Data quality and management issues in SSEPRs and other record sharing.

Application to be considered for the John Perry Prize

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Project being submitted:
Identification of the data quality, patient safety and clinical governance issues surrounding single shared electronic patient records (SSEPRs) and other types of shared electronic patient records (SEPRs) and my actions to get the issues clarified and addressed by the appropriate bodies.
The work is ongoing.

Introduction

The re-organisation of medical care under the recent NHS reforms has led to a situation where medical care is routinely provided by a number of different organisations, and, with increasing complexity, it has become ever more important that medical records should be appropriately available to both health care professional and patients and their carers involved in the care of individual patients.
However, although a great deal of attention has been given to the patient consent, security and confidentiality issues involved in sharing records, less attention has been given to the creation and management of the records and shared records themselves, or to the organisational issues involved when care of an individual is provided by different organisations and care provided by one may impact on the care provided by another.
This is the area in which I became interested in late 2007.

Background.

The NPfIT requires a Detailed Care Record (DCR) which is defined as a locally held single electronic medical record for each patient held on a LSP (Local Service Provider) server.
In NME (North, Midlands and East Cluster where CSC is the LSP) this has been interpreted as meaning a single record of prime entry i.e. a SSEPR (examples TPP SystmOne and in the future Lorenzo), although the wording appears to mean that the DCR is a *locally* shared record – not a national one.
Some LHCs (Local Health Communities) have developed different means of sharing patient records including the use of EMIS Web (Liverpool, Gateshead, Tower Hamlets) and data warehousing of entire EPRs pioneered by Graphnet in Hampshire : these approaches have different confidentiality, security, consent and responsibility issues, but all depend on the quality of the data in the contributing EPRs.
The work I have done on this problem started in late 2007, stimulated by a presentation from Rotherham at the 2007 PRIMIS+ conference, and having my worst fears confirmed in discussions at the East of England NPfIT event in November 2007.
This led to a submission to the NPSA (National Patient Safety Agency) (Appendix A) in December 2007, which in turn was followed by CfH (Connecting for Health) awarding a

contract to the RCGP to examine the issues of Shared Record Professional Guidance [1] (to be published on 18th August 2009.)

My work consisted of the following

- Identification of risks in SSEPRs
    - Data quality when different organisations are entering information in the same record
    - Issues around amending the record
        - Where amendment is expected e.g. medication
        - Where errors have occurred (wrong patient, change in diagnosis or diagnosis disproved)
        - Means of doing so.
    - Responsibility for the integrity and quality of the whole record
    - Responsibility for patient care i.e. acting on the information held in the record.
    - I did not attempt to examine issues of security, confidentiality and consent: although these are important in SSEPRs as in all medical records, they lie outside the scope of my project.
- Action taken to pursue the issues:-
    - Report to NPSA asking for SSEPRs to be placed on their Risk Register.
    - Article in HI NOW[2]
    - Letter to informatics in Primary Care[3]
    - Comment article in EHI[4]
    - Presentations UKCHIP workshop and as part of groups at HC2008 (UKCHIP workshop)[5] and 2009 (PHCSG session).
    - Presentations PHCSG Summer Conferences 2008 and 2009 and Annual Conference 2008.[6]
    - Involvement with the SRPG (Shared Record Professional Guidance) project commissioned by CfH from RCGP.

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[1] www.rcgp.org.uk

[2] Is it safe to share a single record? Health Informatics Now vol 2 number 3 March 2008
http://www.bcs.org/server.php?show=ConWebDoc.17923

[3] The Single Shared Electronic Patient Record (SSEPR): problems with functionality and governance Hawking, Mary. Informatics in Primary Care Volume 16, Number 2, July 2008 , pp. 157-158(2)
http://www.ingentaconnect.com/content/rmp/ipc/2008/00000016/00000002/art00010

[4] Does Lorenzo mean the end of GP electronic patient records?
http://www.e-health-insider.com/comment_and_analysis/309/does_lorenzo_mean_the_end_of_gp_electronic_patient_records_tcq
updated URL 01/11/13
http://www.ehi.co.uk/insight/analysis/309/does-lorenzo-mean-the-end-of-gp-electronic-patient-records_tcq

[5] http://www.ukchip.org.uk/ Library – UKCHIP Development Archive UKCHIP at HC2008 and Professionalism and Patient Safety June 2008

[6] www.phcsg.org.uk Conferences bottom of the page “past conference information available here.

    - Participation in a series of CLICSIG workshops related to this topic and held to inform a report for the SRPG project.

Summary of issues in SSEPRs and by extension all automated record and data sharing.

- Three broad categories of risk:-
    - Data quality when different organisations with different semantics and record keeping needs use single record or contribute data to a sDCR (shared Detailed Care Record – summary elements of a DCR whether held permanently or transiently)
        - Semantic interoperability (agreement on meaning of terms)
        - Coding: agreement on which Codes to use in what circumstances
        - Agreement on diagnostic criteria e.g. diagnosis of depression and asthma.
    - Information governance of the record itself
        - Access – who can read the record and what parts of the record can they read
        - Data entry rights – who can make entries into the record
        - Editing rights – who can correct errors and/or amend entries made in:-
            - their own organisation
            - a different organisation
            - the mechanism for resolving conflict when there is no agreement on the need for amendment
        - Medication initiation, alteration, continuation and issuing.
            - When a new medication is initiated, change to previous medication may be needed.
                - Who is responsible for this, and what qualifications are needed
                - Who is liable for any ill consequences and monitoring
                - Who issues the prescriptions – and if not in agreement with the management, what rights does a prescriber have to refuse to continue a prescription initiated elsewhere?
    - Clinical governance of patient care.
        - Medication, including effects on other medications and conditions.
        - Clinical responsibility for holistic care of patient
        - Agreement on interventions, level at which interventions are made and who makes them.
        - Ability of record to enable above. (Organisational systems needed – but outside scope of this project)

All of these are “wicked questions” – which need to be assessed and addressed.: my contribution has been to identify them and contribute to their evaluation.

Where next?

The recommendations in the SRPG Report will need to be examined and incorporated into present and future shared record projects, and I understand that a revision of GPG (Good Practice Guidelines for General Practice Electronic Patient Records) is likely to follow.
Much attention is being devoted by the NHS Information Centre on the training needed by organisations such as Community Care without experience of EPRs and the individuals working in and with them to produce and maintain records fit both for their own purposes and for sharing.
This is work outside my immediate field of action, but I am involved with the NHS IC.

On a personal basis I am looking at the quality of data and records held in GP systems: it may be fit for the purposes for which it is gathered i.e. care of patients and business needs in that particular practice, but does that mean that it is necessarily fit for sharing?
Only 70% of practices signed up for the IM&T DES or subsequent LES – which means that there is no information on data quality in these practices – and presumably some of those undertaking the IM&T DES will not achieve data accreditation.
So how do we know what the standard of data is in the records held in General Practice?

One possible source of information lies in the quality of records being transferred by means of GP2GP.
Assuming that all these records were satisfactory from the point of view of the practice which created the EPR, how do they appear to the practice receiving them? And can any information be gathered on this as a proxy for general data quality in General Practice?

I am currently discussing this with UCLAN and hope to carry my project of a GP2GP survey forwards in the near future.

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Appendix A

Single Patient Electronic Health Record: application to have this placed on the NHS IT Risk Register.

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8/12/07.

Summary.

Shared electronic records i.e. electronic patient records where more than one group enters clinical data (e.g. GP practice and Community services) are being introduced as a means of ensuring that medical information is available at the point of care to those with a need to know.
Regardless of how access to the record is managed, there are fundamental problems in managing such a record, including who is the Data Controller, who can correct or amend the record, and who can be held accountable, both for the record itself and for action on anything entered in the record, when several different organisations are making entries. Failure to address these can lead to degradation of the quality of the record, with consequent risks for the safe management of patient care, and, in the existing model, an inability to correct errors or change medication.

Introduction.
In the NME (North, Midlands, and East) cluster,[i] the strategic plan is to replace existing GP records confined to the individual practice, with electronic patient records fully shared between different organisations with clinical information and prescribing entered by individuals in different organisations.

At present the system being introduced is CSC/TPP SystmOne[7], with the objective of integrating GP and Community systems as a first step in most of the areas where it is being introduced: the strategic plan from CSC is to allow integration with other TPP modules for Drug services, Child Health Surveillance, Prisons and Hospice Care etc. and to extend the shared care record by total integration with Lorenzo[8] by 2010.[9] This is a central server system i.e. a hosted system – records are not held in the practice. Access is allowed by smartcards sign-on and role based access.

There are serious issues about the management of information and responsibility for patient care in any shared record system, but the current situation is as follows.

1. The GP system is the primary system, and information is entered and managed – including prescribing – in the normal way for any GP system.
2. Members of other organisations request a referral from the GP practice to put a patient on their caseload.
   - The referral specifies the level of access to the patient record – which can be anything from demographics to the entire patient record: it is not clear to me whether access permission limited to demographics would allow clinical data to be entered into the clinical record.
   - Referrals are for individual patients, and access is restricted to patients who have been referred
   - While the patient is being cared for by the other organisation, that organisation enters data and prescribes in the single record.
   - Once the episode of care and legitimate relationship[10] has ended, the patient is discharged back to the GP practice.
   - I have no information as to whether this stops the other organisation e.g. Community from accessing the patient record or the information they have entered for audit and administrative purposes, and I am equally unclear as to whether the information can be altered once the legitimate relationship has ended.
3. Data and prescription management.
   - Entries into the single record can be seen by anyone authorised to access the record at an appropriate level, regardless of the organisation making the entry
   - Entries – including prescribing entries – can only be altered by the organisation making the entry in the first instance e.g. a diagnosis entered in the Community cannot be corrected by the GP practice even if erroneous.
   - Prescribing. My information is that the same applies to prescribing – which, since medication will always require adjustment and changing and as prescriptions are frequently started in one setting care but continued in another. With increasing involvement of Independent Prescribers e.g. Community Matrons, lack of clearly defined responsibilities for prescribing – both in terms of initiating and altering or cancelling prescriptions – may well lead to a high risk of prescription errors.

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[7] SystmOne. A GP system developed by TPP (The Phoenix Partnership) specifically as a single database, remotely hosted, and to be fully integrated with their Community and other modules including Drug and Mental Health services and others. SystmOne uses CTV3 – Read Code v 3 – which is different from the majority of other GP systems: most use Read Code v2 5 byte

[8] Lorenzo is the comprehensive system being developed by iSoft for the NHS. CSC now expects implementation in 2010.

[9] Presentation by CSC at the East of England event “Improving Lives Saving Lives – the future of NPfIT” 6/12/07 http://etdevents.connectingforhealth.nhs.uk/1307 PowerPoint by Simon Holt

[10] Legitimate Relationship. The right to access to an individual patient record depends on the need for such access to provide care and has to be formally established before access to the patient record can be allowed via a smartcard.

4. Quality of the patient clinical record/ Data Controller role[11].

- Good Practice Guidelines (GPG) v3.1 (2005) defines the quality standards and governance arrangements needed before a practice can be authorised to keep its patient records electronically: these include maintaining data quality and correcting errors.
- The arrangements for data entry and amendment in SystmOne are such that the practice cannot amend errors made by other organisations, and this has already created problems in Rotherham[12] and elsewhere. [13]
- In some areas e.g. Essex, the risk to data quality appears to be regarded as a risk to QOF – and the Community have been given a list of history Codes e.g. H/O diabetes to use instead of diagnostic Codes.[14]
- Measures taken to protect the business of the practice (such as Code lists which avoid Codes used in QOF) do not protect the integrity of the clinical record – and may be accepted as being valid information.
- If the quality of the GP record is "degraded" (as noted in Rotherham), decisions based on that record will be unsound clinically – and put the patient at risk.

5. Accountability and liability.

- In any clinical situation, HPCs (Health Care Professionals) are accountable for their own actions. The situation is more complicated when using a shared record, where:-
    - Tests and investigations ordered by one organisation e.g. Community require action by another e.g. general practice.
    - Systems for ensuring that relevant information e.g. test results is seen by the appropriate person, and that person is made liable for taking (or not taking) action, and the full consequences of their action or inaction.
    - Medico legal issues involving the status of the record and the liability for lapses in care if important information is overlooked.
    - Whether, if the quality of the patient record is sufficiently degraded, it would be necessary to revoke permission to operate in a paperless environment under GPG.
    - GP2GP. In future, records will be transmitted electronically and incorporated into the new practice's system automatically. It will be impossible to avoid contamination in other practices if the information has been seriously downgraded. [15]

Because of these risks, I am asking that the single electronic patient record should be placed on the NPSA risk register, the risks examined and recommendations made as soon as possible: shared records are already being introduced, and the problems encountered.

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[11] Good Practice Guidelines v3.1
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4008657
Gives the requirements for a practice to be allowed to hold all patient records electronically. It does not address the situation of shared clinical records.

[12] An Insight into TPP Community Templates - The Rotherham Experience
http://www.primis.nhs.uk/pages/conference/2007Presentations.asp
Unfortunately I was unable to attend this session.

[13] Private communication. Practice has a patient with erroneous diagnosis of Diabetes Mellitus entered by Community, and there is no way of altering it.

[14] Personal communication

[15] This will apply especially to SystmOne practices: being a central database, patients are transferred to a new GP practice by changing the access permission to the patient record from one practice to the next: the prospect of true GP2GP – transfer of record from any system to any other system – appears remote as far as SystmOne is concerned.

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[i] Glossary

NME North Midlands East. The three NHS clusters previously known as North-West and West Midlands, North-East and East and East Midlands. There were three different contracts with two different LSPs originally – CSCA held the contract for North-West and West Midlands and Accenture for the other two. In 2006, Accenture withdrew, and its two contracts were awarded to CSCA.

LSP Local Service Provider: contracted under NPfIT to provide IT services to the NHS in an NHS cluster.

CSCA Computer Services Corporation Alliance. The consortium now holding the LSP contract for NME.

SystmOne. A GP system developed by TPP (The Phoenix Partnership) specifically as a single database, remotely hosted, and to be fully integrated with their Community and other modules including Drug and Mental Health services and others. SystmOne uses CTV3 – Read Code v 3 – which is different from the majority of other GP systems: most use Read Code v2 5 byte.

GPG. Good Practice Guidelines v3.1 2005. This is the updated version which includes the requirements of NPfIT and gives the standards for a practice to keep electronic patient records.