ward, more tests are conducted on a patient rather than searching electronic records for recent results, patients are not removed from the intermediate care listing when they die, records are either non-existent or incomplete because of the double input load they create for users etc.

As the final part of the formal process of delivering a system, implementation is often squeezed if earlier stages put pressure on the need to deliver ‘on time and to budget’. The mature parts of this process in the two LHCs are those that have to be undertaken to get the technical system installed; it is the parts of the process that help users make the links between technical systems and their working practices that get squeezed and they remain immature parts of the process.

**9.5.4 Evaluation and Evolution**

Once a system has been implemented it is common practice to evaluate how well it is working in practice (summative evaluation). There are many forms that evaluation can take, ranging from technical evaluations (are there ‘bugs’ in the system?), through user problems with usability and training to cost-benefit evaluations. In the cases we examined we found very few examples of these kinds of formal evaluations although it was common practice to set up a group of user champions who would report to the clinical change facilitators any problems that users were having. One consequence of a lack of formal evaluations is that informatics staff were often unaware of the extent of use or non-use of the facilities in the technical system.

One indirect way in which technical systems were evaluated was that the systems were used to generate reports of healthcare pathway performance. These reports shed light on the performance of the technical system in two ways. First, if the data is inadequate to produce complete reports, one reason may be that users are not using the system to enter all of the details of their operational work. Second, failure to meet targets may in part be because the technical system is not performing well or the users are unable to exploit its potential to help them achieve pathway targets. In all the pathway developments e-health systems were perceived as vital to the success of the pathway and hence, one way of evaluating the technical system is by evaluating its role in overall pathway success. However, there is no evidence in these cases that this is a deliberate aim of measuring performance against key performance indicators.
One reason why formal evaluations are not undertaken may be that there is very little evidence of the systems that are implemented achieving a steady state which might support a ‘before’ and ‘after’ comparison. There is an assumption in system development that after implementation there is a period when the system is in use and a new level or form of activity can be detected. There is nothing in the data from these cases that suggests any kind of steady state develops. Following implementation of system changes, it looks as though a process of emergent behaviour begins as users come to terms with new ways of working and that this results in requests for system changes that trigger bottom up forms of development and, as a consequence, the technical system continues to evolve. It is notable that the meetings established in the action research cycle (Appendix 3), which were often conducted between 6 to 12 months after data was collected for the cases, gave many examples of the continuous development of the systems that had been studied. As was remarked in one of the meetings, ‘e-health systems development is like painting the Forth Bridge; it never seems to end’.

It is possible to discern three drivers for the continuous evolution of these systems. The first, as described above, is user learning; as users experience the system and see its potential and its disadvantages so they exert pressure for changes in what has been provided and, in both LHCs, this is expected and there is a mature process for collecting and processing such requests. The second force is the delivery of subsequent parts of the technical system; in most cases the first implementation is just part of the planned system and there are second and third waves, covering, for example, in FEP the links between FUSION and Paris, the implementation of telehealth equipment etc. The third force is the continuing changes that occur in the organisational environment of the pathway as organisational re-configurations take place, as new national initiatives are launched etc which can change what is expected of the pathway and, as a result, what the technical system needs to support. Together these forces create a need for the technical system to keep evolving. For the most part this seems to become a series of smaller bottom up projects building on the system infrastructure already in place but with major convolutions at intervals when new top down initiatives require more radical change.

9.6 Conclusions

This review demonstrates that there are pockets of mature practice in the way that systems are developed in the two LHCs; for example, the process of creating and approving business plans, the project management of technical aspects of the development and the use of clinical facilitators or hybrids to support the interaction between informatics specialists and the user community. However, as one of the informatics directors remarked in a feedback session (Appendix 3), there
is no overarching process in place that can deliver a large project such as may be required for integrated care across a whole healthcare project. Such a process has not only to manage the stakeholder interests of many agencies and disciplines but has to integrate three interrelated but quite different strands of development in process, organisational design and technical system development. If we add that such a programme cannot be delivered in a short time, it is also necessary to acknowledge that the organisational turbulence in the NHS is going to mean the programme will be subjected to changing requirements during its lifetime. It is perhaps not surprising that these programmes become fractured in their delivery. On the basis of this limited sample, the overall effect appears to be that as a result, the system that is delivered is focused more on serving commissioning and management requirements than on operational needs to share information. What appears to happen is that, once a system is in place, compensatory developments occur in the evolution of the system to meet requirements that were not addressed in the first delivery. Whether they can actually be met depends on resources available for internal developments, on technical system flexibility and on governance issues. The e-health strategies in the two LHCS, although different, both emphasize the creation of an IT infrastructure that can facilitate the sharing of information for integrated care. The aim is to achieve this by (a) using a primary information system that is flexible and can be configured to meet different user needs and (b) using ‘middleware’ systems of various kinds to make links between systems. As a result an evolution appears to be occurring in both LHCS in which there are pockets of integration amidst an array of systems they are not currently inter-operable. Whether the technical bases created in the two LHCS are sufficiently robust and resilient to cope with the on-going requirement for evolution is a question for future research.
10 The State of the Art on ‘Seamless Healthcare’

10.1 Aims and Methods Revisited

The aim of this research project has been to examine the issues that surround the sharing of electronic patient information across organisational boundaries and thereby to explore how e-health systems are contributing to the delivery of seamless care. We had an overall understanding at the outset of the project of the electronic systems available in the two LHCs but we had limited knowledge of where those systems supported the sharing of information across organisational boundaries. For this reason we adopted an emergent research approach in which we began with a broad scoping exercise, mapped 9 pathways, selected 6 to collect evidence of user experience with e-health systems and studied the systems development process in relation to 4 of them.

In order to understand in depth what happens when information is shared across boundaries and how these systems are developed, the research has inevitably become progressively more focused. Nevertheless the broad scoping work undertaken initially and the action research work in which the results were fed back to a wide cross section of healthcare staff have provided an opportunity to test what conclusions can be generalized across the LHCs.

This chapter begins with a summary of the major findings of the research and this is followed by a discussion of three key themes that have future policy and research implications.

10.2 Summary of the Main Findings

10.2.1 The ‘state of deployment’ of e-health systems

Although some groups of staff still rely on paper records nearly everybody makes use of an electronic system of some kind. Most of the systems cannot share information with other systems and it is a strategic objective in both LHCs to create an IT infrastructure that makes this possible. Different strategies have been adopted in the LHCs to promote the sharing of electronic records; Northamptonshire have followed the NPfIT approach of adopting a single system for all to use whilst Walsall have adopted a portal approach.
At present, in each LHC, there are circumstances where it is possible to share electronic records and other circumstances where it is not. The overall picture might perhaps best be described as a ‘patchwork quilt’ and as a ‘work in progress’. But the accounts reported here do illustrate the process of sensemaking undertaken by health professionals and managers. We have seen how those involved construct sense out of the information systems they have available, blending various paper-based and electronic sources to enable them to deliver health care (see Figure 10.1).

There are many different methods by which staff can share patient information. Some may be classified as ‘electronic’ and others as ‘non-electronic’ but there are a range of methods that might be described as ‘partly electronic’. Although it might be assumed that ‘electronic’ is the final solution, in some cases the ‘partially electronic’ might be a solution well suited to the particular sharing that is needed. Within the ‘electronic’ category there are also significant variations, for example, between the single record approach in Northamptonshire and the Walsall approach which is to provide access to many records. A classification of different methods of sharing information is presented in 10.3.1 below together with a discussion of the implications of each method.

The NPfIT was intended to deploy detailed electronic care record systems that would enable all staff to share a single patient record. This system was not deployed during the research period although other applications of the national programme have been deployed, some as general purpose database systems (SystmOne and iPM).

10.2.2 Factors Defining What Needs to be Shared: The Significance of Pathways

Our search for critical circumstances where there is a need for ‘seamless care’ across organisational boundaries identified healthcare pathways as the major highways that patients’ travel which lead to situations where close co-ordination across boundaries is needed.

In the NHS in recent years there has been wide recognition of the need to achieve integrated care in healthcare pathways and many strategic initiatives have been put in place to construct processes for pathways and to organize healthcare resources from different agencies to deliver integrated care. In all the cases we examined there was an assumption that e-health systems would be developed to support the delivery of integrated care in the pathway.

Mapping nine healthcare pathways demonstrated that there were different kinds of task interdependencies at the organisational boundaries in the pathways which have implications for the type of co-ordination that is necessary. The three forms of interdependency we examined mapped onto
three forms of relationship well known in the NHS and each of them has different implications for the sharing of information:

- **Pooled Interdependence.** In unscheduled care many healthcare staff in a variety of agencies might need access to an electronic patient record. Given that in unscheduled care the patient’s symptoms are unknown, the information required may be uncertain. Common access to a database is an assumed solution and the content required is problematic. This is the territory that the NPfIT Summary Care Record was designed in serve but it has not been deployed in these LHCs.

- **Sequential Interdependence: the Handover or Referral.** The handover involves a specific relationship (referrer to receiver) and usually a specific form of information sharing related to the patient's condition.

- **Reciprocal Interdependence:** Shared Health and Social Care means that different agencies and disciplines are caring for the patient in the same timeframe and they have to co-ordinate the care they each give. Sharing information in this case is within a limited and often virtual ‘team’ and has to be ‘up-to-the-minute’ so that real time co-ordination can take place.

The implications of different kinds of task relationships for the e-systems that need to support them are further explored in the section 10.3.2 below. The three task relationships we have explored may not be an exhaustive list but serve to show that, when the operational needs for sharing information are examined, different kinds of requirements for e-health systems emerge.

**10.2.3 Top Down National Influences on e-System Development**

The national roll out of NPfIT applications had less of an impact on developments in the two LHCs than we had envisaged. Nevertheless there was evidence of the use of NPfIT general database applications (SystmOne and iPM) and specific applications (PACS and Choose and Book). Two conclusions about the general database applications can be drawn. First, installing the application is only a small step on the way to the successful harnessing of its potential to contribute to healthcare. The case studies demonstrate the extent of local design work that is necessary to develop and mount a useful service using the facilities these applications provide. Second, to enable this local design work to be successful, the general-purpose system has to flexible and resilient. Both systems offer flexibility but design teams needed considerable ingenuity and the use of other middleware products to meet the requirements of users. The contracts for the NPfIT applications are held by Connecting for Health which makes it difficult for local designers to request system changes from suppliers with the consequence that they sought other workarounds to avoid such requests.
Although national NPfIT applications had limited influence on local developments, three other kinds of national policies had a profound effect on them. First, national policies for healthcare pathways lead to multi-agency process design projects in LHCs and to new multi-agency resourcing arrangements to deliver the new pathway. It was widely assumed that these changes would also need e-health system developments to enable information sharing across each pathway. Second, national policies for information governance are implemented in the e-health service delivered to users. As a result they determine user registration, role based access and processes for getting permission to share records all of which determine what a user can access. In the cause of protecting the confidentiality of patient records, these processes can impede efforts to share information, especially in time critical situations and where shared care requires the sharing of patient information across agencies and disciplines. Third, NHS organisational changes have created a frequent requirement to change the organisational configuration of agencies in the LHCs with the result that ownership of projects, the role of each agency in a project and the technical systems to be deployed can all change during the life of a development with consequences for its direction and momentum.

As multi-agency, multi-disciplinary developments there were many stakeholders who had requirements when an e-health system to serve a pathway was being developed. In the developments we observed, very little attention was paid to the requirements of the front line staff who needed to share information to co-ordinate care in the pathway. Similarly there was no direct voice for the patient in these developments. The requirements that were privileged in these top down developments were those of the commissioners and the managers whose prime concerns were to deliver a pathway that met national targets and standards. As a result the prime drivers in constructing the information service for a pathway were the collection of information to show how well it was working and the control of input and access within governance policies. e-Health systems can serve many different purposes and, where pathway development has been a driver, enabling the commissioners and managers to monitor and manage the pathway have been the initial considerations.

**10.2.4 The Experience of Using e-Health Systems**

Utilising e-health systems is part of the working practice of most of the healthcare staff we surveyed. Few questioned the use of the technology, only the appropriateness of particular systems facilities for their work. Obtaining some benefit from using e-health systems appeared to make staff more aware of how much more useful these systems might be.

It was not our purpose to make a cost/benefit assessment of the e-health systems that supported the sharing of information across boundaries but many examples were given of where this was being beneficial to front line staff and even more of where it could be beneficial. The general benefits
reported included the great speed with which information could be obtained, e.g. electronic discharge summaries, and the ability to obtain important clinical information, e.g. the drugs a patient is taking.

The majority of benefits obtained or desired, however, were highly contextual. The vertical axis of the pathway maps reveals the tasks that healthcare staff undertake as their part of the healthcare pathway and the significant benefits that are sought are whether the e-health system can aid them in these tasks. Can, for example, a failsafe officer (Retinopathy Chapter 7) discover whether a diabetic patient has attended an appointment at an acute hospital or can a rapid response nurse get rapid access to a patient’s record before deciding whether they can be treated in their own homes or they need to go to hospital? (FEP Chapter 8). Seeking the general benefits of e-health systems may miss the many specific contributions they can make to integrated care.

The benefits of e-health systems reported by the managers of pathways were considerable. The aggregated reports of patients’ progress through pathways and the statistics produced of the resources being deployed, gave managers better information tools to assess the benefits of the pathways and how performance could be improved. An important tool was the reporting of the data held in the e-health systems in relation to kpis (key performance indicators). However, there is considerable evidence, especially in relation to the development of the FEP (Chapter 8), that careful, focused definitions of kpis are necessary if misleading conclusions about pathway performance are to be avoided.

Whilst staff were generally positive about current e-health systems and even more positive about what might be achieved in the future, front line staff had many misgivings about the situations they found themselves in, as evidenced in the examples below.

The needs of those who commission and manage pathways are for structured, aggregated information that demonstrates, for example, whether performance targets are being met. Structured records can also serve to standardize the care that is given. However, pre-structured records may not enable operational staff to record what they regard as particularly salient patient information and may mean they have to respond to questions that are not necessary or are repeats of what has been recorded previously. For those receiving the information, lengthy, structured records can be too generic to be useful.

There were many examples of occasions where staff found that, because of information governance policies, they were effectively denied access either because seeking permission to share took too long or they did not have appropriate access rights. Clinical staff who were used to asking administrative staff to enter data into systems could, for example, find their staff did not have ‘rights’ to do this.
Inputting data to e-health systems was contentious for a number of reasons. First, there was often a need to re-enter data that had already been recorded in another system. This was particularly the case when the first record was paper based e.g. as SAP documentation, and it is then necessary to find a computer to make an electronic record. A related issue is that much of the data input is of little service to the person doing it; it is subsequently used by a manager or a person in another agency, e.g. the preparation of medical discharge summaries. Users in this position often expressed the view that the system was a time waster, preventing them from spending time with their patients. There can be little incentive to record full and accurate information under these circumstances. A further issue related to data input was the awareness of staff that the system would be treated as the ‘formal’ record used for assessments against targets, audits etc. In many circumstances considerable care was taken to report patient care in a way that served the interests of the healthcare staff making the report.

Although, in most cases, users were seeking more information about patients, there was some concern that there could be too much information available and this might make it difficult to locate critical information, sustain the standard and integrity of the information etc. This was of particular concern to GP users of the single record in Northamptonshire, where voluminous and potentially inaccurate information could be included by other healthcare agencies, and of some users of FUSION in Walsall who, in the case of patients with multiple conditions, could be searching for information on many different databases. In time critical situations this could represent a serious problem. Information poverty could rapidly be turning into information overload in some situations. It led to requests for more up-to-date, overall summaries, such as electronic discharge summaries and the overview held in SAP, so there was always an overview that could be widely shared.

Of the many stakeholder interests that shape the form of e-health systems, the patient’s voice is perhaps the weakest although many other stakeholders speak for them. The governance procedures for access to records exist for example to protect patient’s interests but healthcare staff, particularly in unscheduled care settings, report that patients expect them to be able to access their records automatically and are surprised when their permission has to be sought.

10.2.5 The Response of Frontline Users and the Evolution of Working Practices

Many staff delivering care in healthcare pathways have access to e-health systems that enable some degree of information sharing across organisational boundaries. The evidence suggests they have been active in responding to this situation and that in the adoption process of these systems a variety of new working practices have emerged.
Where users have perceived direct benefits from the system for their own working practice, the system has been adopted as intended. For example OptoMize is used to send appointment letters to diabetics (Chapter 7) and FUSION is accessed where deemed relevant to support unscheduled care (Chapter 6).

However, when the use of the system is problematic for users in the ways discussed above, practices have been sought to minimise the problems. If, in the community for example, you cannot easily get to your base to inspect records and up-date your own, then working out where you might be able to ‘drop in’ to do the work becomes a good strategy (Chapter 8). If putting information into the record has implications for management reports, you delay, batch, re-organise, minimize or otherwise massage the input to have the best effect on the reports (e.g. Chapter 7). If it is difficult to get information quickly, you manage without and re-do tests etc as necessary to be safe in the treatment of the patient. If you cannot officially access patient information that you need, you ask a colleague who does have access to tell you about it. Information sharing amongst colleagues in multi-disciplinary meetings is governed more by a collective sense of what is in the patient’s interest than by the rigid rules of role-based access held within the e-health system. Faced with receiving information in many different forms, GP practices opt for a ‘fail safe’ process of printing it all out and then scanning much of it into their patient records. Many staff reported that, when faced with difficulties, they had become adept at ‘finding a way’. In some cases this makes good use of the computer provisions, in other cases it does not.

Users do not necessarily treat the systems they make use of as finished. The local culture in both LHCs is one where there are on-going relations between user communities and local informatics staff, especially with the ‘hybrid’ clinical change facilitators who have a clinical background1 (pp 72-74). This link means that users can highlight both problems they have with the technology and opportunities they see for beneficial developments. In some cases it is possible for informatics staff to act upon these suggestions and create internal projects that lead to enhancements to systems. In this way, the e-health system can evolve in an organic manner to meet progressively more of the needs of front-line staff.

Over time this emergent process changes both working practices and the e-health systems. It can be seen as a series of local sociotechnical adjustments to compensate for perceived dysfunctions in the initial ‘roll out’ of the system and to enhance local performance. These developments could challenge the original purposes of the e-health system and, in both LHCs, a review process is undertaken before changes in the technical system are made.
10.2.6 Developing e-Health Systems for Integrated Care

Although great strides have been made in both LHCs to provide e-health systems that enable information to be shared across organisational boundaries, there are no examples of e-health systems that support an entire pathway. There are always boundaries to agencies that are ‘outside’ the reach of system. Similarly, although there is provision for sharing information, staff can always point to ways in which it could be enhanced. In all cases therefore, there is potentially a lot more that could be done.

There is evidence that more top down projects are being undertaken that seek to create seamless care across a whole pathway. Such projects represent a considerable challenge because they need to be:

a) multi-agency initiatives,

b) developments that involve integrating process, organisation and technical change, and

c) sustained over time and in the context of ongoing organisational turbulence.

In most cases, the developments become fractionated and certain elements take precedence over others, e.g. constructing e-health systems that facilitate the monitoring of the performance of the pathway.

The landscape of e-health systems that support co-ordination across LHC healthcare agencies is an evolving one with a great deal of unfinished business. Its evolving shape appears to be a product of four forces (a) top down national influences through IT programmes, pathway developments and information governance policies, (b) local LHC priorities for working on inter-agency co-operation, (c) an evolving awareness amongst the user community that creates bottom up pressures for system improvements and (d) local informatics policies and strategies that attempt to create a resilient IT infrastructure by using a mixture of flexible database systems, middleware systems and specialist systems that can cope with the emerging demands of the other three forces. As a contribution to the debate about top down versus bottom up design, this research demonstrates that what is happening in practice has top down, ‘middle out’ and bottom up contributions. This issue is examined further in 10.3.3 below.

10.3 Themes in the Provision of e-Health Systems for support integrated care

As a grounded and emergent programme of research, this project has identified many factors that are contributing to the shaping of e-health
systems to support integrated care. We have identified three themes that bring together many of the issues and provide a focus for policy debate and the identification of future research priorities.

10.3.1 Methods by which patient information can be shared

Figure 10.1 lists a variety of different ways in which operational staff share information across organisational boundaries. They have been placed in a rough classification from methods that loosely couple the healthcare staff in the sharing and those that involve a much tighter form of coupling. Here we have drawn upon Weick’s classic coupling concept. By ‘loose coupling’ in this context we mean that the content and form of the shared information can be defined by the sender or owner and, when received or accessed, the recipient has freedom to decide what to do as a result. It is a process of sharing information that leaves significant degrees of autonomy in the hands of both parties. In ‘tight’ forms of coupling the form and content of the information may be pre-structured and the content added by the sender or depositor may have implications for recipients over which they have limited control. Tight forms of coupling embedded within the e-health system imply a loss of autonomy by the parties involved: in effect the benefits of sharing through the e-health system carry with them the disbenefits of loss of control.

The looser forms of coupling are the traditional, non-electronic forms of sharing; the sending of letters and faxes etc. In many cases these are free text and this allows senders freedom of content. Recipients, for example in GP practices, are also free to extract from these communications as they wish, modify codings etc. The disbenefits may be the slowness of the communication, the variable quality of the content and its possible irrelevance to the particular concerns of the recipient.

In the middle of figure 10.1 are an array of methods of sharing that are partly electronic which are slightly tighter in their forms of coupling. Some of these methods are partly social in the sense that information is shared by co-located individuals who may be from different agencies and disciplines, e.g. in multi-disciplinary meetings. In this situation each participant may be able to access structured information relating to their agency/disciplinary but they can pool it, negotiate meaning and decide with their colleagues what is in the best interests of the patient. The ‘loose’ element of the coupling is in the autonomy they have in ‘sharing with colleagues’ when they are co-located. In these methods the focus of the local ‘integration of care’ debate is in the social setting rather than in the technology. The disadvantages of these methods are that people have to be co-located at least for the period of the meeting for this kind of sharing to be possible. Undertaking ‘virtual’ meetings is not an approach that was in evidence in these LHCs.
The methods that are purely electronic involve tighter coupling although there is variation because of the different forms of electronic system. The access to many different databases permitted by FUSION controls and structures the data that is placed in the databases but leaves the person seeking information considerable autonomy over what they do with it. There

<table>
<thead>
<tr>
<th>Loose Coupling</th>
<th>Mode of communication</th>
<th>Title</th>
<th>Description</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Non-electronic</td>
<td>Traditional ways of sharing information</td>
<td>Letters, faxes, the telephone, shared documentation and meetings</td>
<td>Telephone referrals Multi-disciplinary meetings SAP</td>
</tr>
<tr>
<td></td>
<td>Semi-electronic</td>
<td>e-mail attachments</td>
<td>Attaching patient record to e-mail</td>
<td>OOH reports to GPs</td>
</tr>
<tr>
<td></td>
<td>Co-location, separate access</td>
<td>Agency staff have access to different systems but are co-located</td>
<td>Social workers in Intermediate Care</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Supported multi-disciplinary meetings</td>
<td>Meetings of many disciplines in which each have their own access to electronic records</td>
<td>MDMs between social and community care stroke units</td>
</tr>
<tr>
<td></td>
<td>Electronic</td>
<td>Read only access to multiple records</td>
<td>Access to records held by others</td>
<td>FUSION providing access to many records</td>
</tr>
<tr>
<td></td>
<td>Direct electronic messaging</td>
<td>Electronic inputs going directly in to patient records</td>
<td>Blood test reports to GPs</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sharing a single record</td>
<td>Access and contributions to a shared record</td>
<td>SystmOne – shared access to a single record</td>
<td></td>
</tr>
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Figure 10.1 Loose and Tight Forms of Coupling in Methods of Sharing Information
are several advantages to this approach: each database has a clear ‘owner’ who is responsible for the accuracy of the data and, because they are loosely connected, it is simple to add new enquirers using role based access criteria to control what access is permitted. The PATH LINKS system is a slightly stronger form of coupling because data can go straight into a patient’s record although it is usually checked beforehand. The single shared record in SystmOne represents the strongest form of coupling because it is a commonly owned record where agencies with appropriate responsibilities have to respond to the content although they have no control over it when it is entered by others. It is clear from the case study data that this is a particular concern of GPs who retain an overall responsibility for their patients but lose control of what they regard as the accuracy of the record (chapter 6). The great benefit of the single record is that ‘everybody is singing from the same hymn sheet’ but it has major implications for the respective roles and responsibilities of agencies in different healthcare roles.

It is an assumption of the NPfIT programme that, in order to achieve ‘seamless care’, it is necessary to create a single patient record that can be shared by all. When there is a strong need to use a ‘pooled’ record by non-co-located staff there is an argument for this solution but the implications for the roles and responsibilities of healthcare staff need careful examination as does the argument that they should retain ‘ownership’ of the parts of the database for which they have responsibility. The use of a portal approach that provides comprehensive access to a patient’s record but keeps the databases under separate ownership is one way of creating shared access in tune with the roles and responsibilities of healthcare staff. The findings of this research also suggest that there may be good reasons to retain and promote many of the other methods of information sharing in figure 10.1. In some cases they are well geared to the kinds of information sharing tasks that healthcare staff have to undertake, for example, the way information support might be given to a team engaged in ‘shared care’. There is also a salutatory lesson; it may be that some significant stakeholders wish to implement e-health systems that have tight coupling in order to enforce control and standardization. The evidence of this research is that, if that is done and in the eyes of the operational healthcare staff it robs them of the autonomy they need to provide the best of integrated care for their patients, they will opt for one of other methods of information sharing, e.g. pooling information with colleagues, to avoid what they regard as inappropriate constraints.
10.3.2 The many functions of electronic patient information systems

In adopting a pathway orientation we have focused on the tasks that staff undertake in the pathway and the task interdependencies between them. This has revealed a wide variety of roles that electronic patient information systems play for different stakeholders. The e-health systems we have studied are (1) repositories of clinical and administrative information, (2) they play a transactional role in care e.g. OptoMize sends pre-formatted letters to patients, (3) they act as communication channels between specific healthcare staff, (4) they are control agencies for the governance of information and (5) they generate reports that provide management information for managers and commissioners etc. Some stakeholders have more of a ‘stake’ in some of these roles than others. Although there are some e-health systems that serve only a specific function, the drive for integrated care is leading to greater use of general-purpose systems to serve all these functions.

When a system serves different purposes for different stakeholders there are inevitable tensions to work through in the design process. We can distinguish three particular tensions that are common in the cases we have examined. First, there is a tension between management needs for a system that structures and standardizes the patient data held in the system and the needs of a very varied set of frontline staff who need to store, access and communicate patient information relevant to the tasks they undertake. Second, there is a tension between the need to protect the confidentiality of the patient and the need for frontline staff to share information with one another and, in particular, to get an overview of patients who often have multiple conditions. An important question has to be how integrated, seamless care can be achieved whilst placing great limitations on what healthcare staff can share? A third tension is between the desire for the technology to be the integrating mechanism, i.e. by having one single patient record that everybody uses, or relying on the healthcare team in the pathway to be the integrating mechanism with each agency having its own record and sharing the record with others as appropriate to the care of the patient.

We observe in these case studies that there are particular patterns being played out in the two LHCs. The tension between management needs and frontline staff needs is played out through a top down design process that gives priority to management requirements and a bottom up, evolutionary process that subsequently, pays attention to the specific needs of front line staff. The tension between patient confidentiality and information sharing privileges patient confidentiality because access rules are built into the system but staff adopt various workarounds to avoid the difficulties this creates for them. The tension between integration in the technology or integration within the healthcare team, is played out differently in the two
LHCs with Northamptonshire adopting a strategy of integration through the technology and Walsall, with its portal approach, taking a route in which integration is undertaken by the healthcare teams accessing a variety of different technical systems. These strategies will reflect the different path dependencies between them and reflect underlying self-reinforcing processes.

The objective of this research was to examine the degree to which e-health systems are supporting efforts towards cross-organisational integrated care in a number of healthcare pathways. What is striking is that, perhaps because of the way the tensions above are worked through, very little priority is given in the design processes to the kind of integrated care that needs supporting in these pathways. We have, for example, noted the differences in task interdependencies in the pathways and these have implications for the numbers of people who need to share information, what they need to share and when and how they need to share it. However, in only one case (Diabetic Retinopathy) has a system been developed specifically to match the characteristics of the pathway. Suppose the designers of e-health systems for each pathway started with a clean sheet, i.e. could first analyse the requirements for information sharing amongst the healthcare staff in the pathway and then develop an e-health system to meet these requirements? In unscheduled care they might produce a version of the summary care record in which many healthcare staff could access limited information about a lot of patients (but perhaps only those within the LHC). In pathways such as stroke and diabetic retinopathy, characterized by sequential interdependencies, they might produce e-health systems that focused on point-to-point communications of a specialist nature but with opportunities for free form electronic dialogues to deal with the many queries that inevitably arise in handovers. An analysis of the needs of health and social workers to share information quickly although they are not co-located in intermediate care and care for the frail elderly might lead to the kind of systems being developed in the emerging discipline of CSCW (Computer supported cooperative work) which specializes in computer-mediated support for virtual teams. Although there is no evidence in our case studies for this kind of approach to e-health systems design it is being pursued elsewhere in relation to computer support for multi-disciplinary meetings in healthcare.

10.4 The findings in relation to emergent research results and policy debate

At various points in this report we have noted recent research results from other studies and the on-going policy debates about how to deliver effective e-health systems. Below we bring together these developments to explore how the findings from this research relate to other research findings and to the debate about how to deliver e-health systems that facilitate seamless
care. The aim here is to highlight how our results relate to other research and to specify where there are significant gaps in research coverage in relation to six themes.

### 10.4.1 Pathways and e-system support

This research has identified care pathways as a significant focus for work on information sharing across organisational boundaries. Pathways cross organisational and discipline boundaries and there are many issues about sharing patient information at these points. Integrated care within care pathways is now a major research topic\[^{56, 57, 119}\], but, although it is often presumed that e-health systems will have an important role to play in achieving integrated care, relatively little research has been conducted on progress with this ambition\[^{54, 55, 58}\]. There is now a growing literature on each of the major pathways, for example, in strokes\[^{111}\] and in the care of the frail elderly\[^{101}\]. Again the research that has been done with respect to specific pathways has paid limited attention to the e-systems that support them. The care of the frail elderly in their own homes is something of an exception because of the burgeoning literature on telehealth\[^{112}\] but the focus here tends to be on the role of the technology that is placed in the patients’ homes rather than the broader issues of the range of e-systems needed to support the multi-agency teams providing the care.

The focus in this research on different kinds of task interdependency demonstrates pathways require a variety of kinds of information sharing and this has significant implications for the design of e-health support. There is some literature that relates to each of the major kinds of task interdependency. For example, Greenhalgh, Stramer, Bratan, Byrne, Russell, Hinder et al\[^{8}\], in evaluating the Summary Care Record, draw attention to the issues of trust and ownership that arise in relation to pooled interdependency. The handover has been studied as a medical issue by Meum and Ellingsen\[^{109}\] and electronic support for shared care in multidisciplinary meetings by Hardstone, Hartwood, Proctor, Slack, Voss and Rees\[^{113}\] and Li and Robertson\[^{110}\]. However, this research is specific to a particular context and is not, for example, related to the broader issue of integrated care in healthcare pathways.

### 10.4.2 The delivery of care as an emergent sociotechnical phenomenon

The picture of healthcare delivery as a complex, variable and essentially emergent process, that this research reports is mirrored in the research literature. Much of the literature focuses on work within particular agencies or locations, e.g. in intensive care\[^{31}\]. Our study suggests emergence and coping with ‘messy’ variance is a characteristic of all pathways. In contrast e-health systems tend to be designed to promote standard forms of treatment within pathways. Harrison, Kopell and Bar-
Lev\textsuperscript{34} report one of a number of studies to use a sociotechnical systems framework to explore the unintended consequences of e-health systems, in this case to describe how the mismatch between the model of the task embedded in the e-health system and the task that healthcare staff confront leads to frustration and workarounds. The unintended consequences of system use is also a feature of studies of electronic information systems outside the NHS, for example, the studies by Peckover, Hall, White\textsuperscript{125} on electronic systems to support the social care of children. The frequency with which these kinds of findings are reported suggests that there are important questions to address about the systems that are necessary to support variable and emergent task behaviour. In the NHS context it also focuses attention on two specific tensions in the requirements for e-health systems that are addressed in sections 10.4.3 and 10.4.4 below.

10.4.3 Privacy vs information sharing. This research found evidence that a fundamental tension exists between the need to keep patient information private and the need to be able to share information amongst healthcare workers treating a patient. At present the information governance procedures for accessing patient records are dominant with the result that many front line staff report difficulties sharing information and resort to a variety of work-arounds to overcome limitations set by the technology. These findings are replicated in the literature, e.g. in the examples Greenhalgh, Stramer, Bratan, Byrne, Russell, Potts\textsuperscript{7} give of the use of the Summary Care Record. Caldwell\textsuperscript{130} provides a graphic account of the effect full adherence to information governance procedures would have on a typical ward round. Although there are many examples of the problems caused by this conflict there is no systematic research of the issue.

10.4.4 E-health system support for operational work or for management. The second fundamental tension we have noted in the requirements for e-health systems is between creating a system to serve management needs and designing one that supports the information sharing needs of operational front line staff. In the systems we have studied the requirements of management have been dominant. Berg, Langenberg, Berg and Kwakkernaat\textsuperscript{31} also records that in the systems they studied the requirements of ‘secondary’ users, i.e. management, have priority over ‘primary’ users i.e. front line staff. A similar phenomenon is reported in the non-NHS literature where the implications for non-adoption by front line staff who are expected to serve a system rather than use it are widely discussed. Grudin’s Law, for example states that ‘when those who benefit are not those who do the work, then the technology is likely to fail, or at least, be subverted’\textsuperscript{114}.

10.4.5. Strategic issues in delivering e-health systems. At the outset of this research the NHS England approach within the NPfIT was to promote
seamless care by the roll-out of common e-health systems across all healthcare trusts. In 2011 the National Audit Office concluded that the problems of this top down approach were such that ‘the core aim that every patient should have an electronic care record under the Programme will not now be achieved’\textsuperscript{17}. Subsequently in September 2011 the Department of Health\textsuperscript{115} reported that ‘the government announced today that the NPfIT would be dismantled’\textsuperscript{115}. In the years before this announcement there had been a steady move away from the policy of all trusts having identical systems towards a greater degree of choice at the local level. The debate about the rival merits of top down, middle out and bottom up approaches is now a lively one\textsuperscript{29}. What is missing from the research literature and from the policy debate is the recognition, as expressed in the findings of this research, that there needs to be mutually supportive design activities at the top, middle and local levels.

This research also draws attention to the need to differentiate between the locus at which design decisions are taken and the technical solutions that are adopted. It is possible, for example, to adopt a single shared database approach across agencies as a result of a middle out strategy as well as a top down approach. As we have noted there are alternative technical approaches to providing shared access to electronic patient records. The portal approach adopted in Walsall is a major alternative and it is an approach being adopted elsewhere, notably by the NHS in Wales in the development of the Welsh Clinical Portal\textsuperscript{116}. The use of other middle-ware products to link existing systems is another possible technical strategy as, indeed, is the local mixing of all three technical approaches. This research demonstrates that the alternative technical structures have different implications for the user community: some approaches, for example, offer flexible infrastructures that can evolve and change as health care pathways evolve and change. There appears to have been no systematic research undertaken on the implications for user communities of the different technical solutions to sharing electronic patient information.

10.4.6 The local delivery of e-health systems. The analysis of four design processes in this research has demonstrated the wide array of design decisions that need to be taken at the Local Health Community level if an e-health system is to be a useful aid to integrated care delivery. The maturity framework presented in chapter 9 shows the multi-agency, sociotechnical nature of the design processes that are required. It is now common for researchers to emphasise that the successful delivery of e-health systems is not a technical challenge but a sociotechnical challenge, e.g. Berg\textsuperscript{32} (1999) and Eason\textsuperscript{14}. Robertson, Cresswell, Takian, Petarakaki, Crowe, Cornford et al\textsuperscript{13} draw particular attention to this requirement in reporting their evaluation of the NPfIT Detailed Care Record. In their evidence to the British Computer Society review of the NPfIT, Peltu, Eason and Clegg\textsuperscript{117}, make the case for a programme based on a sociotechnical approach.
The evidence from this research shows that, in the trusts studied, many sociotechnical practices are in place, especially the use of hybrids to facilitate on-going dialogues between computer professionals and healthcare staff, but that these practices are patchy and often informal. There has been little research on the detailed practices of trusts in the local design and evolution of e-health systems and as a consequence we do not know whether the strengths and weaknesses of the practices we observed are characteristic of local design across the NHS.

10.5 Conclusions

Within the two LHCs studied, we have found areas in which substantial progress has been made in creating working forms of e-health systems to support integrated care in healthcare pathways. These islands of progress have produced solutions that are quite different from one another and they are the result of evolutionary processes over many years in the face of many difficulties. As a result, there are parts of the systems development process that are quite mature in the ways in which the challenge of integrated design is tackled. However, current electronic support for integrated care can only be described as patchy and, to build on what is already in place, there is a need to create more mature systems development processes that can cope with the many challenges of bringing together a diverse set of stakeholder interests across a number of different healthcare agencies to create not just technical systems but sociotechnical systems geared to the specific needs of healthcare pathways. The emerging research literature from studies of e-health systems in the UK and around the world, concurs that the issues affecting the up-take of e-health systems are more sociotechnical than technical in nature but there has been relatively little systematic research of the links between healthcare processes, the organization of health care agencies and the design of e-health systems to facilitate the sharing of patient information.
Chapter 11: Reflections and Recommendations

11.1 Aims

We set out in this research with four aims as stated in the research proposal:

1. To explore by longitudinal study the barriers/facilitators in the development of e-health systems and the outcomes achieved when used across organisational boundaries in two PCTs.
2. To explore, for each PCT, the differences between systems created as a result of national and local strategies to produce platform-independent electronic systems and those locally developed as a result of inter-organisational initiatives.
3. To examine whether an action research framework in which usage reports are provided every three months, alongside feedback sessions to managers and end users, can promote effective take-up by providing an evidence base of benefits and barriers.
4. To synthesise the results with other studies of inter-organisational healthcare systems and similar systems outside healthcare, to produce guidance on the development and evolution of successful systems.

The purpose of this chapter is to reflect on the degree to which these aims were met and to make recommendations based on the findings of the research.

11.2 Meeting Research Aims in a Turbulent Organisational Environment

This research was undertaken during a particularly turbulent time for NHS Trusts and for the delivery of e-health systems. We made substantial progress with each of the research aims but it required a flexible and emergent approach to detailed research design. We believe that future research on e-health systems in the NHS will also be conducted in a turbulent environment and we reflect on the obstacles we faced and what was necessary to overcome them in the hope that this will be helpful to those planning future research in this area.

11.2.1 Barriers and facilitators to inter-organisational information sharing. The focus on healthcare pathways proved a major route to identifying the key areas of task interdependence that required active information sharing between healthcare agencies. This approach enabled us to track barriers and facilitators along each pathway and demonstrated that to be truly useful an e-health system has to be able to support healthcare staff working in many different contexts. However, tracking the use of e-
health systems along healthcare pathways led to a number of research planning issues. Initially we did not know which e-health systems supported which pathway and which healthcare agencies were involved in each pathway and the mapping of the pathways took a substantial amount of time in the first part of the research. Before this was undertaken it was difficult to provide the detail required for ethical clearance. Obtaining clearance for research also required the support of each of the NHS organisations to be involved and, because this study was intrinsically multi-organisational, it was difficult to proceed with user interviews until we were clear about the organisations involved in each pathway. In practice we did not achieve the goal of being able to interview all the main players in the pathways described in chapters 6, 7 and 8: we could not for example interview the staff of local ambulance trusts or of social services. Similarly we were not able to interview patients about their views on electronic patient records and we found ourselves studying e-health record systems without having access to the records because access was limited to healthcare workers with a responsibility for the patient. For similar reasons we were unable to observe healthcare staff using e-health systems. We were able to familiarize ourselves with the systems in general by accessing demonstration records used in training but we were not able to verify what we were often told, for example, that records are often incomplete or very limited in the information they held. In these respects our experiences were similar to those of our respondents; although their intentions are entirely appropriate, information governance policies were a hindrance to the access needed for research purposes.

Despite these limitations we were able to demonstrate the varied contexts in which e-health systems were used and the variety of requirements they needed to meet. Given the limitations of access we conclude that our results are likely to underestimate the variety of contexts in which healthcare is delivered and therefore that the requirements for e-health system support are likely to be even more varied than we have been able to represent.

11.2.2 National and local design processes The examination of national as opposed to local design processes that we had originally planned was constrained by the non-delivery of the NPfIT national systems during the period of the research. We cannot therefore report the process by which a new national system would be ‘rolled out’ in these trusts. To compensate for this we chose to examine design processes that involved some of the systems previously delivered within the NPfIT and found that each middle out design process in the Local Health Community was deeply influenced by national policies. What was striking was that these influences were not only national information technology policies but also information governance policies and policies specific to each of the healthcare pathways. As a result the research addressed the national versus local design issue in a more contextualized manner and revealed a complex set of influences and design mechanisms which adds richness to the debate about top down, middle out and bottom up design.
11.2.3 Action Research  We had originally intended to share the results of the research with the informatics and healthcare staff of the trusts from early in the research programme. As a result of the issues discussed in 11.2.1 above, the case study results reported in chapters 6, 7 and 8 were not available until near the end of the research period and feedback to stimulate the action research cycle was limited to the last few months of the programme (and is described in appendix 3). In one of the trusts in particular the feedback was widely welcomed because it provided new evidence about barriers and facilitators to e-health system use and focused attention on embryonic sociotechnical design practices that local staff could see could profitably be developed. For the researchers this process provided a mechanism for checking the wider validity of the research findings and, had the action research cycle continued, could well have generated new research insights as new design practices were implemented. Research on design practices is inevitably limited to practices that are already in place and, if practices identified as a result of research are to be explored, action research provides an immediate vehicle by which this can be done.

11.2.4 Synthesising the results and generating guidance There have been relatively few studies of the inter-organisational use of e-health systems with which the results of this study can be directly compared. However, there are many studies of pathways and of e-health systems as reported in section 10.4, that provide indirect evidence. The barriers to and facilitators of use that this research reveals are frequently reported elsewhere and the dominance of technical rather than sociotechnical design methods is also a contemporary theme following the dismantling of the NPfIT. What is missing from the research literature is a systems perspective on the role of e-health systems in integrated care that comes from exploring the interaction of process, organisational and e-health dimensions within a single research study.

A major form of guidance that could emerge from this study is in respect of the design processes necessary to deliver e-health systems to support integrated care across health and social care organizations. It would be problematic to formulate guidance on the basis of a study of four design processes but there is a long-standing non-NHS literature on the sociotechnical design of IT systems that provides many concepts of potential use within the NHS. We have used these concepts as a framework in chapter 9 to explore the maturity of the design processes we have studied as mechanisms for the delivery of inter-organisational sociotechnical systems. The results show where there is good practice and also where there are gaps that could be filled by the methods used elsewhere. They also raise questions about design policies and practices needed at a national
level, at the level of the local health community and also in terms of the local, bottom up evolution of systems. Some of these issues are taken up in the recommendations presented in section 11.3 below.

11.3 Recommendations

As a result of the findings of this research study we offer two kinds of recommendations. First there are recommendations for the design and implementation of e-health systems that are intended to support integrated care within healthcare pathways that span organisational boundaries. Second, there are recommendations about the form and content of research that might expand our understanding of the role of e-health systems in integrated care and the design methods for introducing new systems into the NHS.

11.3.1 Recommendations for the delivery of e-health systems to support healthcare pathways. The design process for e-health systems has to accomplish a variety of difficult challenges, it has to: (a) enable sharing of information across organisational boundaries; (b) control access to protect patient confidentiality; (c) provide a useful service for a user community which includes managers, auditors and a rich variety of front line staff; (d) cope with changing requirements as user needs change; (e) be able to respond to healthcare process and organisational change. These varied demands have implications for technical solutions and for design processes.

1. Technical strategy. There are a range of technical solutions which offer opportunities for users to share patient information: they can all use the same database; they can use a portal to view different databases; they can use ‘middleware’ so that, for example, specific data can be extracted from one database to another. Each of these options has different consequences for the user community and in choosing a strategy and specific technical systems trusts need to recognize the implications for the user community. It is particularly important to recognize the varied demands that will be placed on any system and that there will be many pressures for the service to continue to evolve. This places a premium on the flexibility of a system, the degree to which it can be customized and the ease with which evolution is made possible.

2. National Strategies. The most important lesson of this research for national strategies is the need to follow ‘the principle of minimum critical specification’ if sufficient flexibility is to be created for local design and evolution. National IT policy has already moved away from selecting the systems that trusts implement but there remain several topics that need addressing at a national level if the NHS is not to slip back into a silo approach in which there are many systems that cannot share data. National strategies can ensure, for example, that only systems that use common data standards that facilitate data sharing can be procured in the NHS. It
may also be important to review information governance policies to examine whether more flexibility can be provided so that healthcare teams can establish their own procedures for securing patient privacy. Similarly, in the design of national frameworks for healthcare pathways there needs to be greater freedom for local healthcare communities to shape the pathways to meet local and evolving needs.

3. Local Health Community Strategies. This research suggests that the goal of integrated care is most usefully sought at the level of the local health communities where all the relevant agencies operate. At this level there is a need to establish and maintain projects that are (a) multi-agency, (b) sociotechnical, i.e. deal with process, organization and technical design and (c) engage all levels and types of users. The evidence of this research suggests that project leaders should work on the principle of what might be called ‘natural fragmentation’, i.e. that any project will tend to separate into isolated parts unless continuous efforts are made to sustain integration. Thus different agencies will pursue their own agendas, technical developments will become separated from organizational ones, management goals may be pursued at the expense of providing a good service to front line staff etc. Achieving the goal of integrated care depends on sustaining integrated design before, during and after system implementation. The maturity framework presented in chapter 9 identifies the issues that need to be addressed at these different stages of development and could well be developed as a tool to aid the mature management of complex inter-agency projects.

4. Local Bottom Up Design. Current development processes appear to give least attention to the information sharing needs of front line staff. To correct this, formal mechanisms need to be introduced to analyse the needs of staff during systems development and to improve the capability of hybrid staff to work with the user community on the specification of systems. The fluid nature of the healthcare world also means a capability needs to be kept in place to develop the learning of users and to revise e-health systems to sustain and improve the service they provide for users. Again the maturity framework offers a perspective on the capability that is required and the mechanisms by which the continued development of systems can be pursued.

11.3.2 Recommendations for research

1. Research Methods. As a result of our experience in conducting this research we would recommend that future studies of IT applications in the health service are commissioned bearing the following in mind:

a. If the issue is the development of service delivery there is little point in assessing the impact of a particular IT application. Any studies should start from the perspective of the service being delivered in order that the role, benefits, barriers to use etc can be seen in the appropriate context.
b. Given the instability in the health service, any research design must be sufficiently robust to be able to achieve its research objectives by different routes when conditions change, e.g. an expected development does not take place.

c. We have learned most from this research by being able to undertake qualitative analysis that respects the very different contexts in which users work and use e-health systems. As a result we would be suspicious of the value of any study that accumulated data over a number of users and was not able to account for specific user responses by reference to the sociotechnical context of their particular roles.

2. Research Themes. It is widely presumed that e-health systems are, or will be, a significant contributor to the achievement of integrated care across the agencies involved in healthcare pathways. Our research leads us to the conclusion that e-health systems can make a very significant contribution but only if they are tailored to the specific characteristics of the tasks in the pathways. Our work has examined a limited number of pathways and has identified a range of issues that require further research. The answers to these questions could make a significant contribution to the potential of e-health systems being fulfilled.

The following are questions that might further explore the barriers to use, benefits that can be achieved and unintended consequences of e-health systems:

a. Can e-health systems be designed that serve all of the different requirements of the user community, e.g. to serve front line information sharing needs as well as management needs?

b. Is good information governance to protect the privacy of patient records compatible with the sharing of information necessary to achieve integrated care?

c. Are the findings of this research, e.g. the dominance of management requirements over front line needs, found in e-health support for other pathways?

d. Can ‘workarounds’ be studied as examples of local sociotechnical system failure, i.e. do they demonstrate when there is a mismatch between what the technical system facilitates and what the user community need in order to undertake their work?

e. Are there particular settings that pose problems for the achievement of integrated care that are worthy of special investigation? Examples might be electronic information sharing across the health and social care divide and e-health support for the multi-agency, ‘virtual teams’ necessary to deliver healthcare to the frail elderly in their own homes?

f. What the implications for ownership, responsibility and trust of different forms of information sharing, e.g. from tightly coupled sharing where everybody uses the same database to loosely coupled sharing where
each agency has its own database and controls what is shared with others?
g. What e-health systems most effectively support information sharing in the different forms of task interdependency, e.g. in pooled interdependency where sharing is many to many, in ‘handovers’ between specific agencies and in situations of ‘shared care’?

This research has also identified a number of themes that relate to the design processes by which e-health systems for inter-agency integrated care can be created.

a. What is the impact of different technical strategies for sharing information, e.g. shared databases or portals, for the evolution of systems?
b. What is the impact on the adoption of e-health systems of different patterns in the locus of design, e.g. more emphasis upon top down, as opposed to middle out as opposed to bottom up design?
c. What is the impact on the adoption of e-health systems of design processes that seek integrated, multi-agency, sociotechnical design as opposed to those that focus on technical system delivery?
d. To what extent are the capabilities available and the mechanisms in use within Local Health Communities geared to the delivery of e-health systems that support integrated care, e.g. can local teams deliver across the range of issues in the maturity framework?

11.4 Conclusions

As a grounded study this research project has been able to show that e-health systems can make an important contribution to the achievement of integrated care across healthcare agencies but it has identified many barriers that limit what is achieved in practice. It confirms what others have reported: that many of the issues are sociotechnical in character rather than technical. Switching the focus from systems in use to systems in design has demonstrated a need for the matching of the technical system to the healthcare pathways to be undertaken at the level of Local Health Communities where agencies can co-operate in finding effective solutions. The analysis of what is required to deliver multi-agency, sociotechnical systems to support a wide range of users who operate in a changing healthcare environment has highlighted the challenges involved in delivering successful systems. It is to their credit that in many areas the two PCTs we have worked with have, by dint of informatics staff and users working on the issues over many years, gradually evolved systems that are enabling information sharing in significant ways. If future studies are able to hold in focus the service to be delivered, the users and agencies who deliver it and the technical systems that support them it should be possible for future research to help articulate the practices necessary to make integrated care a more systematically achievable goal.
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Appendix 1

Other Pathways

1. Introduction

This appendix provides details of two pathways that were mapped as part of the research programme but were not developed as full cases. They are both cases from Northamptonshire; the multiple sclerosis pathway and the palliative care pathway.

2 Multiple Sclerosis (MS) Pathway

2.1 The Pathway Map

Figure A1.1: The Multiple Sclerosis (MS) Pathway
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<tr>
<td></td>
<td>Patient to GP with urinary incontinence</td>
<td>Patient attends for diagnosis</td>
<td>Care plan for patient Help with daily living</td>
<td>Assessment for wheelchair</td>
<td>Ongoing healthcare support package in place</td>
</tr>
<tr>
<td></td>
<td>Treatment by Continence Service</td>
<td>Suspected MS</td>
<td></td>
<td>Intensive home care assessment</td>
<td>Social care package in place</td>
</tr>
<tr>
<td></td>
<td>Patient to GP with mobility issues</td>
<td></td>
<td></td>
<td>Social care referral</td>
<td></td>
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<tr>
<td>Linked Pathways</td>
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<td>Roles and Agencies</td>
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<tr>
<td>GP</td>
<td>Physiotherapy</td>
<td>GP</td>
<td>MS Specialist Nursing Service</td>
<td>Social Care</td>
<td>Social Care</td>
</tr>
<tr>
<td>Continence Service</td>
<td></td>
<td></td>
<td>Physiotherapy/OT</td>
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<td>Equipment Services</td>
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<td>Interdependencies</td>
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<td>Communcations</td>
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<td>IT Systems sharing possible</td>
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<td>sharing not possible</td>
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<tr>
<td>Vision EMIS Anglia ICE</td>
<td>SystmOne</td>
<td>ELMS ePEX TIARA Interim Therapy Solution</td>
<td>ePEX ELMS CareFirst</td>
<td></td>
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<tr>
<td>GP alternatives: SystmOne</td>
<td>SAP Contact Assessment Paper referrals</td>
<td>SAP Contact Assessment Paper referrals</td>
<td>SAP Contact Assessment Paper referrals</td>
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<td>Sequential</td>
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2.2 The Interdependencies in the Pathway

The Multiple Sclerosis (MS) pathway is an example of a long-term condition that can slowly worsen over many years. The pathway is sequential but the stages may take many years; it is characterised by periodic assessments that may lead, as mobility etc gets worse, to a wider and wider array of healthcare and social care becoming necessary. The table identifies the main healthcare services that are likely to be needed but, since the condition can have wider medical consequences, other services may also be required. Although it is a sequential process, the pattern is that other services are added to the care process rather than one service handing over to another. As a consequence, within each stage when the condition has fully developed, there is a wide array of services that are dealing with internal sequential interdependencies (known as ‘shared care’ in the NHS).

2.3 The Organisations and Agencies Involved.

The process begins with the GP and, in time can make use of an array of services offered by Northamptonshire Provider Services. Initially the GP may refer the patient to the Incontinence Service and then to Physiotherapy. When MS is suspected, the MS Specialist Service become involved, leading to the involvement of Occupational Therapy, Equipment Services and Wheelchair Services. When long-term support is needed for the patient to live at home District Nurses, the Intermediate Care Team and Social Care may all become involved. Most of these services are within Northamptonshire Provider Services. It seems likely that the most common pattern to emerge will be a regular ‘team’ (GP, MS nurse, District Nurse, Social Care Worker) will care for and monitor the patient’s condition and bring in specialists as and when required.

2.4 Information Sharing

Northamptonshire Provider Services makes widespread use of SystmOne and, since this is dominantly a community care pathway, it is possible that many of the services will be able to share the patient information that accumulates as the long-term condition develops (Physiotherapy, OT, MS Nursing, DN, ICT, Continence Services, Wheelchair and Equipment Services). When the GP is also using SystmOne there is the possibility that these services (with the GPs permission) can access the GP record and that the GP has direct access to the assessments and treatments being provided.
by the services. In this scenario it would only be Social Care, making use of the CareFirst system, that would be outside the electronic sharing network.

However, it is more likely that information sharing will not be extensive. Where GPs use another systems, access to their records by the community services will not be possible. It is not possible at the moment for community staff to access SystmOne in the patient’s home and hence paper records are held there whilst SystmOne records are updated in the office. The record held at the patient’s home is SAP (Single Assessment Process), an assessment process shared across community services and social care. An electronic version (eSAP) is under development but was not available during the period of this research.

3 Palliative Care

3.1 The Pathway Map

Figure A1.2: Palliative Care Pathway

See next page
<table>
<thead>
<tr>
<th>Pathway</th>
<th>1 Patient referred for palliative care</th>
<th>2 Palliative Care Assessment</th>
<th>3.1 Palliative Care at Home or Nursing Home</th>
<th>3.2 Hospice Care</th>
<th>4 Death</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Referral from oncology (acute trust) or GP</td>
<td>Bi-weekly Shared Care Assessment Health Care Plan (Physical &amp; Mental), Social Care Plan</td>
<td>Deliver regular care Provide specialist care Social Care</td>
<td>Intensive Health &amp; Social Care (av. stay 13 days) Specialist Care</td>
<td>Certification Family Support Record Closures</td>
</tr>
</tbody>
</table>

**Linked Pathways**

<table>
<thead>
<tr>
<th></th>
<th>Hospital Admission</th>
<th>Hospital Admission</th>
<th>Funeral Services</th>
</tr>
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</table>

**Roles & Agencies**

|        | GP | District Nurse | Oncology, Acute Trust Hospice Nurses MacMillan Nurses Marie Curie Hospice@Home Social Care MacMillan Nurses Marie Curie Hospice@Home Lymphoedema MND Team Macmillan Welfare Rights Family Work Team OT, Physio, Social Care Social Care LN, Nursing Home Staff Hospice Nurses Hospice Nurses Social Services |

**Interdependencies**

|        | Sequential Referral | Internal & external real-time reciprocal few-to-few | Internal & external real-time reciprocal few-to-known few | Internal & external real-time reciprocal few-to-known few | Sequential Referral |

**Communications & Paper Record Systems**

|        | Referral Paper Discharge Medical Records | Shared Care Assessment (incl. preferred place of care) CHC (funding) bid | Death certificate Return of records to GP/Acute Trusts |

**IT Systems sharing possible**

|        | Community Providers & Local GPs SystmOne | Community Providers & Local GPs SystmOne | Community Providers & Local GPs SystmOne | Community Providers & Local GPs SystmOne |

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## 3.2 The Interdependencies in the Pathway

The only sequential aspects of this pathway are the referral in and the process that follows death. The process in between appears to be regular assessments of the patient’s condition with movements between home and the Hospice for medical and social care as necessary. There is the potential of re-admission to hospital but the process is designed to avoid ‘unnecessary admission to hospital’. The main part of the pathway is intensely reciprocal between many different agencies and may involve many iterations between assessment and care, and between care at home and in a hospice (in this case Cynthia Spencer Hospice for South Northamptonshire and Cransley Hospice for North Northamptonshire).

## 3.3 The Organisations and Agencies Involved.

The process begins when an Acute Trust (probably Northampton General or Kettering General and probably the Oncology Department), or the patient’s GP decide (in consultation with the patient) that no more treatment is useful or possible and ask for the patient to be given palliative care (essentially kept free of pain). A referral is then made to the Palliative Care Team. Thereafter, because this is likely to be a period of weeks/months during which the patient’s condition will change and deteriorate, as initial assessment is made and repeated frequently (up to twice a week) as necessary. The alternatives for care are for the patient to be cared for at home, in a Nursing Home or in a Hospice. When the patient is at home a District Nurse co-ordinates care, when in a Nursing Home it will be local nursing staff and in the Hospice it is co-ordinated by the Hospice matron. The assessment is made (and reviewed) by a multi-disciplinary team that creates and reviews a ‘shared care’ record. There is likely to be a core multi-disciplinary team involved regularly in this process (the District Nurse, the Hospice staff, hospice@home, Macmillan Nurses, Marie Curie Nurses and Family Welfare) supplemented as necessary by specialist staff (MND, Lymphoedema, OT, Physiotherapy etc). The assessment covers the physical welfare of the patient, the mental condition of the patient and social care needs. In the last six weeks of life the assessment team can apply for CHC (Continuing Healthcare) costs in competition with other pathways for those with long-term conditions, e.g. MND, MS. The process involves Social Care Services/Macmillan Welfare Rights and the Family Work Team who might all have a role in guiding the patient and their relatives to services that might provide social and welfare support. When the patient dies there are support services available, especially in the Hospice, to
support family members (Bereavement Support, Chaplain) and formal processes to complete to certify death, to inform various authorities and to return records and update the information of agencies (GP, Acute Trusts, Registrar of Births and Deaths and Social Services) who need to complete and close their records of the patient.

3.4 Information Sharing

There are many agencies who could potentially be involved in the palliative care of a patient, and who need to share information in real time, but at present there is no shared electronic information system. Staff who are part of Northamptonshire Provider Services, e.g. the District Nurses, OT and Physiotherapy) have access to SystmOne as do those GP practices who have adopted the system. This means that some sharing of electronic records is possible between staff in these agencies. It is highly likely that the patient will have had one or more hospital stays and that there will also be an Acute Trust electronic patient record in iPM, ICIS or Lorenzo. The Palliative Care team based at the Hospice use ePex to develop their record and is shared by all the agencies based at the Hospice, i.e. it will include Macmillan nurses, hospice@home, Marie Curie etc. Social Services are also likely to create their own electronic record for their client in Care First. There is the potential therefore that at least five detailed electronic records exist for the patient. The most important one during Palliative Care is the ePex system used by the Palliative Care team but it is not inter-operable with any of the other systems. In time The Palliative Care staff at the Hospice hope also to use SystmOne which would extend sharing with Community Services and potentially some GPs.

In the absence of electronic sharing, messages between services and shared records are paper based and, because there are likely to be many occasions when sharing is urgent, an emphasis is placed on mechanisms for rapid transfer of information – e.g. faxing discharge notes and referrals, sending a taxi to get medical records etc. There already exists a complex paper-based ‘pathway’ with its own special documentation, e.g. a shared care record for palliative care which includes the patient’s wishes for where care will take place, e.g. to go to a hospice rather than to return to hospital, and the CHC (continuing healthcare) form by which application is made for the funding of services in the last stages of life.
Appendix 2

Meetings of the Frail Elderly Pathway Design Groups

Fifteen meetings of the e-health development groups for the Frail Elderly Pathway in Walsall were attended between September 2010 and June 2011. A summary of the deliberations of these meetings is given below.

Three meetings of the steering committee for the implementation of the Frail Elderly Pathway were observed between September and December 2010. The meetings were attended by representatives of a wide range of agencies and, despite a changing membership from meeting to meeting, agreement was reached on terms of reference for a joint implementation plan. The commissioners confirmed the budget for pathway development and drew attention to the expectations for savings. Emphasis was placed on setting kpis that reflected the impact on the overall impact on health provisions, i.e. savings on hospital admissions, and not just the performance of the pathway. Although there was discussion of procedures and resources in ICT, e.g. the provision of extra beds, most debate was about the links with other pathways and disciplines, e.g. with community matrons, palliative care, falls and the medical contribution to the pathway. These discussions extended to discussions with other agencies, for example, to the ambulance service about how they would refer patients to the pathway. There was a lot of concern to ensure that all the agencies that related to the pathway were made aware of how it would work, for example, ensuring junior doctors in A&E were aware of the criteria for avoiding hospital admission. The development of shared e-health systems was also debated, for example, arranging shared access to FUSION and Paris by healthcare and social care staff. Social services had already deployed telecare equipment to patients with long-term conditions and there were discussions about their possible use in the frail elderly pathway.

Six meetings of the e-SAP Informatics Board were attended between January and June 2011. These meetings were chaired by a user (a Community Service Manager) and included a project manager and programme manager from IM&T, representatives from ICT and the Acute Trust and from Social Services. The meetings were to manage a project under the PRINCE2 project management process and a PID (Project Initiation Document) was agreed that aimed to run a trial of e-SAP within six months. There was considerable scepticism expressed by the users about this ambition because many promises about eSAP in the past had come to nothing. The programme manager was unwilling to give firm promises on delivery dates because, as a result of 35% cuts in IM&T resources, he had
very little internal development effort that he could devote to the programming that was necessary. The aim was to capture SAP information electronically and input it to the patient’s record in iPM. The summary information (the overview and contacts sheet) would then be made accessible via FUSION. It was hoped to extend the access to FUSION by Social Services staff so that they could access the SAP summary information. Similarly, the plan was to make Paris records available via FUSION to healthcare staff. There were several programming challenges to be overcome. The main one was that iPM and FUSION used different Master Patient Indexes and work had to be done to find a way of resolving the differences. Development work was also necessary to create an iPM ‘workaround’ that would enable eSAP inputs to be added to the patient record. Finally a ‘cleansing’ process was taking place with a sample of Paris records to examine the issues of accessing them via FUSION. During the course of these meetings additional finances were found within the Frail Elderly programme in order that extra developer effort could be obtained to progress this work.

The plan was to capture SAP data in the patient’s home by using a DigiPen, a pen-like device that was used to write on specially prepared paper. A copy could be left with the patient’s SAP documentation but the pen retains an electronic store of the information that can be downloaded to iPM on return to the office. A trial of DigiPens was to be undertaken by District Nurses later in the summer although it would not use SAP documentation. Another trial of the same technology was being undertaken in a neighbouring trust and its results were considered in these meetings. They demonstrated that the technology worked well with completely structured documents (where the technology only had to recognise what box had been ticked) but it was less reliable in recognising free text handwriting. This was a concern to the meetings because they could not see that free text entries in SAP could be eliminated. It raised the possibility that a better option might be to use laptops for gathering SAP data because the other Informatics Board was considering their use for other purposes in the Frail Elderly Pathway.

At the end of this series of meetings the technical problems of implementing SAP had not been resolved and the project manager recommending cancelling the DigiPen trial because it was not likely to add anything to the development programme.

Between January and June 2011 six meetings were also attended of the Frail Elderly Informatics Board. These meetings were chaired by a member of the Business Change Facilitation Team and had a similar membership to the eSAP Board but with greater numbers reflecting a broader range of developments. The meeting similarly managed a project under PRINCE2 and agreed a PID for the project. The project had several strands to its development work; the creation of a ‘virtual ward’ for the Frail Elderly Pathway, arrangements for Paris/FUSION access, the issuing of
laptops to healthcare workers, the possibility of installing telehealth equipments into patient’s homes and the collecting and reporting of information against kpis for the pathway.

The ‘virtual ward’ was to be a list of all the patients currently on the pathway that could be accessed on FUSION and would give basic information about each patient. It could be used to access a more detailed record in iPM which would include clinical details. If the telehealth implementation was successful it could include up-to-date test results and would enable staff to monitor a patient’s ongoing condition remotely. By the end of the series of meetings the informatics staff were able to demonstrate the virtual ward as it would look in FUSION and plans were being made to demonstrate it more widely in the Trust. The specification for laptops to enable healthcare staff to access patient records whilst away from the office and potentially record the outcome of visits was debated in these meetings and a trial was planned of a laptop already being trialled by midwives. Particular concerns were expressed by users about the weight of laptops, the connectivity that could be obtained and the problem of how to leave a paper copy of documents with the patients. They did not wish to add the weight of a printer to the equipment to be carried but could not think of another way round the problem. Given the delays in progressing this strand of the programme, at the end of the series of meetings, they had decided against a trial and planned to issue a small number of the laptops to the rapid response team who were deemed to be in greatest need to mobile working.

The presence of representatives from Social Services facilitated the development of mechanisms by which Paris and FUSION records could be accessed. The process planned was to move in stages, first with an extension of access to FUSION by social care staff and Paris by ICT staff, secondly to access to both systems from one computer and then to FUSION providing access to Paris. The consideration of the telehealth equipment involved specifying the range of test results they wished to capture and checking how easy it was to install and dismantle the equipment quickly because they only wanted to use it during the acute phase of care. At the end of the series of meetings demonstrations of the equipment had been arranged. Social Services already had a stock of this equipment and the meeting encountered some complex procedural issues about whether they could buy some of this stock quickly or whether they had to go through a formal purchasing process and who they had to refer to in order to make progress on this issue.

A considerable part of many meetings was devoted to the design of information reports about the Frail Elderly Pathway that reflected a range of kpis for the pathway such as the number of patients on the pathway, the length of their stay on the pathway, their destination on discharge and the decrease in admissions of elderly patients to hospital. It was the evidence of
savings being made that were most important to the commissioners and the early evidence was disappointing. However, the meetings noted that the SMART kpis (the operational way in which they were measured) were rather blunt ways of assessing the impact of the pathway. The measure of elderly patients being admitted to hospital, for example, included those coming for planned procedures when the pathway was only intended to affect the numbers of emergency admissions. The meeting agreed revised ways of assessing kpis but it did not have the authority to change them; proposed changes had to be referred to the commissioners.

The staff attending these meetings evinced considerable frustration about the slow progress that was being made. This was in part because the IM&T Department had very limited resources they could devote to these developments. However, it was also caused by the need to keep referring back to the many bodies that had authority with respect to the plans they were making; to the commissioners, to social services, to the parent body steering the pathway implementation, to a body responsible for new pathways etc. It meant a considerable amount of time was devoted to working out who had to be informed and to delays whilst this process took place. At the end of this series of meetings very little change had been made in the e-health facilities available to healthcare workers although a lot was planned. In the final meeting the project manager put all the activity strands ‘on red’, i.e. posted them in the project management documentation as being likely to miss their targets. However, the users remained convinced these were necessary developments for the success of the pathway and were determined to continue their efforts.

Subsequent to these meetings all activities were given new target dates, the informatics service was provided with resources to undertake programming and work continued to deliver the various e-health contributions to the Frail Elderly Pathway.

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Appendix 3

The Action Research Cycle

1 Introduction

In the final period of the research the results of the pathway studies were fed back to relevant stakeholders in the two Local Healthcare Communities. This process went further than feedback to include an engagement in an action research cycle. According to Ramirez and Bartunek\(^\text{93}\) an action research cycle involves:

- Systematically collecting research data about an ongoing system
- Feeding these data back to the system and conducting a collaborative diagnosis of the data
- Taking action based on the diagnosis, and
- Evaluating the results of the action.

The first phase of this cycle was the collection of case study evidence reported in chapters 6, 7 and 8. In the final period we fed back the data and worked with staff in both LHCs to jointly consider the implications of the results for their future e-health systems development. In the time available there was no systematic evaluation of the results of this action. However, in this appendix, we reflect on the achievement of two related purposes of this action research cycle and thereby undertake our own evaluation. The two purposes were:

- To feed our results directly into the ongoing systems development ‘action’ and provide a relevant evidence base that local developers could use in their future decision-making.
- To feedback our results to the wider community of relevant stakeholders in each LHC and thereby check the validity of the results and potentially enrich the evidence base by capturing the views of other stakeholders.

In practice, because feedback was in some instances up to a year after data collection, the action research process also served a third purpose, that of up-dating the research team on recent progress in systems development.
2 The Process

In some forms of action research it is necessary to create an action forum to take ownership of the research and of the action that might flow from it. In this case there were ongoing groups associated with most of cases that were studied and in some of them, the research process included attending their systems development meetings. The majority of the action research process was therefore a case of feeding the research results into an ongoing programme of ‘action’.

In each of the Local Healthcare Communities an action research process was planned with the local collaborators in the research and with the IM&T senior staff to achieve the following:

- To feedback results at a strategic level to local policy makers
- To feedback results in relation to each pathway that was studied to those concerned with the further development of that pathway

In both of the LHCs the timing of these action research events (June and July 2011) coincided with major organisational changes. In Walsall the merger of the Acute Trust and the Community Trust took place on 1st April and the implications for pathways and for shared e-health systems were being worked through in the subsequent months. In Northamptonshire, the bulk of Community Services joined the Mental Health Trust in Spring 2011 and the IM&T service in the community became part of the Mental Health Trust. Also in both LHCs this was a period in which GP commissioning groups were becoming more involved with PCT commissioning activities.

These major organisational changes affected the action research cycle in different ways. In Walsall, for example, the merger of Community Services and the Acute Trust meant a series of meetings were being undertaken about the new opportunities this presented. As a result not only were feedback meetings well attended but members of the research team were invited to attend some of these meetings to further examine the value of the research findings in relation to pathway development decisions that were being taken. In Northamptonshire, by contrast, staff, particularly those in the IM&T Department that was being moved, were so preoccupied with working through the consequences of the merger that only a few small-scale feedback meeting could be undertaken in the timescale available. It is intended that the process will continue beyond the end of the research period. We concluded that there was also another factor that explained the different responses. Walsall is a compact geographical area with a long tradition of close working between the different agencies that includes close links between informatics staff and their user communities. As a result it proved relatively easy to bring mixed discipline and mixed agency groups together for feedback discussions. Northamptonshire is a much bigger geographical area with more separate agencies and less regular contact between informatics staff and user communities. As a
consequence it was too big a task in a short timescale to bring together appropriate audiences for the feedback process.

3. Action Research Feedback in Northamptonshire

3.1 Strategic Discussions with IM&T Staff

In a meeting with two senior members of the IM&T Directorate it was confirmed that the main strategy continued to be the further adoption of SystmOne although some efforts were being made to look at more use of middleware solutions where they are relevant. In discussing the findings on the development processes the directors, who both had non-NHS backgrounds, said they had been surprised that there was not an overarching strategic process for systems development in the NHS that was multi-agent and multi-strand.

They also expressed the difficulty of establishing such processes in the organisationally turbulent world of the NHS. The recent splitting of provider services had meant, for example, that they now found themselves responsible for GP services although, as commissioners that was not technically their job.

3.2 Pathway Discussions

3.2.1 The Out-of-Hours Service

A meeting was scheduled with doctors proving the out-of-hours service to discuss the research findings about unscheduled care and the reports provided to GP practices. In the event the meeting was postponed until after the research period because a new company had recently taken over the OOH service and the doctors who planned to attend the meeting were uncertain whether they would have a role in the service in the future. It is also a possibility that the service will no longer make use of SystmOne and be able to share the patient record with GP practices.

3.2.2 Intermediate Care and CESC

A meeting was organized to feed back the results of the intermediate care study reported in chapter 8 to the clinical change facilitation team. In the event one member of the team was able to attend. The meeting validated the conclusions presented in chapter 8 and, in particular, the clinical change
facilitator commented on the ‘sharing’ of the patient’s record between Community Services and GPs who were users of SystmOne. She acknowledged that some GPs did not like ‘their’ records being swamped by detailed accounts of community care. However, she pointed out that the link to this part of the record was just an item on the top menu and could be easily ignored. She felt the comment was symptomatic of an attitude that remained that we did not all share the same record that was the patient’s record but that it was considered to be the GPs record. She recognized that some diagnostic codings entered into the patient’s record would have consequences for the GP because they would be expected to follow them up. However, she said community staff were being educated to avoid certain definitive codings that had this kind of implication.

Most of the meeting was concerned with the progress of work on e-health developments in relation to the new CECS (Community Elderly Care Service) over the past seven months. The clinical change facilitator reported that, for a period of several months, there had been a series of weekly meetings which included all the leading stakeholders in CECS (the commissioners, Nene Commissioning (the GP led consortium), the Acute Trusts, ICT and the informatics service). The CECS pathway was now in place and the work of the informatics team was complete ‘except for a few loose ends’. They had been asked to develop assessment and care plans for three additions to the original ICT service. These were a pharmacy service, which introduced a new group of users, a cellulitis module and an assessment process for gerontologists from the Acute Hospitals who would be attached, part time, to ICT, to provide medical input for the elderly patients. All of these additions posed new challenges for the templates in SystmOne but all had been accomplished and rolled out. The cellulitis module, for example, meant that the SystmOne records needed to contain camera images of skin inflammations and this was now in place. She said that, in all, they had implemented 20 assessments and 20+ care plans as standardized ways of working across the ICT. Their normal process was to make an evaluation four weeks after deployment and they would do this in the near future.

She reported that one aspect of the deployment had been a disappointment. The peer training process had led to very patchy training of the user population with the result that she was unsure about the quality of records in some parts of the service. Fewer peer trainers had been trained as planned and there were now only two left. They had been allowed only 2 hours to train their colleagues and this had not been enough. The clinical change facilitators had, she said, learned some lessons from this and were now producing training materials to support the deployment process.

Mobile access to SystmOne by the staff of the ICT had made very little progress. The strategy was to create locations where they could ‘drop in’ to check patient records and up-date them but only three locations had been created which was not enough given the size of the county. Similarly the issue of using SystmOne for scheduling had not been pursued because the
database was not as yet sufficiently stable and well used to provide a valid basis for scheduling.

The ‘refresh’ objectives had been achieved for ICT but there were still parts of community service, for example, Wheelchairs and Falls, who were not using the system. However, the clinical change facilitator team was now reduced to three and was spread too thinly over many projects for the further spread of SystmOne in Community Services to have priority. One of the features of the feedback was our commentary on the role of the clinical change facilitator team and she said they were wondering if it had a future in the merger because the mental health trust already had an IM&T team although she believed it to be more technically oriented. She also reported that the mental health workers in the trust were already ‘paperless’, i.e. already made use of some form of laptop, and she wondered whether that would give these developments more prominence for community services because they had now merged with the mental health trust. She reflected that their work tended to consist of picking up issues as and when they became priority.

3.2.3 Diabetic Retinopathy Screening

Two members of the retinopathy screening service discussed the findings and considered how the e-health systems OptoMize and Quest Browser might be developed to provide more support. They agreed with the evidence presented in chapter 7 that the various boundaries between OptoMize and other systems were the issues to focus on:

- Quest Browser is now used every three months to up-date the GP lists but it does not solve the problem of the many changes that occur daily. They knew of other trusts where a system like Quest Browser was used to sweep the GP systems every day to up-date the lists of patients with diabetes and felt that was the only way of dealing with the problem.

- The mobility of patients was getting greater and tracking them across the county boundary was becoming a bigger issue. They signaled in particular the growing problem of students who stayed registered with their home GP but were in effect residing elsewhere and were not at home when asked to make an appointment for screening. They had had one case where a student had developed a sight-threatening anomaly that could have been picked up earlier by screening.

- They now had access to the appointments system in both Acute Trusts which had made easier the task of Failsafe in checking that patients had been seen by Ophthalmology. However, the problem of up-dating the records in OptoMize after treatment remained. The Ophthalmologists often did not tell Failsafe what assessment they made or what treatment was provided but it was a requirement on the Diabetic Retinopathy Screening Service that all such information was in the system. Similarly neither patients nor Ophthalmologists told Retinopathy Screening when the patient was referred to Ophthalmology.
by another route. The patients assumed, under these circumstances, there was no need to go for screening but the national framework required that they be screened as normal.

- In connection with the Acute Trusts they also suggested that the OptoMize list of patients should be made available to the hospital systems. It would mean the hospital would know whenever they were admitting a patient with diabetes. Since it did not seem likely the SCR would be introduced, this seemed a good way of making sure the information would be available. However, the suggestion had run into governance issues about getting permission from patients etc.

Although they felt these were areas where integrated care could be improved they were pessimistic anything useful could be done because of the iron grip that the national screening board and the commissioners kept on what had to be done. In their view there were many requirements that were unnecessary and overly restrictive – such as getting proof to take people off lists. They had really had very little influence over the design of OptoMize 2 because its design was specified to the suppliers by the national screening board. The requirement to report kpis every month meant a great deal of time was spent worrying about targets rather than delivering the service and failing to meet targets could involve the loss of significant funding.

4. Action Research Cycle in Walsall

4.1 Strategic Discussions

A meeting was held to report back overall findings to two senior members of the informatics service. They confirmed that the FUSION approach was to be continued and that there were many evolutionary developments in process. FUSION was now a rather old system and they would like to replace it with a new portal which could have, for example, more advanced search facilities. However, the cost cutting exercise they were going through made this unlikely for the present. It was also making it difficult for them to respond to all the requests they were getting for system developments. There was a strong interest across the LHC in multi-agency co-operation to deliver more integrated care and they wanted to create better e-health services to meet these requirements. They invited us to join a ‘visioning event’ that was exploring these opportunities (see 4.2) below.

They also responded to several specific issues in the research report.

- The question of too much information becoming available. It looked as though, for some people, FUSION now gave them access to many
sources of patient information and users were losing sight of what was available. It may need a ‘relaunch’ to remind users what was available and it may be necessary to help people focus on what was relevant to them.

- Engagement with GP systems. The big difficulty they faced was gaining access to GP systems which seemed largely a matter of gaining their trust. They were moving forward because they would soon be able to make available via FUSION the information from GP records that would have been in the SCR had it been available.

- ‘Bottom up developments’ They recognized from the evidence that most attention in e-health system development in the past had been upon pathway management and that more needed to been done to ensure systems supported the integrated care work of frontline staff. They felt that the business change facilitation section was well placed to achieve this re-balancing.

4.2 The Visioning Event

This one-day event, under the banner ‘Integrate to Improve’, reviewed the current state of information sharing in Walsall LHC and how it might be improved in the future. It was led jointly by a member of the commissioner’s planning group and the head of informatics. It was attended by over sixty people and included representation of all of the agencies and disciplines in the LHC and included three members of the research team. In the introductions the head of informatics reported some of the findings from the present research study.

There was a wide-ranging review of the benefits of using e-health systems to facilitate information sharing and that this was declared to be a ‘no brainer’ – it was obviously the route to take. The obstacles to getting better sharing using e-health systems were hotly debated although very few felt there were technical problems; FUSION, in particular, was providing a flexible and evolving mechanism for information sharing. The barriers that were important included restrictive governance issues, for example, the problems of role-based access and of getting permission to share. It was suggested, for example, that patients be asked explicitly what they wanted kept confidential and that everything else should be freely shared amongst health professionals. The other main barriers were seen to be the absence of trust between the various agencies which meant they did not wish to share information with one another and they did not trust the information they received from one another. Being able to access GP records was seen as a major goal and there was a plan to discuss the way forward with the GP commissioning group. Other goals were to extend sharing more widely with non-NHS agencies such as Social Services.

4.3 Pathway Discussions
4.3.1 LMC Presentation of Unscheduled Care

We made a presentation to the Local Medical Committee that was focused on unscheduled care and the receipt of reports by GP practices. There was general agreement with the conclusions presented in chapter 6 (one of the GPs was moved to say it was ‘a really useful study’) and there was a discussion covering the following issues:

- **Control of patient records by their GP.** There was general agreement that the GP should have to have the right to judge what the record says about a patient. There should be a way of enabling OOH doctors who used a structured system to report to select ‘might be’s’ in drop down menus and in codes.

- **The implications of unscheduled care clinics seeing the full patient record.** Several of GPs commented that seeing a full patient record might create governance problems. If you saw something was wrong you may be under an obligation to put it right (and that may be difficult). If it were possible to see the full record in OOH, it might be deemed, if there were a problem later, that you should have studied it and found the relevant information that was available there. And yet you may be short of time to explore the whole record. Doctors may need to be careful about the amount of information they have available to them.

- **The mixture of records reaching the practice.** It was generally agreed that the volume of information reaching them about patients and the mixed forms in which it arrives creates an onerous administrative load.

- **The Summary Care Record.** It was felt the SCR might provide the right amount of information for many situations but there was uncertainty about the future of the system.

The meeting asked the research team to present the results more fully to an open meeting the LMC would convene (see 4.3.2).

4.3.2 LMC Invited Open Meeting

Over twenty people attended this meeting from the hospital, community services, informatics, GPs and their practice staff. Three patient representatives also attended.

The dominant theme in the discussion was the need for more shared access to patient records and the problems of obtaining appropriate access;

- There is a need for more collective thinking about how to solve the conundrum of access across the health agencies vs the privacy and security of patient records. The patients need to be involved in this and need to be more aware that the health staff caring for them need more
freedom to share information. One of the patient representatives who had opted out of the SCR, said that, having participated in the debate, he could now see the need and he wished the rest of the public had the same opportunity to engage in this discussion.

- It may not be necessary to share the whole patient record. For unscheduled care it could be, for instance be the SCR plus the last two GP consultations. Others said that a summary overview plus the contacts sheet kept in SAP might be more useful.

- If a patient is admitted to hospital, temporary access to their GP records could be given. However, the patient would have to give consent to this. In order to give hospital staff access to GP records, how difficult would it be to set up a system that could provide all patients with a password for their record so they could give it to the hospital on admission?

- Care pathways. There were special needs for information in relation to the care pathways patients might be on and for quality care there was a need to study exactly what is needed at different points in the pathway. This would be in the best interests of the over 75 frail and elderly population which is growing quickly in Walsall.

- Mobile Access: Integrated care in the community meant having access to records wherever you were. The district nurses and other community staff want to use laptops during field visits and this would also help the inefficient double entry of data that they currently have to make.

### 4.3.3 The Stroke and Frail Elderly Pathways

A joint meeting was convened to feedback the results on these two pathways (presented in chapters 7 and 8). About 20 staff from the two pathways attended, including three social workers. The main issues considered were as follows:

- The progress that has been made and the progress that could be made. There was recognition that a lot of progress has been made in the provision of e-health information, especially in relation to the Stroke Pathway. There is a lot of information in a lot of different systems and, mainly through Fusion, some of it can be shared. However, there is a lot more that could be done and there is some frustration that many of these things are taking longer than planned and are difficult to keep moving. There was also a recognition that this may be a continuous process, i.e. rather than achieving the perfect system, the amount and frequency of change might mean we have to continue the quest for the ‘holy grail’

- There were lots of examples where information is available but it is not accessible or in an appropriate form for use at the operational level. For example, medical information is available but not accessible to
community staff, Fusion does not give access to previous patient information etc that would be useful, the therapists in the Stroke Ward have a system but no hardware from which to access it, Paris has useful information in it but, at best, community staff have to use a separate system to use it etc. One of the consequences of the imperfect access to information is that a lot of repetition is necessary – asking the patient for their details yet again – which, with the problem of having to enter the same data into different systems, means that a lot of time is devoted to paperwork rather than the patient. It was felt that, up to now, systems have either been designed for medical use (some of the data on FUSION) or for management (the Stroke Pathway and iPM).

- There was recognition that the amount of information available could build up to a level that made it unusable and the ‘contacts and summary’ system in the community was highlighted as a possible way forward. Similarly more access for more people of things like the medical discharge summary would be helpful.

- There was recognition that in Social Work they were some way ahead in working electronically (‘paperlite’) and had made some progress in mobile working in the community and that NHS community staff might be able to learn from their experiences.

- There were a mass of improvements and new developments that people wanted to see but the frustration was the time and delays caused by Informatics implementing the changes. There was recognition that Informatics were under great pressure and were spread too thinly across two many projects. In relation to management reports from the Stroke Register, there was frustration at the time it takes to modify reports and make them more useful and a feeling that staff might be taught how to make this kind of change (and, for example, the contents of standard letters) without having to wait for a lengthy informatics change process.

- Although there was sympathy for the pressure that Informatics were under, there was also recognition that users did not find it easy to work with informatics staff. They felt that requirements were often misunderstood and that a language gap existed between the two communities. Some of the users present felt that they often agreed to proposals from Informatics because they did not understand them and did not feel able to challenge them.

- There were many comments about senior management and senior planning groups etc. There was recognition that with the recent merger some of the organizational boundaries were getting more blurred but there was a strong feeling that senior people dealt in visions and strategies and there was little concern for the operational difficulties that resulted. Similarly, there was a feeling that lots of projects were started without the resources or IT staff to see them through and that
more needed to be done to establish priorities and assign appropriate resources to see them met. It was hoped that the current review of Informatics would help to set priorities that would lead to achievements against those priorities. One group made the point that, whilst we pursue new e-health systems for management purposes we needed to remember this was all in the interests of the patients and we might do well to ask the patients what would be priority for them.

- There was some pride in how far they had come despite all that had to be done and that it tended to rely on people who had been around for a long time who always went the extra mile – beyond the formal arrangements. Several people mentioned that without the very active championing of a leading member of the Community Services staff, it is doubtful that the FEP pathway would have made any progress and that it was encouraging many others to put the extra effort in.

4.3.5 ‘Walking Through’ the Stroke Pathway

Members of the research team were invited to join a one-day ‘walk through’ of the stroke pathway to review how it was presently operating and to consider possible ways further integration might be achieved particularly in the light of the recent merger (1st April 2011) of the acute and community trusts which removed an important organisational boundary in the stroke pathway. The meeting was led by a senior member of the unscheduled care planning staff and attended by nursing and therapy staff from the Stroke Ward and nursing staff from the Community Stroke Unit.

The ‘walkthrough’ began with the admission of patients to A&E, considered their movement through the scanning unit to the Stroke Ward and their destination after discharge which in many cases was Community Care and Stroke Rehabilitation. At all stages of the process, the meeting considered the process (particularly looking at changing kpis and the barriers to achieving them), at organizational issues (particularly how to achieve flexible working between nursing and therapy staff currently working in Acute or Community settings) and documentation and e-health support for the process. Although it was generally considered that a great deal of progress had been made in creating an integrated care pathway for Stroke many areas of possible improvement were identified many of which related to documentation and e-health. The members of the meeting had previously received copies of the results of the stroke pathway case study and these were instrumental in framing the debate about e-health developments for stroke.

The discussion of documentation and e-health support both validated the conclusions drawn in the case study, especially about the partially joined-up nature of the e-health support at present and led to a consideration of actions that could be taken to provide a more tailored and comprehensive service to the stroke pathway. The following specific issues were discussed.
• **The re-entry of data:** The need to collect data manually both in the ward and in the community and then to enter it electronically into a number of different systems was recognized as a major problem to overcome. In part this relates to the need for mobile technology, e.g. tablets or laptops, that can be taken to the bedside or to the patient’s home but it is also about not having so many different systems.

• **The CIMMS System:** The Acute Trust OT and Physiotherapists revealed that they used an electronic system called CIMMS to record their patient interventions and it had no interfaces with other systems. As a result they had to re-enter data into FUSION and other systems. It was agreed they would explore the possibility of links between CIMMS and FUSION.

• **The reason for different systems:** The staff commented that they had to enter different information into different systems because they were needed for different purposes and they considered the possibility of one set of detailed information from which extracts could be taken for different purposes. One of the problems was that staff caring for stroke patients were also serving other kinds of patients and issues about their deployment required different kinds of entries than those for stroke patients. In addition stroke patients were often being treated for other conditions.

• **The TIA:** Most of the systems were set to support the main Stroke Pathway but there was a significant number of cases of minor strokes (TIAs) that led to a different pathway. A sub-section of the FUSION Stroke Register now dealt with TIA patients and there was a need to link this more directly to the TIA pathway, e.g. to the regular TIA clinics to which patients may well be referred.

• **The Reporting Process:** The meeting reviewed the various reports that FUSION generated from the Stroke Pathway against the various kpi requirements. It noted that the needs kept changing, that there was currently very little data in respect of the community work with stroke patients and that, if kpis switched to being outcome based rather than process targets, there would be a need to completely revise the structure of the records so that different reports could be generated.

• **The Boundary with Social Services:** The Re-ablement initiative made it more imperative that there were shared records between health and social care and many Stroke patients had complex social care needs. There were likely to be new members of staff based at the hospital who would manage the social and health care needs of stroke patients and they would have a special need to be able to access both FUSION and PARIS records.

• **Revisions to FUSION:** There was already a number of revisions of FUSION for the Stroke Pathway waiting for informatics to enact and this review suggested many more were necessary. Each change in the
report list, for example, required a system amendment that could take months. The Stroke staff wondered whether there were ways in which they could interrogate the data and generate their own reports partly to help them with immediate management issues, rather than having to rely for every change on the informatics staff.

- **An e-SAP Process for Stroke:** Reviewing the community documentation the meeting looked at the possibility of moving from the current cumbersome paper-based SAP process to e-SAP. One of the problems was that SAP was general purpose rather than specific to Stroke patients. The meeting wondered whether continuing along the current path of local fixes to each issue of integration that came along might be the wrong approach. The staff wondered whether a new start might be better, one based on an electronic SAP which could be started with the first stroke assessment in the hospital and go with the patient as they progressed through the pathway.

### 5. Discussion

The feedback meetings enabled the research team to present the research findings to a wide cross-section of staff, especially in Walsall, and three factors stood out:

1. that better integrated care is a priority for everybody,
2. that, as one person put it ‘it is a no brainer’ that e-health systems will be needed to help achieve better integration and
3. that the research results showed the progress that had been made but also the many barriers that still existed.

The feedback discussions revealed how the development of e-health systems had continued since the research data were collected (often over a year before) and confirm the evolutionary nature of these developments. They also suggested that, given the cut-backs and mergers, it was getting progressively more difficult to make substantial bottom up progress.

There were striking differences both in the scale of feedback and in the nature of the discussions that occurred in Walsall and Northamptonshire. Where feedback discussions were possible in Northamptonshire the general tenure was that there were many barriers to progress but there was little that local health staff could do about them; in both pathway development and in e-health systems design they felt that all the power lay at a national level so that bottom up initiatives stood very little chance of success against the might of the top down machine. In Walsall by contrast, whilst there was a recognition of the top down drivers, there was a belief that local action, joined up across the LHC, could deliver systems that would help with the
integration of care across local agencies. And, as evidenced by the attendance at the meetings in the action research cycle, there were considerable numbers of people from all agencies willing to engage in a debate to shape future e-health systems for the community.
Appendix 4

Audit trail – amendments to original objectives

From the start the research team where confronted with a mismatch between their planned schedule for commencement of work on certain aims and the constraints of ethics (LREC) governance process. This we reported in our first SDO Progress Report (dated 15.05.09) along with our proposed amendment, to restructure the phases of the project to fit within the constraints. This was discussed within the group as early as 21 August 2008 (Research Management Group meeting), based on the paper presented by Ken Eason (‘A possible case study structure’). We had already delayed the start of the project until the November in anticipation of completing the LREC processes in advance of commencing the research, which was too optimistic.

A year later, at the Research Management Group meeting (Item 6: 15 June 2009) we were again adapting our research plans to deal with the realities of NHS research governance. We were particularly challenged with how we could possibly research any patient information crossing any organisational boundary within the NHS. Here we received helpful practical advice from our Northants PCT colleague (Phil Hurd). Once we had identified the persons involved with ‘handovers’ of information between organisations or different professionals (e.g. GP and community nurses) we could interview them without full LREC clearance so long as we did not have sight of any clinical records. This was a major breakthrough.

At our January 2010 Research Management Group meeting we discussed and agreed the Project Plan (Jan-Nov 2010) presented by Ken Eason. This was not a radical departure but specified clearly our intended programme of research for the year. The plan identified 3 case studies for each PCT for the first ‘State of the Art’ stage, to be joined by an overlapping Action Research stage from March 2010 (focused on 2 cases in each PCT – one local and one a national development).

A month later at a meeting of the researchers (Core Research Meeting 3 February 2010) Ken Eason and Patrick Waterson introduced ‘design maturity’ as a means of integrating action research methods and the theoretical analysis of the process. This is based on the capability maturity model pioneered by the Carnegie-Mellon Univeristy (see final report para. 9.3). These ideas were presented in detail in Ken Eason’s ‘Action Research’ paper (May 2010) that informed our discussions at the subsequent Core Researcher Meeting (25 May 2010).
Six months later, at our next Core Researcher Meeting (12 October 2010) we further adapted the mapping (‘state of the art’), development and implementation and action research aspects of the research (as set out in the original proposal) which needed to be further modified in order to complete the project. This meant completing the development and implementation component largely separately from the action research.

It was at our next researchers’ meeting (8 December 2010) where we agreed the final form of the action research (Item 3). Ideally this would take the form of workshops involving members of the multi-disciplinary care pathway teams. This was something we were able to achieve within the Walsall LHC (FEP/Stroke workshop, 16 June 2011) but not in Northants (where the teams had been disbanded), but we were able to feedback and discuss the Intermediate Care pathway with the remaining member of the team (14 July 2011) and the 2 members of the Retinopathy team available (12 August 2011). The discussions further clarified our analysis. In addition, we presented and discussed our project, with a particular focus on the ‘Out of Hours’ pathway with the Walsall Local Medical Committee (28 April 2011). We were unable to provide a presentation or workshop for the Out of Hours GPs at Northants because the service providers had changed, but we did provide a copy of the relevant chapter of our report for the Chair of the service (email 20 July 2011) and received an invitation to do a presentation for GP CPD training at an unspecified time in the future (emails 28 July and 1 August 2011).

Thus we changed the planned phasing of the research from 5 overlapping phases set out in Table 1 Case Study Methods in original proposal (#1705) to a three stage model: Stage I mapping out e-supported pathways, then in Stage II carry out more detailed case studies of a selection of these. There was also a Stage III of action research feedback which in the event could only be carried out in the final months of the project (see also Chapter 11 para 11.2.3). The research was carried out during a particularly dynamic time within the NHS organisations and for the NPfIT programme which also meant we had to adapt to further exigencies. In the first few months, however, the main impact was that we had to revise the following aims: (1) capture user experience and opinions; (2) provide action research feedback and reviews from month 4 onwards; (3) access usage data to identify who uses what functions/data. None of these could be directly tackled in the first twelve months until LREC approval had been gained. Moreover, given the multiplicity of e-health systems we had identified in the mapping phase and the ethical difficulties of having direct access to patient data we decided to drop usage data collection in favour of identifying the specific functions of systems that each user made use of. Another consideration following the limited access our LREC ethics approval provided was that we could only interview PCT personnel and not NHS or other health workers working in related organisations although we did eventually gain clearance (LREC letter 21 June 2011). By then it was too late to be of any substantial benefit for our research work.