

Data quality and management issues in SSEPRs and other record sharing

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My submission for the John Perry Prize

- ⇒ Work on the problems – and patient safety issue – in SSEPRs (Single Shared Electronic Records) in UK Primary Care.
- ⇒ Action taken in pursuit of this.



Who I am and why I act the way I do!

- I blame James Read (and the CCC)!
- 1994, Read Code Conversion, 4->5byte
- Being rolled out nationally, all systems
- 14/2/1994, installed in my practice – disaster

- What I learned from experience
- Value of PHCSG
- Cassandra can't expect to be popular
- “If you want something done, do it yourself”
- If you've got access to strings, pull them!
- Don't expect to be kept informed



Clinical & Information Governance in SSEPRs

- Started at the PRIMIS+ conference October 2007
- Realised extent of problems by November
- Discussed at the EoE NPfIT event Nov. 2007
- EoE is in CSC LSP area and no apparent concern over difficulties being encountered in Rotherham & elsewhere.
- Submitted to NPSA as patient safety risk with request to be placed on IT Risk Register
- February 2008 CfH commissioned report on Shared Record Professional Guidance from RCGP (released 18th August 2009)



My reasons for concern

- ⇒ Detailed Care Records
 - Mandated by NCRS
 - Not clearly defined
 - Best definition “a single local record for every patient”
- ⇒ Only DCR planned including secondary care is Lorenzo Regional Care
- ⇒ Partial primary care solution: TPP/CSC SystemOne



What are the problems?

- In a SSEPR, considering the record itself
 - Who controls read and write access?
 - Who is the Data Controller – and what does this mean in a SSEPR?
 - Who can correct erroneous or evolving entries in:-
 - Their own organisation?
 - A different organisation?
 - An organisation which no longer has a Legitimate Relationship with the patient?
 - How is medication managed?
 - Who is responsible for the quality of the whole record?



Problems of Clinical Governance

- ⇒ In a SSEPR,
 - Who is responsible for the whole patient?
 - How is medication managed when prescribers are only trained in one aspect of care?
 - Independent prescribers are trained in one area only
 - Who is responsible when their prescribing affects areas outside their expertise or requires alteration of other medication?
 - Responsibility for on-going management
 - How is responsibility for action – or inaction – allocated and enforced?



Medical records – including EPRs

⇒ Why keep records in the first place?

- Aide memoir for managing patient
- Communication with other HCPs
- Medico-legal
- Management within unit/organisation
- Financial
- NHS management

⇒ Shared Records of Prime Entry

- Entire record available
- Record requirements may differ
- Is there Semantic interoperability?
- Management of:-
 - Record
 - Medication
 - Patient



Sharing records/data and sharing information

- Not the same thing
- Co-ordination of care needs more than records
- Patient personal health plans & Care Pathways.
- Medication – initiation and overall management
- Hand-overs
- Legal liability



Action taken

- Identify and elaborate problems
- Discussed conclusions and implications
- Brought to attention appropriate authorities
 - EoE CIO and CSC EoE representative
 - NPSA (National Patient Safety Agency)
- CfH commissioned report from RCGP on Shared Record Professional Guidance in March 2008
- Report released 18th August 2009



Meanwhile behind the headlines...

- Lot of discussion within PHCSG
- Brought to attention PCT and locally
- 3 CLICSIGs
- Article in HI Now
- Letter to editor Informatics in Primary Care (with response from John Parry of TPP)
- Comment article in EHI April 2008 (Does Lorenzo mean the end of UK GP EPRs?)
- Presentations at UKCHIP workshop & PHCSG conferences



Where are we now?

- ⇒ General agreement that there are problems with automatic sharing EPRs, both as SSEPRs and summaries
- ⇒ These problems as much organisational as records



Problems involving record include

- ⇒ “ownership” of record
- ⇒ Quality of data – and whether fit for purpose in a different organisation
- ⇒ Record keeping needs in different organisations
- ⇒ Alterations
- ⇒ Medication management
- ⇒ Who is 'Data Controller'?
- ⇒ Impact of record on other users



Organisational problems

- ⇒ Management of medication – and changing medication
- ⇒ Agreement on responsibilities
- ⇒ Overall management especially when co-morbidities
- ⇒ Legal accountability



Other issues...

- ⇒ Terminology and Coding
 - Do Terms & Codes exist for non-GP purposes?
 - What happened to the Clinical Terms project?
 - SNOMED-CT?
- ⇒ Presentation of information in different settings
- ⇒ Cross-UK countries & international communication
- ⇒ Patients, security & privacy



Discussion

- ⇒ I think we've come a long way, but with increasing provision of care in different settings,
- ⇒ What needs to be done *now* to prevent future problems?
- ⇒ Questions/discussion

