Case studies

The South Warwickshire NHS Care Records Service Demonstrator Project: lessons for the National Programme for IT

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ABSTRACT

The NHS Care Records Service (CRS) is a major goal of the National Health Service (NHS) Modernisation Programme. It will provide for 24-hour access by clinicians to electronic patient records and the integration of information from previously separate databases, reducing the ‘seams’ between primary and secondary care, between out-of-hours and ordinary working hours, and ultimately between health and social care. Such integration is likely to affect not only individual patient care, but also public health including disease surveillance, and the monitoring of clinical activities including the achievement of clinical governance targets. The potential benefits for patients, practitioners and managers are numerous. However, the process raises issues over confidentiality, data protection and data quality. During 2003 a project was undertaken in South Warwickshire to develop an NHS CRS widely available to primary care clinicians in the region. This was part of a wider initiative funded by the NHS Connecting for Health (NHS CfH). Twenty-six out of 36 local practices took part, providing a combined database of 181 961 clinical records. All but one of the original objectives was achieved. Lessons were learned which could usefully inform the development of the CRS more generally in the NHS.

Keywords: care records service, information storage and retrieval, medical records systems – computerised, interoperability

Introduction

A number of recent directives point towards database integration as the way forward for health informatics in the National Health Service (NHS), including Information for Health and Delivering 21st Century IT Support for the NHS: national strategic programme. Significant barriers remain, however, particularly at the interface between health and social care. These include not only issues of confidentiality and patient consent, in the context of the 1997 Caldicott Review and the 1998 Data Protection Act, but also those of data quality and software compatibility. Potential benefits of database integration include access to clinical records, investigation results, and allergy and medication histories by clinicians dealing with patients ‘out of hours’; electronic linkage between primary and secondary care units; the detection of population-level changes in morbidity patterns, including infectious diseases; improved communication between professionals using the databases; and, increasingly, the use of such data for research.

Twenty-four-hour emergency access to medical records is one of the defined objectives of Information for Health, to be achieved by 2005. Because these records are traditionally held in general practice (GP) premises, and such premises are no longer the usual point of delivery of out-of-hours care, this objective unavoidably requires external access to practice-held records. The move towards increased access and
information flow may be contrasted with the ‘need to know’ principle that is central to the Caldicott Review. For an integrated database system to satisfy both guidelines, clearly defined protocols governing rights of access are required. One of the successes of the project we describe was the achievement of this outcome. The project objectives are shown in Box 1.

Box 1 Project objectives

- To create a working model of rapid primary care record integration for South Warwickshire Primary Care Trust.
- Where applications cannot be demonstrated within the schedule, to complete the design and planning to illustrate what can be done and how.
- To explore the implications and benefits in process and technical terms of using the Demonstrator and of hosting GP software systems.

The South Warwickshire Demonstrator Project

South Warwickshire Primary Care Trust (PCT) is situated in the West Midlands, south of Coventry and Birmingham, serving a population of 249,000. A district general hospital at Warwick provides the majority of secondary care services. Within primary care there are 36 general practices and approximately 142 general practitioners. At the time of this project all the practices were computerised to varying degrees and the majority had links to hospital databases for transmission of laboratory data. In addition to general practices, GP hospital facilities, physiotherapy units and NHS Acute Trust community clinics took part in this project.

The global information technology (IT) company IBM and Newchurch (a United Kingdom [UK]-based private health informatics company that specialises in primary care database management) were contracted to manage the project in collaboration with local stakeholders. Newchurch were responsible for the protection of data held in a central repository located at Teddington, Greater London. Every 24 hours the repository was updated by downloads from the source systems. Data quality was improved by cleansing and standardising the coding. This information was accessible to authorised users over the NHSnet, and access to the repository occurred both through fixed-line NHS connections and mobile devices. The user interface, the ‘Primary Care Information Solution’ (PCIS), was available at 320 access points at general practice surgeries, hospital Accident & Emergency (A&E) departments, GP hospital wards and community-based clinics. Each user accessing the system was allocated a security level. ‘Sensitive’ or ‘confidential’ information was identified and the user’s security level determined how much information was accessible to that user. Whilst the project was established on the basis of ‘implied consent’ (patients aware of the project through publicity and unhappy about it could withhold their records, but otherwise would be included), access only actually occurred with the patients’ expressed consent at the point of care. For instance, a patient seen in the A&E department would be asked to consent to access to their general practice records by A&E staff. This process could be overridden if the patient was too unwell to discuss it, but otherwise ensured that a patient unaware of the project could dissent to access if they wished. Staff undergoing training in the use of the system were made aware of the audit trail facility which records every instance of access, including the user’s identifier.

Software compatibility

In addition to confidentiality issues, a further obstacle to database integration is the diversity of software providers in primary and secondary care. To overcome this problem, a wider system capable of incorporating a number of software providers was required. The Health Care Interoperability Forum (HCIF) exists to promote information flow and the operability of alternative software in the shared NHS environment. The HCIF is a UK-based commercial co-operative that subscribes to Health Level 7 (HL7), an international body ‘providing standards for the exchange, management and integration of data that support clinical patient care and the management, delivery and evaluation of healthcare services.’ The UK component, HL7UK, provides the currently accepted guidance on interoperability within the NHS. The software systems involved included: from general practice: EMIS, Vision and Torex (now iSOFT) GP systems; from the PCT: CISS (Community Services) and CPA (Mental Health) Systems; and from Warwick Hospital: Torex PAS and Anglia Reporting Systems. Data flow between different web-based units was facilitated through the use of extensible mark-up language (XML). XML is a more flexible language than hyper text mark-up language (HTML) but is simpler to program and more usable than standard generalised mark-up language (SGML). The use of XML in this project was an important means of achieving interoperability.

This project, funded by the NHS Programme for IT, was one of a number of similar initiatives, including Electronic Record Development and Implementation Programmes (ERDIPs). The collation of information on the same individual from different sources was made possible by the use of a Master Patient Index (MPI).
The Master Patient Index

The MPI is based on patients’ NHS numbers, allowing ‘registration’ to occur above the practice level. The current system of practice-based registration (in which patients registering with a new practice automatically trigger the cancellation of their previous registration) ensures that they can no longer be registered in more than one general practice. This contrasts with other medical registers (such as hospital laboratory databases) where it is not as easy to ensure that the same patient won’t be counted twice. The same MPI principle has been used in Canada, where the Integrated Health Research Network database collates information across Quebec, serving an integrated system of care between hospital and community services.13 In the MPI used in this project, NHS numbers were aligned with PCT-held patient demographics and Warwick Hospital casenote (‘UR’) numbers, in order that both hospital and community data could be integrated without duplication. The prime identifier for all patients was their NHS number.

Outcomes of the project

Box 2 Outcomes of the CRS Demonstrator Project

- 26 out of 36 practices daily contributed data to a centrally hosted CRS repository. This represents approximately 181 961 patients from a total list of 249 000, or 73% of the PCT’s active patient list
- 498 user identifiers issued and 300 staff attended formal PCIS training sessions
- Integration with CISS (Community Health), CPA (Mental Health), Pathology and Radiology, providing a wide range of patient data available to authorised users
- The creation of a security model, accommodating PCT and practice positions on confidentiality and consent within available national guidance
- Agreed security profiles for different categories of users of the central system (GPs, practice staff, out of hours, A&E, mental health professionals, non-mental health clinicians)
- System configured to meet the needs of primary health community and participating acute trust groups
- The ability to view radiology and pathology results associated with the patient record

Box 3 Usage of the system

- There are 320 instances of the PCIS at general practices, community health offices, GP wards, physiotherapy, the A&E department of Warwick Hospital, and other centres.
- Between January and July 2005, there were approximately 7200 log-ins to PCIS from practices, non-practice users and the PCT. Approximately 25% of activity arises from A&E departments in the region.

Lessons learned

The following issues arose during this project, and are discussed in more detail in the End Project Report:15

1 A CRS based on GP records is possible to implement and can lead to improved patient care. The project was delivered within the anticipated time-scale and the overall budget. Examples of comments from system users are given in Box 4.
2 IT needs integration with change management for rapid adoption. The project suffered from a lack of
incentives beyond the perceived utility of the end result, and receptiveness was variable. Participation was voluntary, and as the facility was not underpinned by a specific change management programme, the CRS was seen by some as an IT initiative rather than a wider modernisation opportunity. Most activities in the project required negotiation with clinicians for access to services, and this inevitably took a lower priority to clinical care.

3 Confidentiality and consent issues. Lacking precedents on which to base specific confidentiality guidelines, the model was developed through extensive discussions between the project board, patient representatives, PCT Caldicott Guardians and practices. This process took longer than expected, but was felt to be crucial to the project. The need for detailed negotiation must be accounted for in planning and scheduling similar projects elsewhere. A nationally agreed ethical framework for such projects would assist considerably, but there will always be local issues and obstacles to negotiate.

4 New communications strategies are needed. Apart from the PCT board, a number of local stakeholder groups received formal presentations, including the Acute Trust Board, the Medical, Nursing and Allied Health Professionals Committees, the Shadow Patient Council and the Community Health Council. Progress on the project and its outcomes were also communicated through PCT newsletters, and through direct communications from the GP ‘champion’ and the PCT IM&T manager to local practitioners and users. However, a future communication strategy could be more tailored to the needs of disparate users from different backgrounds, to avoid the information overload that can easily result in the ‘default delete’ option when presented with promotional material.

5 An integrated environment introduces complexity. The project identified the need for a Representative User Forum to advise on the delivery of the project and prioritise any enhancements. Such a forum was initially involved in the early stages but tended later to fragment so that advice was gained from individuals rather than the forum itself thereafter. There were problems integrating certain hospital casenote (‘UR’) numbers with NHS numbers, and the more widespread use of NHS numbers would have simplified integration. The system was operated through the NHSnet and was therefore dependent on its performance. During August 2003 the MSBlast virus, which caused extensive damage to web-based systems generally, resulted in a failure of retrieval of data to the central repository for eight days, requiring a catch-up period. Future developments of the CRS will require attention to this issue of vulnerability at the system level.

6 Don’t call it a ‘Demonstrator’. This term tended to portray an experimental rather than ongoing status for the project, which meant that some individuals were unclear how much it justified their time. Extension of funding has enabled the system to remain in operation following the end of the project.

7 Strategic health authorities, PCTs, GPs and suppliers can work together to achieve a CRS. The project benefited from excellent relationships between all the parties concerned, who shared common aims and objectives. The CRS both requires and builds on such relationships through its integrated structure.

Box 4 Examples of user feedback

‘With the PCIS we were able to obtain information on the drugs that the patient took regularly, giving us the knowledge of what a patient’s drug history was.’

‘An elderly lady came to A&E in an ambulance from a nursing home without a nurse in attendance. When the doctor started to take the history, it was evident that she was unable to recall her past medical history. PCIS enabled us to get this, which then enabled us to deliver appropriate nursing care.’

‘The patient had an ECG taken which showed an arrhythmia; we needed to establish whether this was new or old. By accessing the PCIS we were informed that it was old and therefore prevented a hospital admission.’

‘The PCIS enables us to establish what a patient’s tetanus status is.’

‘The patient said that the morning pills she took were white, and the evening pills were pink; PCIS provided us with the information to establish the names of the drugs she was taking.’

Discussion: the future

The technical success of this project in providing a shared software environment for the NHS Care Records Service at the PCT level was clearly demonstrated. In the process, a number of issues relevant to the ongoing national integration of NHS databases were identified.

Obstacles to integration include technical issues such as software compatibility and standardisation of record keeping.16 Huston emphasises that information technology itself will not solve the problem of
poor record keeping, and recommends that clinicians rather than managers should lead the process of standard setting. Data quality is also a potential problem. Ideally, universal patient identifiers are required for optimal record linkage, and inaccuracies in patient records might in theory be amplified by database integration. Methods of measuring data quality are known, but patients may remain concerned unless ownership of information is clear and strictly controlled, so that the benefits of information sharing can occur without loss of confidentiality. In a qualitative practice-based study, Ward and Innes have shown that whilst patients expect their doctors to limit access to their records appropriately, they also expect them to make relevant information quickly available across the health service where needed. This is a difficult but important balance to strike.

This project was undertaken within a fixed timescale and budget, but the facility remains in use and could be extended in future as the NHS undergoes further modernisation. Access to the system from secondary care (other than GP wards) was limited to A&E, but PCIS units could in principle be set up in hospital outpatient departments as well as inpatient wards, intensive care units or theatre recovery. The system may also be used to support the development of GPs with Special Interests (GPSIs), as this role expands in future years. The Master Patient Index, which allows PCT-level registration to occur, could be used to provide more adequate registers for specific clinical conditions. These not only include diagnostic groups (such as diabetes, for the targeting of patients for interventions such as community retinal photography), but also those with different conditions but sharing similar or overlapping needs. An example of this is the ‘ELDIT’ study (Epidemiology of Liver Disease In Tayside), which used the same principle of database integration, including biochemistry, immunology and virology laboratory sources. Diagnostic algorithms have been applied to this combined database to classify individual cases, recognising patterns through collation of information from multiple sources. In addition to established conditions, data from previously isolated sources might facilitate the identification of patients at risk of certain conditions, where risk factor profiles are complex. These might include children at risk of abuse, or the identification of patients likely to require hospital admission in the near future, an area currently under investigation by the King’s Fund.

The latter two groups might particularly benefit from the inclusion of social services data, not included in this South Warwickshire project but a potentially valuable source for inclusion in the future. Similarly, the inclusion of dentists’ and opticians’ reports might further amplify the potential of the model for inter-professional communication to the benefit of patients.

Limitations and future research needs

This case study has described the establishment of a local Care Record Service in South Warwickshire. The benefits of this service have not yet been formally researched following the project’s completion, but during its creation the same sorts of issues and obstacles to implementation found elsewhere were identified. To justify the costs of such systems, added value above existing facilities to both patients and clinicians need to be demonstrated. In a series of case studies and in-depth interviews across four acute NHS trusts, Hendy et al have uncovered the ‘sociocultural’ as well as logistic challenges of such integration, particularly within the time-scales initially proposed by NHS Connecting for Health. This Demonstrator Project needs to be similarly researched through a more extensive evaluation of the system’s usage, exploring not only the technical and logistic barriers to its ongoing delivery, but also the qualitative issues of acceptability and perceived benefit from the perspectives of patients and practitioners.

ACKNOWLEDGEMENTS

We would like to thank the Project Board and all those involved from IBM, Newchurch and the South Warwickshire Primary Care Trust, particularly David Harry, Head of Information Technology.

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**CONFLICTS OF INTEREST**

None.

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*Accepted September 2005*