The implications of e-health system delivery strategies for integrated healthcare: Lessons from England

Ken Eason [a,*], Patrick Waterson [b]

[a] Bayswater Institute, 9 Orme Court, London W2 4RL, UK
[b] Loughborough Design School, Loughborough University, Loughborough, Leics. LE11 3TU, UK

ABSTRACT

Purpose: This paper explores the implications that different technical strategies for sharing patient information have for healthcare workers and, as a consequence, for the extent to which these systems provide support for integrated care.

Methods: Four technical strategies were identified and the forms of coupling they made with healthcare agencies were classified. A study was conducted in England to examine the human and organizational implications of systems implemented by these four strategies. Results were used from evaluation reports of two systems delivered as part of the NPfIT (National Programme for Information Technology) and from user responses to systems delivered in two local health communities in England. In the latter study 40 clinical respondents reported the use of systems to support integrated care in six healthcare pathways.

Results: The implementation of a detailed care record system (DCRS) in the NPfIT was problematic because it could not meet the diverse needs of all healthcare agencies and it required considerable local customization. The programme evolved to allow different systems to be delivered for each local health community. A national Summary Care Record (SCR) was implemented but many concerns were raised about wide access to confidential patient information. The two technical strategies that required looser forms of coupling and were under local control led to wide user adoption. The systems that enabled data to be transferred between local systems were successfully used to support integrated care in specific healthcare pathways. The portal approach gave many users an opportunity to view patient data held on a number of databases and this system evolved over a number of years as a result of requests from the user community.

Conclusions: The UK national strategy to deliver single shared database systems requires tight coupling between many users and has led to poor adoption because of the diverse needs of healthcare agencies. Sharing patient information has been more successful when local systems have been developed to serve particular healthcare pathways or when separate databases are viewable through a portal. On the basis of this evidence technical strategies that permit the local design of tight coupling are necessary if information systems are to support integrated care in healthcare pathways.

© 2012 Elsevier Ireland Ltd. All rights reserved.

1. Introduction: e-health systems and integrated care

Coordinating healthcare in complex cases can involve many different healthcare agencies and a major goal in many

countries is to use e-health systems for health information exchange in order to share information about patients across agencies in order to promote 'seamless' care. One of the debates about achieving this goal is the organizational level at which it has to be undertaken: it cannot, for example, be achieved completely 'bottom up' with every healthcare agency developing its own system because this would make it very difficult to share information between agencies. Is it necessary therefore to have a 'top-down strategy' where systems are defined at a national level? Or could there be, as Coiera et al. [1,2] have suggested, a 'middle out approach' where systems are defined at the level needed for coordinated care? An issue that is linked to, but conceptually separate from, the question of the organizational focus of the development is the technical strategy used to deliver the shared information service. It is notably that at the top down, middle-out and bottom-up levels a number of different technical strategies are in use around the world. The questions this paper addresses are (i) what implications do the different technical strategies have for the users of shared patient information and (ii) how does the choice of technical strategy relate to the organizational focus of design?

This paper reports findings about the use made of national e-health systems deployed in England and findings from a study in two local health communities in England that looked at the extent to which e-health systems support health information exchange across the organizational boundaries between healthcare agencies. This was the EPICOg project (Electronic Patient Information Crossing Organizational Boundaries) [3]. The systems that were investigated in this study were the products of both national and middle out strategies and used a number of different technical strategies. This enabled us to examine the implications of the different strategies for the sharing of patient information by healthcare staff engaged in the delivery of care. We have used the broad term 'e-health' to refer to all of these systems because, although they all hold electronic patient information, they may take many different forms.

The first section of this paper outlines the technical strategies that were in use. The implications of these strategies for the users of the systems are then reported together with their responses to system deployment. The paper concludes with an exploration of why users responded in different ways to these technical strategies and discusses the implications for the delivery of e-health systems to support integrated health care.

2. Alternative technical strategies for the delivery of e-health systems

In Fig. 1 different technical strategies for healthcare information management are identified that were found in practice in the EPICOg project and that are in use in different parts of the world. We have used the concept of coupling [4,5] to differentiate between these strategies. Coupling is a systems concept that defines the relationship between sub-components of a system. A tightly coupled system is one in which a change in one sub-system has a direct and significant impact on another component. In a loosely coupled system sub-components may be part of the same system but a change in one does not

directly affect the other or, if there is an impact, there are contingencies that mean the impact can be moderated. In this study we are concerned with the database of patient records delivered by each of these technical strategies and the degree to which it is coupled to user systems, i.e. the processes by which healthcare workers contribute to and make use of electronic patient records. In examining coupling in relation to the sharing of electronic patient information we have explored three elements that relate specifically to the data held in these systems: tightness, range and scale. We have placed these strategies on a scale from tight to loose coupling in Fig. 1. In this context a tightly coupled e-health system is one in which all users are working with an identical database of patient records. Working with a tightly coupled system gives a user the benefit of shared functions and data but at the cost of losing local discretion and control. Users have to provide data in prescribed ways and make use of the data in the form that it is provided. A loosely coupled system is one in which, whilst there are ways of sharing patient data, users may be using different databases and may therefore retain some local control over what they input to the system and how they use it. The second component of coupling is the range of data being shared and therefore involved in the coupling. A system may, for example, provide comprehensive patient data or only a sub-set of the information available about a patient. The final component is the scale of the population using the coupled system. At the extremes the system may be available to all healthcare workers in a nation or may be restricted to two specific healthcare agencies that are cooperating in a particular healthcare pathway.

Fig. 1 identifies four strategies for health care information management that were found in use. The tightest form of coupling was a comprehensive patient database system that was to be used across a whole health service. This was the Detailed Care Record System (DCRS) implemented as part of the NPfIT (National Programme for Information Technology) in England [6]. This was a national system intended to contain a wide range of data accessible by a large and diverse population of healthcare professionals. Another strategy is to achieve tight coupling at a national level but only in respect of a sub-set of patient data as in the National Patient Summary (NPO) in Sweden [7] and the Summary Care Record (SCR) in England [8]. In both cases the intention is that this limited set of data be made available to a large-scale population. A strategy that has existed for many years is to support specific healthcare information exchange, i.e. to provide a system for sharing a limited set of patient data in support of a particular process and between a limited set of healthcare agencies, for example, in providing pathology laboratory reports (e.g. Path Links in the UK) or e-prescription systems. We have defined this as a looser form of coupling because the tight link is restricted to a particular healthcare function and only a limited set of users share data using the system. Another looser form of coupling is the portal approach in which, via a web browser, a user can view the information held about a specific patient held on a range of different databases. This approach is a looser form of coupling because each agency is able to maintain its own database whilst enabling sharing by permitting 'read only' access to others. This approach can enable a large number of users to share a wide range of information. This is the approach adopted in

Nature of Coupling	Technical Strategy	Description	Range and Scope	Examples
Tight ↕ Loose	Comprehensive, shared database systems	All patient data is held on a single database	Wide scope, large user population	NPfIT DCRS (England)
	Summary care records	A sub-set of patient Information is shared by many healthcare agencies	Limited data widely shared	NPfIT SCR (England)
	Process support systems	A limited set of data is transferable from one local system to another	Limited data locally shared	1. E-Prescription 2. Test results
	Portals	Web based system that provides access to a range of databases	Wide scope, large user population	1. The Welsh Portal 2. P-CEHR (Australia) 3. FUSION (Walsall, UK)

Fig. 1 – Alternative technical strategies for sharing electronic patient information.

the Welsh National Portal [9] and in P-CEHR in Australia [10] and we have found it in use in some local health communities in England, e.g. the FUSION portal in Walsall.

There are also other mechanisms by which patient information may be shared electronically, for example, documents can be sent as attachments to secure e-mails. However, the list above constitutes the major ways in which the goals of sharing electronic patient information were being pursued in the studies to be described below. Our hypothesis in undertaking this analysis was that the systems that involved tighter forms of coupling would have different effects on healthcare staff and on the delivery of integrated care than would the systems that embodied looser forms of coupling.

A subsidiary hypothesis concerned the relationship between the technical delivery strategy and the organizational locus of design. Sharing data across health agencies implies some degree of agreement in the use of systems, the data content etc. In some health services it may be possible at a national level to get agreement for all agencies to share the same patient database. The top down delivery of a comprehensive database system may therefore be possible. In other circumstances the agreement to co-operate may be at a regional level or may be for a looser level of co-operation that does not imply everybody using the same system (a middle-out approach). At a more local level, a bottom up approach may be agreed in which sharing is limited to links between systems in two agencies. It may well be that some technical strategies are only effective when delivered at a specific organizational level.

This analysis is restricted to technical strategies in use in England. However, if it demonstrates that there are implications for users of using particular technical strategies at specific organizational levels of design, we would expect the results to have implications for the use of these technical strategies elsewhere in the world.

3.   Methods

In England the dominant strategy for sharing electronic patient information in the last decade has been the NPfIT (the National Programme for Information Technology), the largest part of which was a national strategy to deliver detailed care record systems (DCRS) to every healthcare agency in the country. However, although this has been the dominant technical strategy, the other strategies listed in Fig. 1 have also been adopted in England. The strategies are used to deliver electronic patient records to different communities of users. However, they have in common that the intended users are healthcare staff who have some duty of care towards the patients whose records are being viewed. None of the systems to be described are intended for use by the patients themselves. In the systems with the widest scope the users may be medical, nursing staff or other clinical specialisms as well as administrative staff and they may be located anywhere in the country. In the systems with more narrow scope the population of users is also healthcare staff but it may be limited to a particular location or healthcare organization.

Our aim in this paper is to use two sources of data to explore the human and organizational implications of systems delivered by different strategies: first, the evaluation literature about the national e-health applications in the NPfIT and second the results of the EPICOg project. Between them they provide evidence of the impact of the four approaches in Fig. 1.

The aim of the EPICOg project was to examine the degree to which electronic health systems supported the sharing of patient information across the organizational boundaries that separated the healthcare agencies that needed to cooperate to provide integrated patient care. To achieve this aim we focused on the use of electronic patient information in

established healthcare pathways in local health communities, i.e. mechanisms agreed between local healthcare agencies that served to coordinate the care of patients as they moved through the different phases of care involved in the treatment of specific conditions. We examined nine healthcare pathways in which integrated care required coordinated contributions from a variety of healthcare agencies including General Practitioner (GP) Clinics, Acute Hospitals and a range of community based services. Coordination required the sharing of information about the patient and the study examined what technical services were available to support the electronic sharing of this information, what impact they had on healthcare staff and what contribution they made to integrated care. The study was conducted in two local health communities in the midlands of England, the county of Northamptonshire (serving 680,000 residents) and the metropolitan borough of Walsall (population 253,000). The majority of journeys taken by patients as their conditions were treated took them to various healthcare agencies within the local community and this was the level at which most sharing of information was necessary to provide integrated care. The pathways studied included the stroke pathway, the treatment of the frail elderly in their own homes, unscheduled care by out-of-hour doctors and a diabetic retinopathy screening programme.

In order to examine the implications of each technical strategy for healthcare agencies we have employed concepts from sociotechnical systems theory [11] as embodied in the ORDIT methodology (Organizational Requirements for the Determination of Information Technology)[12]. Sociotechnical systems theory views work organizations as systems in which social systems (people in work roles) and technical systems are interdependent in the production of work. The ORDIT approach provides a means of modelling the social system in terms of the responsibilities and obligations of each agent with respect to the work to be undertaken. It models the linkages between the social system and the technical system in terms of the requirements these responsibilities place upon the service needed from the technology. In the context of healthcare agencies using e-health systems therefore the modelling will show the 'read' and 'write' access requirements an agent will have of the system in order to fulfil their responsibilities. By comparing the coupling intrinsic to the technical design strategy with the responsibilities and requirements of the healthcare users we can assess the implications of each approach for the user population.

An initial review of the e-health systems in use by the staff delivering the nine pathways in the two local health communities revealed that a total of 24 systems holding electronic patient information were in use of which seven provided mechanisms for sharing this information across organizational boundaries.

One was a shared detailed care record system (DCRS) implemented as part of the NPfIT deployment and another was a portal system providing access to many databases. Five of the systems provided local support for the sharing of a limited set of patient information. There was no example in the EPICOg study of a system that enabled limited data to be shared widely. As a consequence in the analysis presented in Section 4 we rely on a published evaluation of the Summary Care Record (SCR) system that was also deployed in the NPfIT.

In order to examine the implications of sharing information by using these systems the collection of data in the EPICOg project was in two stages. Initially, working with clinical and informatics staff, mappings were constructed of the social system and technical system linkages i.e. the functions and data provisions of these systems was mapped to the major users of these systems in the nine pathways. The mapping, process identified the user population for each system and, in the second phase semi-structured interviews were undertaken with a purposive sample of clinical and administrative staff that represented the different roles contributing to six of the healthcare pathways. Forty interviews were conducted, between 5 and 10 for each pathway. The interviews explored the user's experience of the linkages with the technical systems, their inputs to the systems, the use they made of the patient information held in the systems and their assessments of the wider implications of the systems for the healthcare they delivered in the pathways. The results show how well the electronic systems supported individual healthcare professionals in the different healthcare agencies and, by reference to their behaviour with the systems, the extent to which the systems were supporting the goals of integrated care within each pathway. The final report of the project (3) provides the full results for each pathway. In this paper we report the impact on the pathways of the different technical strategies used to deliver shared patient information.

4. The impact of different technical approaches on healthcare agencies

4.1. *National shared databases*

The decision in 2002 of the Department of Health in England to launch detailed care record systems (DCRS) applications across England as part of the NPfIT represents a major national attempt to get healthcare agencies to share the same patient database. Initially the country was divided into five regions and all healthcare agencies in a region were to adopt a single DCRS. The aim was to replace any existing electronic patient information systems that were in use with a standard 'best of breed' application. In the terms adopted for this analysis this strategy was attempting to achieve a tight coupling between a database and a large-scale user population across a wide range of patient data. The aim was to create 'many-to-many' connections, i.e. many clinicians and others will be inputting to the record and many users will be accessing the record.

After a decade pursuing this strategy it is possible to review its implications for the healthcare agencies involved and how they have responded to its implementation. We do so here at two levels, first, with respect to the overall progress made by the national programme and second by looking at a particular example of a local health community where a DCRS was in use.

Of all the applications delivered as part of the NPfIT, it is the DCRS programme that ran into most problems. The National Audit Office that evaluates the use of public funds in the UK concluded in an evaluation in 2008 that "the plan to deliver detailed care records was 4 years behind schedule" [13] and in 2011 that "the plan was un-achieveable" [14]. One of the oft

stated problems was that "one size does not fit all" [15], i.e. that a single database did not fit the needs of all the different healthcare agencies that were expected to make use of it.

Healthcare in each locality in England is the responsibility of an NHS Trust. There are over 400 trusts in England including Acute Care Trusts, Primary Care Trusts, Mental Health Trusts and Ambulance Service Trusts. Between them the trusts deliver a very wide variety of healthcare services and implementing a single patient database system for all to use proved a major problem. Eason [6], for example, cites the case of Mental Health Trusts in London who found that the DCRS they were expected to deploy, developed in an acute care context, had no provision for recording the details of patients who were sectioned, i.e. required to be held in secure wards. Mental Health Trusts were required by law to hold this information and, as a result, they were unable to accept the new system. Across the programme the mismatch between what the systems provided and the responsibilities and needs of healthcare agencies led to many other kinds of trusts declining to implement the national system they were offered. As a result the NPfIT began to deploy a broader range of systems and, towards the end of the programme, local health communities (in which there may be a number of trusts) made their own decisions about the systems they would implement. As a consequence the scale of the user population sharing information through each system became much smaller than originally envisaged.

When a DCRS was deployed the local health community often found they had a major task to configure it in a way that would map onto the needs of the variety of health agencies that were intended to use it. Not only did the technical system need tailoring to local needs but the work processes of the health agencies needed adapting to the requirements of the technical system. A major evaluation of the deployment of the DCRS [16] across England concluded that realizing the benefits of a standard system in each local health community was a major task and that addressing it required an incremental and iterative process that could take many years. The national policy has now shifted from a requirement that all trusts use the same system to a requirement that they use systems that meet standards for data handling that would permit sharing of data between systems. The result has been that sharing the same comprehensive patient database is now a local albeit a multi-agency ambition rather than a national goal.

In one of the midland local healthcare communities we studied in the EPICOg project a DCRS that was part of the national programme had been rolled out across a substantial number of local healthcare agencies including community services, General Practitioner (GP) clinics and GP out-of-hours services. The two local hospitals did not, however, use the system. The database in use was based on the detailed electronic patient record held by the GPs but all who used the system could access and add to it. We explored the implications with several of the healthcare agencies [3] involved in the unscheduled care pathway. In this process a patient may attend a number of different healthcare access points, for example, Accident and Emergency, Walk-In Centres and GP out-of-hours services, and be given medical advice. The results of this engagement are then communicated to the patient's GP for possible follow-up. We interviewed ten staff

in the unscheduled care agencies and in GP clinics to explore their use of and reactions to sharing the common comprehensive patient record in the DCRS. For the staff involved in unscheduled care access to the full patient record was invaluable in many instances although the volume and complexity of unfamiliar records could be difficult to navigate in what were intended to be short patient encounters. The GPs, however, experienced many problems with the shared record. It had previously been 'their' record in the sense that they controlled what went into it and who had access to it. Now there was no clear clinical ownership of the record: it was everybody's record. This meant, for example, that out-of-hours doctors could insert diagnoses that the patient's GP did not believe were accurate. The GPs were responsible for following-up such diagnoses on behalf of their patients and they wanted the right to challenge and change such entries before they became a permanent part of the record. The GPs also found that, if a patient had an extensive period of community care, the record would be overwhelmed by detailed accounts of the daily care provided. The GPs also wanted the right to weed such 'transitory' information out of the record so that it contained a smaller, more manageable, amount of significant clinical information. As the record became more 'shared' it was, in their eyes, becoming less useful to them and more problematic because they retained overall responsibility for each patient and were required to follow-up medical issues registered in the record. In the terms used within the ORDIT framework for sociotechnical systems analysis responsibilities with respect to the record had become blurred with consequences in particular for the GPs who retained overall responsibility for the on-going care of their patients.

Another significant issue with this DCRS was that the database was highly structured making wide use of codes for clinical conditions and interventions. The frontline healthcare staff we interviewed, both doctors and nurses, reported that often the database was not particularly helpful to them in delivering day-to-day care to their patients or in sharing information about particular patients with colleagues involved in integrated care. As Berg et al. [17] have pointed out clinical care is often an uncertain problem-solving process where test results are needed to check out provisional diagnoses. The clincians in the EPICOg study reported that they needed systems where trends in data could be stored and hypotheses could be articulated and discussed with colleagues. They also needed opportunities to provide a narrative about patients to share with colleagues in their team or with others to whom they may 'handover' the patients. They found that highly structured and coded databases did not provide effective support for these kinds of clinical activities and we found many examples where staff resorted to 'workarounds', e.g. sent faxes to one another, because they could not share important information with colleagues by using the formal database.

However, there were users of these systems who did value structured databases. As part of the EPICOg project we also interviewed the commissioners and managers of healthcare services and they found them very useful. The structured and standardized forms of the database meant that records could be aggregated and the performance of health services could be assessed against targets, trends in demands on services could be detected, payments could be made to agencies

providing services etc. The structured, shared patient databases had their greatest value as powerful management tools.

In this study and in another conducted in a Mental Health Trust (6) we found that frontline staff who did not find DCRS helpful in the day-to-day process of sharing information with colleagues used many other forms of communication for this purpose. In addition to the use of fax referred to above, other local, perhaps paper-based databases were used rather than the 'official system'. The responses of frontline staff had consequences for the data held by the DCRS. Interviewees reported leaving clinical fields of information blank and only completing fields requiring demographic and administrative information. In the system used in the Mental Health Trust there were unstructured fields intended for additional comments about the patients and interviewees reported using these fields to provide a complete narrative about the patient whilst the structured and coded sections were left blank.

These results demonstrate that at both the level of the local health community and at the level of the individual healthcare worker, judgments are made about the usefulness of the shared data systems in the healthcare tasks for which they are responsible. If the system fails this test it gets rejected or worked around. The goal of achieving a national detailed care record system in England has so far floundered because of the great variety of healthcare agencies and the difficulty of creating a common database that can serve the needs of everybody. Gradually the ambition has shifted from creating a national shared database to more 'middle out' design where agencies in a common locality seek to share patient data. Where we have seen these systems implemented they too have encountered problems because, even at these levels, there are many different responsibilities and many different requirements of the patient database system. On the basis of the evidence from the EPICOg project we conclude that this technical strategy has so far contributed little to the coordination of care between different healthcare agencies.

4.2. Limited data widely shared

Another technical strategy has been to take a sub-set of patient data and make it available to all the healthcare agencies that may need it. This is a looser form of coupling because agencies may retain control over their detailed patient records and only need to cooperate and enter into a tighter form of coupling with respect to a sub-set of information. However, it is a 'many-to-many' application intended for a large-scale user population. The most obvious examples of this approach are the attempts to create summary care records of the vital information about a patient that a healthcare worker may need if encountering the patient for the first time in an unscheduled care setting, for example, in an Accident and Emergency Department. As part of the NPfIT, a Summary Care Record (SCR) application was established that held information about a patient's medication, allergies and chronic conditions on a national database that could be accessed, with the permission of the patient, by any healthcare agency that encountered the patient. This application has been rolled out in parts of England, albeit with difficulty, and a comprehensive evaluation has been undertaken [18] which included quantitative

analysis of over 400,000 unscheduled encounters, observation of 214 encounters and 140 interviews with GPs, staff providing unscheduled care, policy makers and systems designers.

This application was also very delayed in its deployment and became a contentious issue in the national media. It required data to be uploaded from GP patient records to a national database and the evaluation study reported that many GPs were concerned that confidential information was being transferred to a system where they had no control over its subsequent use. They took the view that they had a responsibility for the data that patients had entrusted to them and they needed assurances that it would be securely held in the national database and only used for the purposes for which the patient had supplied it. Whilst some were satisfied by the assurances given and cooperated in the up-loading of the records they held, many others were not and withheld cooperation.

The beneficiaries of the SCR were intended to be healthcare workers encountering a patient for the first time who had no records of the patient. The evaluation reported many examples of the use of the system in such settings. It reports that the summary information was used in a minority of patient encounters but proved of great value when, for example, a patient was unable to report critical information themselves. There were cases, for example, where the patient was semi-comatose. In many instances the clinician needed information other than the summary provided and this has led to requests for an enlarged summary record. A commonly reported problem was the need to request the patient's permission to access the record and, in many accident and emergency cases, this was neither possible nor appropriate. Nevertheless, the general view of those using the system was that it made a potentially significant contribution to the safety of their care for patients.

This example exhibits the problems of what has become known as Grudin's Law [19] in which the success of the system depends on the cooperation of stakeholders, in this case the GPs, who get very little benefit from the system. The beneficiaries are elsewhere in the healthcare system. According to Grudin's Law successful implementation is unlikely under these conditions. It is made doubly difficult in this case because the GPs are expected to comply with systems requirements in order to serve the needs of many other potential users. In their view they are compromising the guarantee of confidentiality they have given their patients and it is hard for them to develop trust in the integrity of a very large-scale technical system that can be accessed by a very large number of (to them) unknown people.

4.3. Limited data locally shared

There is a long history of more modest systems that enable healthcare information to be shared between agencies in a local setting. Examples such as electronic prescribing systems and test reporting systems enable healthcare workers to send data between agencies that are cooperating locally in the process of treating patients. These information systems are typically tightly linked to the particular healthcare process or pathway in which the healthcare agencies are participating. However, in this case the coupling involves a limited range of

patient data and is of limited scope, i.e. the user population agreeing to the coupling is quite small (few-to-few users).

In the EPICOg project we examined two such systems, one more successful than the other. The first was the Path Links system that enables GPs to request blood tests to be undertaken by a laboratory and for the results to be sent electronically to the GP who, after review, can add them directly to the patient's record. We interviewed clinical and administrative staff in six GP clinics and found this to be a widely used and valued system in which all parties were happy to cooperate. The nomenclature used for requesting tests was well understood and accepted as were the forms in which results were reported and all parties benefited from the effective use of these procedures. As a local process, the users were known to one another and trust and confidence in the professional competence of each agency was high.

The other example was a 'middleware' contribution to a diabetic retinopathy screening service. In the UK diabetics are offered annual retinopathy screening because of the danger the disease poses for eyesight. In one of the local health communities we interviewed eight clinical and administrative users of a central screening service that sent annual invitations to diabetic patients to attend their screening clinics. To make these invitations the screening service needed regular information from GPs in order to keep their records of diabetic patients up-to-date. An electronic 'middleware' product was implemented that could search GP patient records, detect any patients defined as diabetics and transfer a limited set of information about those patients to the electronic patient record system of the screening service. On the first occasions when this system was used it captured the details of many diabetics but there were a lot of anomalies that required extensive dialogue between the staff of the screening service and the GP clinics to resolve. The anomalies included patients who had been mistakenly labelled diabetic in the GP records: pregnant patients whose diabetes would be temporary and who did not need screening: patients who had recently transferred in or out of the practice and patients who had previously declined screening, for example, because they are registered blind. The screening service and the GP clinics were working to resolve these issues by a mixture of measures including improving the accuracy of the GP records, making more frequent sweeps through the records because they kept changing and tailoring the middleware software in order that it could detect, for example, when a patient was pregnant. The process was leading to refinements in the technical system so that it was responsive to the variety of circumstances that had to be managed. It was also leading to a growth in understanding and trust between the healthcare agencies about their respective roles and requirements in this process.

Although the second example exhibited some difficulties, in both of these examples there was a desire and willingness to achieve a good quality of electronic information sharing. Several factors appear to contribute to this outcome. First, the necessary coupling in order to share information is local and is limited to the information required to undertake a specific healthcare process. Second, all parties have responsibilities in the healthcare process which the electronic system is serving to facilitate and an effective system would help them all discharge these responsibilities. Third, the linkages between

agencies are between relatively few people in a local setting and there are opportunities to build understanding and trust. Finally, especially in the second case, there were opportunities to customize both the technical systems and working practices at the local level so that a system could evolve that served more diverse needs for information sharing than might have been appreciated in the initial systems design.

4.4. Portal systems

The technical strategy of using a portal provides an opportunity for a large number of users to share a wide range of electronic patient information without the need for everybody to use a common database. In this strategy all healthcare agencies maintain an electronic patient information system suitable for their own needs. Other agencies can view the information in these systems via a portal that provides a window into the information held about a particular patient across a range of databases. As a consequence this is a strategy that permits information sharing by many users but without the tight coupling that is necessary if a single database is used.

In Walsall, one of the local health communities studied in the EPICOg project, a portal system called FUSION had been in use for ten years and was used by several thousand users from a number of agencies in primary and secondary care. Studies of system development documentation and five interviews with systems development staff were used to create both a description of the system and its historical evolution. The portal gives users access to a 'dynamic patient record', i.e. an up-to-date view of patient information held in a variety of hospital records, e.g. ward records, X-ray and test results; to data in a range of community service records and to some of the data in GP records. Users have 'read' and 'write' access to their own databases but can only 'read' the records of the databases controlled by other agencies. Role based access rules are applied so that users can only access databases relevant to the healthcare work they undertake.

This system is used widely across the healthcare agencies in the region and both the numbers of users and the numbers of databases that can be accessed keep growing. Its popularity can be gauged from the fact that informatics staff dealt with a continuous stream of requests from users for additions to the system and, as a result, upgrades were made to the system three times a year. A recent upgrade, for example, was to provide GPs and community staff with immediate access to electronic discharge summaries when patients were discharged from hospital.

Interviews were conducted with 20 users, both managers and frontline clinical staff, who used FUSION in relation to the stroke pathway and a pathway for providing care for the frail elderly in their own homes. Although these staff often had access to other sources of data about patients FUSION was often the first place to look because it was always up-to-date and quick to access. Despite its popularity there were frustrations. A patient with multiple conditions could appear on many different databases and, because each database was designed for local use, the nature of the data, the terms used etc. was not standardized and could be confusing to navigate and understand. There was a view that a top-level summary containing recent critical information about the patient and

their 'contacts' i.e. who was treating them, would alleviate the need for time-consuming searches. Another common frustration was the 'read only' nature of the information. Users often wanted to transfer information to their own electronic records but this was often difficult to do. In some cases it was possible to print the information and, in some GP clinics, this led to administrative staff printing information from FUSION and then scanning it to add to the GP patient record.

Viewed from the perspective of front line staff seeking to deliver integrated care in a pathway, FUSION gave access to comprehensive electronic patient records but not in a way that supported the specific information flows necessary for close coordination. For the managers of the pathways the portal did not make it easy to aggregate records or to make comparisons in the way that structured and standardized single databases made possible. These concerns had been recognized in the evolutionary development of the portal and subsidiary databases had been implemented within the system to support particular healthcare pathways. There was, for example, a stroke register that records information from all the agencies treating a stroke victim and a 'virtual ward' that held all the information about frail elderly patients who were being cared for in the community. These databases are linked to process management software that maps onto the processes within the pathways and support the coordination of care between healthcare agencies.

One of the benefits of this approach cited by the managers of the system was that it was sufficiently flexible to be able to evolve as different demands were placed on it by the frequent organizational changes that took place in the UK National Health Service. For example, if there was a merger of two trusts that used different electronic patient systems there was no immediate need to switch to a common system because FUSION could provide access to both systems. Similarly, it could when necessary be used to give access to users outside the health service. In the treatment of the elderly, for example, integrated care meant integrating health and social care and FUSION was used to give social workers access to specific databases [20].

Although there are disadvantages in having to manage and use diverse databases this approach does provide a loose form of coupling that enables large numbers of users to share information in the interests of integrated care and it does appear to have been widely adopted by the user population in this particular example.

5. Discussion

In the cases presented above each technical strategy has led to a different response from the user population. These cases are all from one country and some of these responses may be influenced by local culture, the particular organization of healthcare agencies in the country etc. However, there is evidence of a strong causal link between the nature of the strategy and the responses of the user population and this may mean these responses are replicated when these strategies are adopted in other countries.

In the case of the comprehensive national database (DCRS) the response was rejection by many healthcare trusts and

a period of extensive tailoring of the system in those trusts that did implement it. Over time, the approach became less national and more regional at a level where the diversity of needs amongst the health agencies could be recognized and embraced by the technical system. Where we were able to examine a system of this kind in local use, the user population had many questions about the relevance, the ownership, the validity and the security of the data held. Fundamental to these responses is the need to share a single database over which no user has control. From the perspective of a healthcare worker it means that if the system cannot support the execution of the responsibilities you have in your healthcare role, you may have to opt out. If you do use it you may have to supply data in a form you may deem inappropriate and you may be expected to act on data in the database you do not believe in. Faced with these circumstances users are active in finding workarounds in order to avoid the difficulties that may be caused.

The Summary Care Record system had a greater degree of adoption perhaps because of its narrower range of data. However, it required GPs to release data from 'their' patient records for which they felt ownership and responsibility into what many considered to be a large void they felt unable to control or trust. The scale of the potential user population meant they could not know what use would be made of 'their' patients' data. As a result many refused to cooperate.

The two strategies at the looser end of the coupling dimension led to a greater degree of acceptance and use by their user populations. In a number of cases it led to enthusiastic action by users to make 'bottom-up' proposals for further development of the system. In the case of the strategy by which agencies share data with one another in relation to a specific healthcare task, the ability to select and develop both how data is shared and who one is sharing it with appear to have been powerful forces in achieving successful adoption. In the case of the diabetic retinopathy screening pathway, the local systems development process was not without difficulties but local control meant the technical system could be customized to meet emergent user requirements. The portal approach was a popular solution with a growing user population and we may surmise this was for three reasons. First, it did not require any health agency to give up a database that was currently serving their specific interests. Second, it provided a window into other databases that could be valuable in providing integrated care. Third, the system was evolving so that specific databases and processes could be added that supported the information sharing necessary to coordinate care in local healthcare pathways.

These cases provide evidence for the way in which different technical strategies relate to three important topics in the contemporary literature on medical informatics:

1. The compatibility of organizational and technical integration. Leutz [21,22] describes a typology of integrated care covering three types of organizational integration: (1) linkage – in which healthcare providers attempt to work together more closely, but still function within their respective organizational boundaries; (2) coordination – where purpose-built structures and mechanisms bridge gaps between services and users, and help to

alleviate confusion, poor communication and the lack of information-sharing; and (3) full integration – where responsibilities, resources and funding for care across agencies are located under one roof. Although the United Kingdom has a national health service, the agencies that provide healthcare within it have a great deal of autonomy and the integration of care resembles the category Leutz refers to as coordination. It is characterized by the local creation of all kinds of mechanisms and processes to facilitate work across organizational boundaries. It is not a case of a central authority establishing common policies, procedures and funding arrangements that integrate care. However, in the deployment of the DCRS and the SCR within the NPfIT, the technical strategy has been full integration, i.e. central decisions were made to make possible full sharing of information through use of common systems. As a result a full integration technical strategy was implemented in organizations that operate a coordination strategy when pursuing cross-organization integrated care. The outcome has been that, where the technical solution does not fit the local requirement, the autonomous local healthcare agencies have adopted their own strategy. By contrast the looser forms of technical strategy permit local agencies to develop technical solutions that match the local organizational mechanisms they are creating to coordinate integrated care. The looser forms of technical strategy appear compatible with local organizations that are developing integrated care through organizational coordination mechanisms. The lesson may be to choose a technical strategy that is in harmony with the type of organizational integration that prevails in the health service.

2. The multiplicity of requirements for patient information and the technical strategy.

As Berg [23] has pointed out electronic patient information systems serve many different purposes and many different stakeholders. The records may be used by managers, for example, to monitor healthcare performance, to understand trends in demand and to apportion funding and resources. They can also be used as control systems for standardizing care and ensuring good governance of confidential information. For the front line staff they are working tools, recording on-going results as the treatment process proceeds and sharing this information across the team providing the treatment. They are also mechanisms for coordinating the handovers of patients from one agency to another. Each of these purposes is associated with the responsibilities of a different set of stakeholders. It is questionable whether a single technical system could be created that could adequately serve all these different purposes and all the different stakeholders. One perspective we can take on the technical strategies is to ask whether they are designed to serve some of these purposes rather than others. It is notable that the shared database approaches that are intended for use by large numbers of users tend to store coded and highly structured information. They are, in a sense, written in a common language so that all users can share a common understanding of the patient. As a consequence they serve the needs of users who are concerned to standardize healthcare and to promote 'best practice'. Such records are also easy to aggregate and this serves the needs

of managers who need to monitor performance, identify trends etc. These are not records, however, that serve the needs of those actively treating patients who are working with provisional diagnoses and sharing with colleagues what alternative treatments might be appropriate. The records that are constructed locally and that allow more opportunity for unstructured narrative are more suited to the huge variety of specific issues that arise on the front line of healthcare delivery.

De Lusignan and Kraus [24] suggest that in healthcare there are two visions of electronic systems that hold patient information. The first they call the electronic patient record and this is the standardized account typical of the large-scale record systems. The second they call service-orientated systems and these are the whole variety of records that are needed by those delivering treatment as they share with one another the progress made by the patient. The nature of these records needs to be tailored to each condition and often to the particular way in which responsibilities for care are distributed in each care setting. The tightly coupled e-health systems in this sample are products of the first vision whilst the more loosely coupled systems lend themselves more to the development of local service orientation.

3. Designing sociotechnical systems for the turbulent world of healthcare delivery. Another theme to emerge from this analysis is that e-health systems are of benefit to frontline staff when they are mapped to specific healthcare pathways, i.e. the solution is a sociotechnical system rather than a technical system [6,11,25]. These are the systems that get adopted and, if they are sufficiently flexible, evolve to match the changes in healthcare organizations and procedures as new treatments become possible, new organizational structures and processes are implemented etc. These kinds of requirements are difficult to meet with a standard database system that needs to remain constant if it is to be shared across a wide range of users. An evolutionary capability that permits iterative mapping to changing healthcare practice is much easier to achieve with technical approaches that involve a looser form of coupling and more limited user populations because local design to match local needs is then possible. Perversely the end product in some cases appears to be a tight form of coupling that permits information sharing in relation to specific tasks in a healthcare pathway. However, the tight coupling is self-selected and limited in its scale to the users involved in that healthcare delivery.

6. Conclusions

There is an obvious logical argument that, if you want to provide integrated care in a health service, all healthcare agencies should share a common patient database. It should ensure they all 'sing from the same hymn sheet'. As a result one of the major technical ambitions in delivering electronic patient records has been to get everyone using the same record. If such a strategy is to be attempted it needs high level adoption, perhaps at a national level, in order to deliver the system to all the agencies that deliver healthcare. This is

the strategy adopted in England in the NPfIT and it has not achieved nationwide sharing of detailed healthcare records. It may be that this outcome is partially explained by the particular characteristics of the National Health Service and of the history and culture of healthcare in England. However, on the basis of the evidence presented here that shows the breadth of the tight linkages it requires, we would expect this kind of outcome to occur elsewhere in the world if attempts are made to deliver standard healthcare records into healthcare agencies with widely different responsibilities. The tight coupling that is required to achieve the sharing of information across the whole healthcare community does not sit easily with local needs to discharge specific responsibilities, to share information with other local agencies and to keep up with the pace of change. National systems, such as the SCR, may be more successful because they are limited to a narrow range of data.

In England, whilst top down attempts to achieve a common database have struggled, there has been widespread adoption by users of more local and more loosely coupled technical systems. In these systems local forms of tight linkages occur and are adopted and we surmise that this is because they are under local control. Such systems are unlikely to lead to the sharing of patient information across the nation but they do appear to be making progress in fostering sharing at the points where healthcare agencies need to cooperate to deliver integrated care. They do so because these technical approaches are better matched to the on-going debates and negotiations that characterize the manner in which semi-autonomous healthcare agencies are developing the mechanisms and procedures to coordinate their care of patients. These are approaches that enable the local joint development of healthcare processes, organizational forms and technical systems: the development of sociotechnical systems capable of delivering integrated care.

This analysis suggests that, in England at least, the greatest progress towards delivering e-health systems for integrated care is occurring at a 'middle-out' level where the agencies of a local health community are meeting together to find ways of cooperating. Where they are able to use technical approaches that involve loose coupling they are able to shape the technical service to match their emerging forms of cooperation.

Where does this evidence leave top down, national strategies? As a growing number of commentators have suggested [6,19,26] it does not suggest everything can be done at a middle-out level. At the top-level infrastructure policies that facilitate middle-out design work may be very helpful: for example, the establishment of standards for data sharing and technical systems procurement policies that require adherence to standards. Such national policies may be necessary to ensure local health communities are in a position to design, implement and evolve systems to meet local evolving needs to provide integrated care.

Authors contributions

Both authors were investigators in the EPICOg project and were involved in the secondary analysis of the data for this paper. The paper has been jointly prepared and edited.

Summary points
What is already known on the topic?

- It has been recognized that there are different technical strategies by which electronic patient records can be shared. However, the implications of these strategies for healthcare agencies has not been systematically reviewed.
- It has been recognized that national 'top down' programmes for delivering electronic patient records have been difficult to implement and that middle-out or more local strategies have been more successful.

What this study added to our knowledge?

- Different technical strategies involve different degrees of coupling between the technical and social systems in healthcare agencies. Nationally shared databases involve tight couplings that do not match the diverse forms of healthcare that are found in healthcare communities. Large systems that involve tight couplings for a sub-set of patient data are more likely to be successful.
- The technical strategies that led to successful uptake involved (1) tight coupling at a local level between agencies engaged in integrated care with respect to specific healthcare pathways and (2) loose coupling in portal systems that permitted viewing of different databases that remained under the control of local healthcare agencies.
- That the combination of middle-out design (at the level where agencies need to cooperate to deliver integrated healthcare) and technical strategies that delivered looser forms of coupling enabled local information sharing to evolve and e-health systems to be widely adopted.

Competing interests

None.

REFERENCES

[1] E. Coiera, Building a National Health IT system from the middle out, J. Am. Med. Inform. Assoc. 16 (3) (2009) 271–273.

[2] E. Coiera, J. Aarts, C. Kulikowski, The dangerous decade, J. Am. Med. Inform. Assoc. 19 (1) (2012) 2–5.

[3] K. Eason, M. Dent, P. Waterson, D. Tutt, P. Hurd, A. Thornett, Getting the benefit from electronic patient information that crosses organisational boundaries. Final report. NIHR Service Delivery and Organisation Programme, Department of Health, London, 2012.

[4] K.E. Weick, Educational organizations as loosely coupled systems, Admin. Sci. Q. 21 (1976) 1–19.

[5] C. Perrow, Organizing to reduce the vulnerabilities of complexity, J. Contingencies Crisis Manage. 7 (3) (1999) 150–155.

[6] K.D. Eason, Local sociotechnical system development in the NHS National Programme for Information Technology, J. Inform. Technol. 22 (2007) 257–264.

[7] A.H. Glenngard, F. Hjalte, M. Svensson, A. Anell, V. Bankauskaite, Health Systems in Transition: Sweden, WHO Regional Office for Europe on behalf of the European Observatory on Health Systems and Policies, Copenhagen, 2005.

[8] T. Greenhalgh, K. Stramer, T. Bratan, E. Byrne, J. Russell, H.W.W. Potts, Adoption and non-adoption of a shared electronic summary record in England: a mixed-method case study, BMJ 340 (June) (2012) c3111.

[9] E-health Insider, Welsh Clinical Portal given go-ahead, 2010 http://www.ehi.co.uk/news/ehi/5539/welsh-clinical-portal-given-go-ahead (accessed 16.03.12).

[10] Z. Morrison, A. Robertson, K. Cresswell, S. Crowe, A. Sheikh, Understanding contrasting approaches to nationwide implementations of electronic record systems: England, the USA and Australia, J. Healthc. Eng. 2 (1) (2011) 25–41.

[11] P.E. Waterson, Y. Glenn, K. Eason, Preparing the ground for the 'paperless hospital': a case study of medical records management in a UK outpatient services department, Int. J. Med. Inform. 81 (2) (2012) 114–129.

[12] K.D. Eason, S.D. Harker, C.W. Olphert, Representing socio-technical systems options in the development of new forms of work organization, Eur. J. Work Org. Psychol. 5 (3) (1996) 399–420.

[13] NAO, The National Programme for IT in the NHS: Progress since 2006, National Audit Office, The Stationery Office, London, 16 May 2008, Available at: www.nao.org.uk/pn/07-08/0708484.htm (accessed 15.03.12).

[14] NAO, The National Programme for IT in the NHS: an update on the delivery of detailed care records systems National Audit Office, The Stationery Office, 18th May 2011, Available at http://www.nao.org.uk/publications/1012/npfit.aspx (accessed 15.03.12).

[15] S. de Lusignan, P. Krause, The Hayes principles: learning from the national pilot of information technology and core generalisable theory in informatics, Inform. Prim. Care 18 (2) (2010) 73–77.

[16] A. Robertson, K. Cresswell, A. Takian, et al., Implementation and adoption of nationwide electronic health records in secondary care in England: qualitative analysis of interim results from a prospective national evaluation, BMJ 341 (September) (2010) c4564, http://dx.doi.org/10.1136/bmj.c4564.

[17] M. Berg, C. Langenberg, I. Berg, J. Kwakkernaat, Consideration for sociotechnical design: experiences with an electronic patient record in a clinical context, Int. J. Med. Inform. 52 (1998) 242–251.

[18] T. Greenhalgh, K. Stramer, T. Bratan, et al., The Devil's in the Detail: Final report of the independent evaluation of the Summary Care Record and HealthSpace programmes, University College London, London, 2010.

[19] J. Grudin, Groupware and social dynamics: eight challenges for developers, Commun. ACM 37 (1) (1994) 92–105.

[20] K. Eason, M. Dent, P. Waterson, D. Tutt, P. Hurd, A. Thornett, The bottom up approach to electronic patient information systems: a focus on healthcare pathways, Inform. Prim. Care. 20 (1) (2012) 1–6.

[21] W.N. Leutz, Five laws for integrating medical and social services: lessons from the United States and United Kingdom, Milbank Q. 77 (1) (1999) 77–110.

[22] W.N. Leutz, Reflections on integrated medical and social care: five laws revisited, J. Integr. Care 13 (5) (2005) 3–12.

[23] M. Berg, Implementing information systems in health care organizations: myths and challenges, Int. J. Med. Inform. 64 (2–3) (2001) 143–156.

[24] S. de Lusignan, P. Krause, Liberating the NHS: an information revolution – think beyond the electronic patient record, think service orientated architecture!, Inform. Prim. Care 18 (3) (2011) 147–148.

[25] M. Berg, Patient care information systems and health care work: a sociotechnical approach, Int. J. Med. Inform. 55 (2) (1999) 87–101.

[26] K. Cresswell, A. Sheikh, The NHS Care Record Service (NHS CRS): recommendations from the literature on successful implementation and adoption, Inform. Prim. Care 17 (3) (2009) 153–160.