

Refereed paper

Bottom-up and middle-out approaches to electronic patient information systems: a focus on healthcare pathways

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ABSTRACT

Background A study is reported that examines the use of electronic health record (EHR) systems in two UK local health communities.

Objective These systems were developed locally and the aim of the study was to explore how well they were supporting the coordination of care along healthcare pathways that cross the organisational boundaries between the agencies delivering health care.

Results The paper presents the findings for two healthcare pathways; the Stroke Pathway and a pathway for the care of the frail elderly in their own homes. All the pathways examined involved multiple agencies and many locally tailored EHR systems are in use to aid the coordination of care. However, the ability to share electronic patient information along the pathways was patchy. The development of systems that did enable effective sharing of information was characterised by socio-technical system development, i.e. associating the

technical development with process changes and organisational changes, with local development teams that drew on all the relevant agencies in the local health community and on evolutionary development, as experience grew of the benefits that EHR systems could deliver.

Conclusions The study concludes that whilst there may be a role for a national IT strategy, for example, to set standards for systems procurement that facilitate data interchange, most systems development work needs to be done at a 'middle-out' level in the local health community, where joint planning between healthcare agencies can occur, and at the local healthcare pathway level where systems can be matched to specific needs for information sharing.

Keywords: electronic health records (EHRs), frail elderly, healthcare pathways, local design, local health communities, sociotechnical systems design, stroke

Top-down and bottom-up systems development

For the past decade, the UK National Programme for Information Technology (NPfIT) has been deploying generic electronic health record (EHR) systems. In this 'top-down' strategy common technical systems are delivered to end user communities where the emphasis is upon technical implementation and change management, on training people, promoting acceptance of the new technology and changing local work practices to get the benefits from it.¹ It is a programme that has encountered many problems.¹⁻⁴ The purpose of this paper is to explore whether EHR implementation is more effective if a more 'bottom-up' approach is taken in which most of the systems development takes place in the agencies where health care is being delivered.

Patient journeys in the NHS frequently take them to many different healthcare agencies and a major role EHRs might play is to enable frontline healthcare staff to share patient information between agencies. For the past three years, in the Electronic Patient Information Crossing Organisational Boundaries (EPICoG) project,⁵ we have been exploring the role that EHRs are playing in healthcare pathways that cross organisational boundaries between agencies, for example, general practitioner (GP) clinics, hospitals and community services. The concept of healthcare pathways and particularly integrated care pathways (ICP) has been growing in popularity as a way of managing complex service delivery offering as they do a way of 'business re-engineering' the process by which the different agencies contribute to the services offered to patients.^{6,7} As de Luc⁷ points out, the pathway concept is being implemented in many different ways for many different purposes. It can, for example, be implemented to help frontline staff coordinate their work or it can be used as a mechanism for management control and standardisation. Whatever the purpose of the pathway, electronic patient information systems are often seen as a key to their successful operation because they can provide up-to-date shared information across the pathway

To facilitate effective healthcare coordination, electronic patient information needs to be accessible and useful to all the agencies along a healthcare pathway. In this project, we examined how well EHR systems support the agencies in healthcare pathways in two local healthcare communities in England, in Walsall and in Northamptonshire. We examined nine different pathways ranging from the stroke pathway to palliative care and retinopathy screening for diabetic patients. The method of study has been in three phases:

- to model the current pathway in terms of the process, the agencies involved and the electronic systems that support it
- to explore with healthcare staff their experience of current EHR systems
- to examine how current systems have been and are being developed and implemented.

The EHRs in place are based on standard electronic products delivered by suppliers and adapted for use in local settings. To illustrate our findings the next section discusses two examples, the Stroke Pathway and the Frail Elderly Pathway for home treatment.

The Stroke Pathway

In Figure 1 a simplified account of the process for the treatment of a stroke victim in one local health community is depicted. It usually begins with an emergency admission to Accident and Emergency (A&E), a transfer for treatment to the stroke unit of the hospital and, if that is successful, discharge to community care for rehabilitation. Thereafter, there is regular monitoring to offset the chances of another stroke. Many agencies and clinical specialisms may be involved in this process: GP clinics, the Ambulance Service, A&E, stroke specialists, specialists in physiotherapy, speech therapy, occupational therapy, etc. and, when the patient is discharged, social care services may also be involved. The treatment of the patient consists of a series of 'handovers' as responsibility for the patient passes from one part of the health service to another. Exceptions to this are the rehabilitation and monitoring phases where 'shared care' may be necessary, when a number of health and social care agencies may simultaneously hold responsibility for the patient.

The treatment and recovery of the patient in this process may depend on shared access to information by all the agencies involved.

In the particular example we have studied, each agency had its own EHR initially but gradually a shared system has evolved in the local health community to support the objectives of the National Stroke Strategy.⁸ This has required not just EHR developments but *process developments*, particularly to coordinate the work of the different agencies, and *organisational changes*, for example, the opening of a dedicated stroke unit in the local general hospital. EHR developments have had to be matched to the roles and responsibilities of agencies in the patient treatment process. One major result is the development of an electronic stroke register into which the accruing details of medical care and treatment are input. The register is then accessible, via a portal, to many of the agencies involved in treating

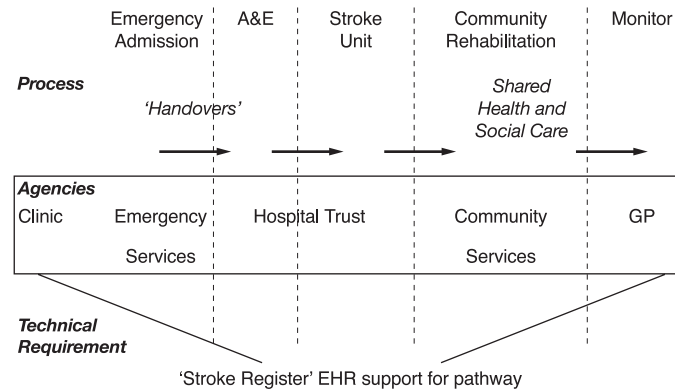


Figure 1 The Stroke Pathway

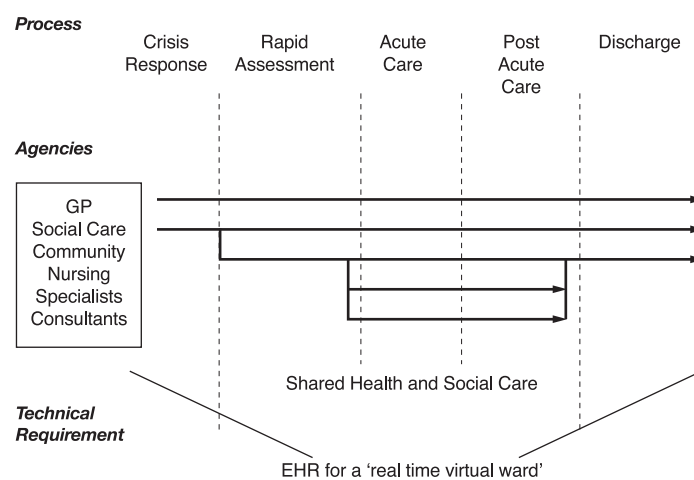


Figure 2 The Frail Elderly Pathway

the patient. Our results show that at present, whilst the stroke register enables common access to the EHR, an emphasis on constructing the record to facilitate management reporting means that it has limited value in supporting the frontline handovers involved in the pathway.

The Frail Elderly Pathway

The treatment of the elderly, who may suffer from multiple chronic conditions, is a national priority in our ageing population. The elderly are often 'frequent flyers' in A&E when they suffer falls or other emergencies. It is generally agreed that if they could be treated at home or elsewhere in the community whenever possible it would be better for both the patient and the health service.⁹ In one of our studies, we examined the development of a system, depicted in Figure 2, which places vulnerable elderly patients on a Frail Elderly Pathway. The definition of the frail elderly has been

problematic and there is no accepted national definition.¹⁰ In the trust in which this study was conducted they are defined as persons over 75 years of age with multiple conditions. Pragmatically, they are people over 75 in crisis that a rapid assessment unit concludes could be successfully treated at home rather than being admitted to hospital. If an elderly patient has a crisis, to avoid unnecessary hospital admission, community staff put in place an intensive care process to treat the patient in their own home. The process in this case consists of recognising the crisis, making a rapid specialist assessment, assembling an acute care team and, when the patient has recovered sufficiently, creating a post-acute team that, in time, can discharge the patient back to their normal social care and GP arrangements. As in the stroke example, this process can involve many different agencies.

In contrast to the stroke example, this process is not a sequence of handovers but involves a rapid 'stepping up' of the number of agencies involved in care in the acute phase followed by a 'stepping down' process leading to discharge. This is an example of shared care, involving both health and social care services, in which

many agencies need to cooperate and act as a 'virtual team' in a limited time frame.

In the example we have studied each agency had its own EHR initially and most sharing of information was accomplished through the paper-based single assessment process (SAP) system. To facilitate an increased number of potentially more unstable patients being cared for in the community, a multistrand programme of development work is being followed that involves the development of new *processes* and *organisational changes* that affect most of the agencies. It is an attempt to provide, for a short time, many of the services normally only available in a hospital ward to elderly people in their own homes. The programme includes EHR developments to enable agencies to coordinate the work they are undertaking. These are the development of a 'real time virtual ward' that will give all agencies access to information about the patient and the implementation of telehealth facilities to monitor the condition of the patient remotely. Major challenges are first, to create systems that enable healthcare and social care agencies to share information and secondly, to manage the conflict between the need for frontline staff to share information and the need to generate management information.

Implications for the development of EHR systems

There are a number of commonalities between the two healthcare pathway developments described above and the others we have studied that have implications for the development of EHR systems:

- They all involve multiple agencies who, for the good of patient care, need to cooperate and to share information.
- They each involve different challenges: different processes, different agencies, different specialisms, different relationships between them, different relations to patients and their social situations, etc.
- These developments are not just about technical systems, they are sociotechnical developments in that they require simultaneous process developments and organisational changes. EHR developments need to be tailored to these changes. This finding reflects a growing awareness that the implementation of health informatics has to be treated as a sociotechnical undertaking.^{1,3,11,12}
- In all cases, EHR systems are in place. However, in most cases there is no one system in use across all the agencies involved in a pathway and sharing of electronic information is patchy, such as between social and acute care and across unscheduled care.

- The development process for systems that enable information sharing tends to be evolutionary, involving many stages, perhaps over many years. This is because of maturation (a gradual realisation amongst local health staff of what can be done and what needs to be done to improve the system) and turbulence (the continuing wave of changes in the NHS that can affect the policies and targets the system needs to serve, the organisational relationships of the agencies involved etc).
- The development of the EHR reflects the issues that surround the implementation of healthcare pathways, e.g. are they systems to assist frontline staff or are they systems for management control?

The implications of these factors for the development of EHR systems are:

- The specific nature of the EHR needs to be tailored to the pathway. It is about supporting a process rather than agreeing the contents of a database.¹³ Both the Stroke Pathway and the Frail Elderly Pathway have EHR systems but they differ from one another considerably in form, function and content. It is only in the local context that the exact form of the EHR can be determined.
- The EHR needs to be tailored to the roles and responsibilities of the various agencies involved in delivering the service and to both frontline staff and management.
- The development and evolution of the EHR needs to be a product of continuing collaboration by informatics staff and the frontline staff of different agencies who deliver the health care. In healthcare pathways that have the most developed support from EHRs, there has been an on-going development programme for the pathway and mechanisms whereby informatics and healthcare staff from the relevant agencies can cooperate in the developments.

The role of national EHR systems

It might seem obvious that a common database system is needed that would enable all the agencies contributing to a pathway to share the same patient information. This has been the strategy in the NPfIT but experience has shown that when generic systems are implemented in national roll-outs this gain comes at a considerable cost:

- Local designers need the opportunity to create a system to serve the particular needs of a healthcare pathway and of its various contributors and a standard system designed for multiple uses may not provide this flexibility.

- National systems tend to be highly structured and to constrain content. They may not permit users in a particular pathway to share patient information in ways appropriate to the health care they are providing.
- It may not be possible for all contributors to a pathway, for example, social services, to use the same system and that makes it difficult to share information across organisational boundaries.
- National systems tend to be implemented with national procedures for data governance, e.g. role-based access rules, which may not be appropriate in some local settings.
- The process of developing integrated local systems involves steady evolution as lessons are learned. It is often quite difficult to obtain specific local modifications to a national EHR system and this can render the system an impediment to the progressive development of local solutions.

In general, the problem of the national system solution is the oft quoted one that 'one size does not fit all'.⁴ This is not, however, an argument for every healthcare agency to develop its own e-health system because this could make cooperation between agencies in the healthcare pathway very difficult. The evidence suggests a need to seek mid-level solutions where local agencies that need to cooperate can find effective ways of both serving their own needs and of sharing information.

Levels of design

A number of commentators, notably in the Hayes report,^{14,15} have pointed to the need for systems development to take place close to the point where clinical services are delivered. In their evaluation of the Summary Care Record, Greenhalgh *et al*¹⁶ refer to the existence of three levels of design; macro, meso and micro. Our findings show the necessity of local development work although we do not discount a limited role for a national strategy. However, our data also point to the significance of a meso level of design. Coiera¹⁷ has stressed the value of a 'middle-out' approach to the development of EHR systems and in this study the most natural level at which to plan EHR developments is that of the local health community where the planning of healthcare pathways across local agencies has to be undertaken. We conclude that there is a requirement for development activities of different kinds at the micro, meso and macro levels of design.

Micro level (specific healthcare pathways)

The 'micro' level is the healthcare pathway in which stakeholders in the relevant agencies need to work together with informatics staff to develop and refine e-health solutions that support the process and organisational developments that are also being implemented to improve healthcare delivery. Note that the micro level is not at the individual agency or trust level because the healthcare task crosses organisational boundaries and this fact of life has to be of central concern even at the local level of systems development.

Meso level (local health communities)

The 'meso' level at which different agencies need most to cooperate in the development of e-health systems is the local health community. At this level, there is a need for partnership agreements that can set priorities for e-health systems, select the systems that agencies will use and establish interagency systems development teams.

Macro level (national)

At the national level, design should not be about rolling-out common systems but about establishing e-health policies that will help agencies cooperate. This is already happening in respect of specifying standards for the catalogue of e-health systems that can be procured that ensure data can be exchanged between systems.¹³ Similarly, policies to protect the confidentiality of patient records could be established that leave room for local designers to find ways of implementing them that work in local circumstances.

Conclusion

There are many other arguments that can be adduced to support a bottom-up approach to e-health systems development, not least of which is the powerful motivational argument that people are much more likely to embrace with enthusiasm a system which they have helped design rather than one 'parachuted in' from outside. However, the fundamental reason why a bottom-up/middle-out strategy is imperative is that, if any e-health system is to be useful and acceptable, it has to meet the needs of those delivering health care at the front line. And frontline delivery in the different healthcare pathways poses many different design challenges that can only be met locally.

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CONFLICTS OF INTEREST

None

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