



Data re-entry overload: time for a paradigm shift in maternity IT?

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DECLARATIONS

Competing interests

RF has served on virtually all UK national maternity notes and IT projects in the last 30 years. From 1990–2001 he was reimbursed by Protos (now iSoft Evolution) for the use of his expert medical knowledge; he has had no commercial connection with them, or any other company, since 2001

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Summary

This paper provides an overview of maternity information technology (IT) in Britain, questioning the usability, effectiveness and cost efficiency of the current models of implementation of electronic maternity records. UK experience of hand-held paper obstetric notes and computerized records reveals fundamental problems in the relationship between the two complementary methods of recording maternity data. The assumption that paper records would inevitably be replaced by electronic substitutes has proven false; the rigidity of analysable electronic records has led to immense incompatibility problems. The flexibility of paper records has distinct advantages that have so far not been sufficiently acknowledged. It is suggested that continuing work is needed to encourage the standardization of electronic maternity records, via a new co-creative, co-development approach and continuing international electronic community debate.

Introduction

The complexities of healthcare data and information create a greater challenge for information technology (IT) than for any other sector.¹ Greenhalgh *et al.* have highlighted the need to challenge the current commercially-driven model of electronic patient records (EPR) with a call for an interdisciplinary debate,² and a recent report from the National Audit Office shows that an investment of billions of pounds has not produced the hoped-for benefits.³ This paper provides an overview of maternity IT in Britain over the past 50 years that may cast light on wider current problems with EPRs.

Since Hamilton introduced the 'Co-op' (co-operation) card in 1956^{4,5} it has been the

practice for expectant mothers in Britain to carry a hand-held paper record. Using the hand-held notes as the main record was initially encouraged by Morley in an African context in 1966.⁶ The 1987 Newbury study,⁷ together with pioneering work in Milton Keynes, the West Midlands^{8,9} and elsewhere,^{10–15} allowed women in Britain to retain their main record, with summaries held elsewhere. Endorsed by the 1989 Cumberlege Report,¹⁶ this is now standard British practice.

'Patient power' and informed choice provided a powerful impetus for a radical re-design of woman-held records,^{17–19} characterized by use of plain English (e.g. 'baby's heart' instead of 'FH' for fetal heart), with the original investigation results and, in most districts, full scan results filed therein.^{20–22} Many now include professional notes

Contributorship

RF initiated and leads the Electronic Encyclopaedia of Perinatal Data (EPPD) project; HP collated and structured the information for the website and carried out literature searches; SB, GC, HP and RF compiled the manuscript and prepared the manuscript for submission

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made during antenatal admissions. Newer versions, such as the National Pregnancy Record Project,²³ the Perinatal Centre Pregnancy Notes²⁴ and the Scottish Pregnancy Record,²⁵ include patient information, checklists, consent forms and much else. Their complexity has grown from the handbag-sized 'Green Notes'²⁶ to the current 75-page St Thomas' Hospital record.²⁷ Credit-style 'smart cards' have been suggested as a replacement for the hand-held record,^{28–31} but these are inaccessible without a compatible reader.³² Accessibility was also highlighted as a limitation of a recent Australian pilot project using personal digital assistant (PDA) devices.³³ Although there was a high satisfaction rate among participants in a recent Swiss trial of USB memory sticks, computer access remains a barrier to use.³⁴

Computer records are like rigid railways not flexible roads

Cost-effective maternity IT systems allow pregnancy data to be entered as a complex series of flow-patterned questions.³⁵ For example, the question 'Was there a labour?' if answered 'Yes', leads next to 'What was the time, and the date, of the start of labour?' whereas when answered 'No', this and many other questions are omitted. Such electronic records are like unique railways, with metal rails providing irreversible alternative routes, not like roads which allow flexible linkages at every junction. Currently, it seems that every authority with a budget has little idea of the long-term unaffordable cost of creating complex, independent systems and then attempting to link them at a later date: each having different track widths, buffer placements and platform heights; each using incompatible telephones, types of brake and traction. This has resulted in health managements everywhere spending millions of pounds installing commercially secret, incompatible and invisible systems. Even when an IT system comes from a single supplier, authorities refuse to purchase it without making local changes which themselves become practically confidential.

A further barrier to the evolution of working maternity IT systems has been a misplaced faith among too many health professionals in the concept of computers as magic.³⁶ Computer-based, electronic medical records are treated as if

useful data will automatically emerge, but all outputs totally depend on the precise wording of the input. Furthermore, the bigger picture of a nationally standardized, user- and system-friendly set of flow-patterned questions, agreed and designed by all those involved in delivering service, is not taken into account. Although these problems are increasingly recognized,^{37–40} proposals still persist for IT decisions to be made locally.⁴¹

Maternity IT in the UK

There have been three major attempts to apply the highest possible standards of traditional IT documentation to maternity care: the MUMMIES data modelling project (1988–1992),⁴² the Data Dictionary (1998–2001) and the National Maternity Services Dataset (2005–2007, 2009–current).⁴³ Analysis of these and several other initiatives by the authors⁴⁴ has led to the following observations: (a) these initiatives, and even official predictions,⁴⁵ usually assume a paperless future – but paper data (often expressed in nuances, stored in different places and on different pieces of paper) will continue to be crucial to the provision of good maternity care; (b) replacing such records by a single electronic 'master copy' is impractical and undesirable; (c) at some point, data will therefore continue to require transfer from flexible paper to rigid computers; (d) a universally acceptable electronic maternity data-set is too complex to be created by small groups of clinical advisors convening only intermittently; (e) clinical staff even in Britain and America can only access terminals and printers reliably connected to maternity computer systems in four places: ultrasound, delivery suite, maternity wards and special care baby units.

These expensive initiatives have acknowledged neither the negative conclusions of the most comprehensive analyses of the acceptability of electronic records in maternity care^{46,47} nor the difficult problems involved in writing maternity software.⁴⁸ In the words of an industry insider, 'We are trying to run an enormous programme with the techniques that we are familiar with for running small projects. It isn't working. And it isn't going to work.'⁴⁹

Calculating the cost of electronic data entry

To quote a midwife involved, 'I spend most of the appointment with my back to the mother, while I enter data into a black hole', and an obstetric registrar, 'I spend less and less time with my patients and more and more time entering data'. Despite early hopes,⁵⁰ there has been minimal progress over the past 30 years towards using electronic decision support to improve the quality of patient care and reduce the risk of human errors.^{51–53}

Using a simplified cost calculation, if, for example, the 'number of scans performed in pregnancy' must be entered for every mother, at about 10 seconds per record, multiplied by 700,000 annual UK births and assuming midwifery pay and overheads at about £20 per hour, then the cost of entering data of no value for individual care will be over 2000 hours of midwife time and will cost over £40,000 annually. The cost of each question may not seem excessive, but when multiplied by hundreds more, purely for retrospective analysis, it becomes clear that limited funds would be better spent on front-line, hands-on care.

Electronic records were envisioned to have many benefits (Table 1) and 'paperless' offices may eventually have advantages, but only for staff logged on in one place for most of the time. Electronic records are impractical for shared care because they need to be reliably accessed by so many different people working in so many different places. Even the iPad fails to meet the unavoidable requirements listed in Table 2.

Need for a fresh start and new framework: the Electronic Encyclopaedia of Perinatal Data (EEPD) as exemplar

A radically different long-term approach to the problems of maternity IT is proposed via the Electronic Encyclopaedia of Perinatal Data (EEPD) website (<http://eepd.info>), which provides a wealth of material, including a repository of maternity and neonatal data-sets used throughout the UK and links to current debates on electronic health records and other relevant resources. It is being developed as an open forum for people to

Table 1

Potential advantages of electronic records

- 1 More reliable collection, selection and distribution of data
- 2 Faster transmission of electronic version of traditional letters and reports
- 3 Potential for the reduction of medical errors through cross-checking, warnings and suggestions
- 4 Potential access anywhere, at any time, to individual patient data
- 5 Legible records
- 6 Better data-sharing with reduced duplication in the recording of data
- 7 Potentially electronically translatable into other languages
- 8 Better quality and quantity of collective data
- 9 Potential for instant off-site backup

share their experience, co-create and co-develop, and thus shape, the future of electronic maternity healthcare records.

Since 1979, RF has created electronic versions of over 100 maternity and neonatal data-sets.⁵⁴ Having rearranged each data-set logically and chronologically,⁵⁵ it became possible to combine them into a single resource document.⁵⁶ It then became clear that if all the proposals and the many answer options of every stakeholder were to be accepted, the data entry workload would cripple any maternity service. Even if women with Internet access were willing to enter much of the data themselves^{57–60} this would not overcome the basic 'quantity of data' problem. Some universal method for prioritization is essential.

'Essential for individual care' or 'Only for analysis'

We propose that every definable item of medical data be categorized as set out in Table 3. This novel classification broadly separates 'individual care' ('above the line') from 'only for analysis' ('below the line'). Table 4 shows how 'above the line' and 'below the line' items have significantly different characteristics. 'Below the line' fields should be flexible and be able to be customized by individual maternity units to collect their own data specific for their needs.

Table 2**When can shared care records become entirely 'paperless'?***A. When electronic records (like paper) are:*

- 1 As secure as a paper document only held by the patient, and/or by her health centre or hospital with all other versions personally unidentifiable
- 2 Hand-held and not connected by any wiring, but never subject to flat batteries or power cuts
- 3 Easily readable anywhere by any authorized person (especially the expectant mother herself)
- 4 Able to accept free text as easily as using a pen (e.g. an adequate keyboard, or reliable voice or handwriting recognition)
- 5 Portable but theft-proof (or not worth stealing)
- 6 Open source – not tied to any specific commercial enterprise
- 7 Crash proof – guaranteed never to be 'network down'
- 8 Virus proof
- 9 Amendable anywhere and at any time by any authorized person using a technique at least as easy, universal and visible as a pen
- 10 Able to highlight vital information as easily as circling or using a red pen
- 11 Easily accessible – without constantly changing, multiple, forgettable passwords
- 12 As cheap, flexible and easily revised as paper (unless management is prepared to fund the far greater expense of a fully functioning electronic system)
- 13 Important entries on previous pages can be as quickly and easily noted
- 14 Never deletable in seconds by human error
- 15 As easy to jot down a series of events without losing the place (e.g. time of decision, arrival in theatre, start of anaesthetic, etc.)
- 16 When it is possible for the complete record to be photocopied and the copy to be securely transferred anywhere it may be required
- 17 Usable without compulsory time-consuming fresh training at each new hospital or health centre
- 18 When complex maternity software can be radically revised as cheaply, frequently and easily as the revision of any hand-held record
- 19 When the evidence base is sufficient to justify the far greater cost of installing and regularly re-writing complex software

B. When chronologically arranged, flow-patterned questions and all allowable answer options:

- 1 Are internationally standardized
- 2 Take adequate account of all interested parties
- 3 Are workload/cost classified and logically prioritized

Time spent on unjustifiable data entry will always erode the time available for the care of individual women. Imagine trying to document without paper the management of a massive haemorrhage while it is happening. But if we accept that paper still has a place in modern medicine, much information can be classified as neither required electronically for individual care nor for routine analysis; the paper record alone being sufficient, especially when documenting a fast-changing event such as in an obstetric emergency.

Not only does every extra keystroke cost but every electronic data item unnecessarily re-entered on paper also costs. Front-line workloads can be reduced by providing a supply of individualized incomplete proformas for later completion by hand, e.g. for postmortem request

or handover to primary care. More use could also be made of computer-generated sticky labels for child health records or the 'special features' areas of the hand-held record.

Once nationally (and internationally) standardized, 'above the line' items will greatly increase the quantity and the accuracy of data for audit, research and management without any extra cost or workload. Using only 'above the line' items, the authors have created a draft 'logical priority' set of flow-patterned standard questions and all allowable answer options.⁶¹ It is suggested that in future all annual statistical reports should be based on an analysis of 'above the line' data items because these data items will generate increasing quantities of workload-aware, reliable and cost-free information.

Table 3**Proposed classification for all electronic health data items ('every extra keystroke costs')***Data entry workload/Cost categories**

<i>A. Priority to 'individual care' items – mainly individual patient encounter assistance</i>	
<i>'Above the line' – once standardized, these items provide a massive quantity of accurate national data for management, without any increase in workload</i>	
1 Downloaded from Patient Administration System	Time and cost free
2 Anything previously copied paper to paper; but now – wherever reliable computer access exists – can just as easily be copied from paper to electronic	Cost neutral
3 Extra cost/workload: but better quality care. The workload and cost must be calculated for each proposal	Extra work but worth it?
4 Electronic transfer from existing computer systems [†]	Time and cost free
5 Electronic transfer to another computer system [‡]	Extra work but worth it?
6 Computer-generated; based on A1–5	No extra work
<i>B. 'Only for analysis' items. Data collected on the computer for management, audit, workload forecasting, research, governance, and critical incident requirements</i>	
<i>'Below the line' items all potentially cause 'paralysis by analysis'</i>	
1 Retrospective analysis only	Always extra work
2 Critical incident/Clinical Standards reporting	Extra work but worth it?
3 Computer-generated – based on B1 and B2	Based on extra work
<i>C. Never electronic</i>	
1 Paper record enough	No extra work
2 Not appropriate for paper or EPR collection	No extra work

*Classification of data items in any maternity computer system will also depend on the limited places where there is always reliable access to electronic records and printers

[†]e.g. Rubella results from pathology to maternity system

[‡]e.g. Entering data at booking about deafness, blindness or the need for a translator is only useful for retrospective analysis, unless it is automatically electronically transferred to the hospital appointments system

Paradigm shift

The value of utilizing the 'wisdom of the crowd' is increasingly recognized in business and the pharmaceutical industry;⁶² failure to engage with it is potentially detrimental to a company's long-term viability.⁶³ It has long been accepted that, whereas the health professional is the expert in diagnosing and offering help and support in managing a condition, the patient is the expert in living with the condition.^{64,65} Although medicine is waking up to using co-production⁶⁶ and social networking to listen to the 'wisdom of the patient', in medical IT systems the collective voice of front-line healthcare staff has only been heard, if at all, via consultation groups of a small number of experts rather than via the wisdom of all those delivering the service who wish to engage in the project.

We propose a Web 2.0⁶⁷ Wikinomics⁶⁸ approach to help nudge users, purchasers and software companies towards agreement on the wording of each core question and all allowable answer options. This will allow increasing interoperability between IT systems and also result in an IT system that is user friendly and appropriate in its data collection. Electronic maternity data could then be used primarily to improve the quality of care for individual mothers and babies, rather than predominantly for retrospective analysis.

Discussion and conclusions

Information technology is much more than mere electronic data. It must always also include improvements in the quality of paper records

Table 4**Key differences between 'individual care' ('above the line') and 'only for analysis' ('below the line') items****A. 'Individual care' ('above the line') items**

Entered on computer primarily for individual care

- 1 More likely to be reliable because the quality of care given to individual patients depends on accurate data entry. Patients, clinicians and colleagues will rightly complain if this is threatened by inaccurate data entry
- 2 If worthwhile for any one patient it will be worthwhile for every patient
- 3 Tendency for core questions to slowly converge
- 4 Likely to be permanently valid
- 5 Once standardized accurate and plentiful workload-free data for analysis

B. 'Only for analysis' ('below the line') items

Data collected electronically purely for audit, management, workload forecasting, research and governance

- I More likely to be unreliable (at 2am who cares 'how many scans?', 'What time did the patient get to theatre?')
- II Samples sufficient (e.g. 1 in 10, or 1 month/year, etc.)
- III Infinite number of potential questions
- IV Hence likely to be many different definitions
- V Unwittingly burdensome current managerial and political priorities

(whether case-notes, pro formas, printouts or information leaflets), accepting that if computers had been invented first, paper and pen might have been considered the greatest IT breakthrough since the dawn of civilization. Complex electronic patient data-sets will only attain their potential when their core questions and the full range of all allowable answer-options are internationally standardized. Without this, clinicians will increasingly be overburdened with data re-entry (e.g. inputting the same operation details separately into maternity, anaesthetic and theatre systems) and managers will continue to believe it feasible for software to be re-written for each new project and site. Such question-by-question documentation requires intense, open, web-based discussions, editable online by interested clinicians with simple word-processing skills and making use of the wisdom of all interested parties.^{69,70} This undertaking will be more complex than the classification of organisms, diseases or operations because, unlike traditional clinical coding, it requires the precise flow-patterning of every question. There is not a choice between 'free text' versus 'coded data' systems;⁷¹ instead, it is necessary to strike the correct balance between the two in a hybrid approach, with relevant codes suggested to the coding clerks wherever appropriate.

Such specifications:

- need to be developed separately in each specialty and subspecialty;
- can only be created by healthcare staff fully aware of the limitations of computers, rather than by IT professionals, as only clinicians can untangle the best wording and most efficient flow-pattern;
- cannot be imposed top-down by Hospital Boards, State or Federal bodies, professional organizations or National Health Service management, nor be modified independently in each locality;
- need the cooperative Internet effort of all interested parties;
- will only become universally standardized if openly available and copyright-free;
- must distinguish between data: (a) transferred from other IT systems, (b) recorded electronically by clinicians as part of individual care, and (c) collected purely for secondary purposes (billing, management, research, retrospective audit);
- will provide abundant, accurate data for analysis without any extra workload; but only when individual care data are paramount and electronically standardized.

Successful information technology requires a commitment to networked thinking which is not only

regional but also national and international in its scope. We agree with Hovenga *et al.*⁷² in this global appeal and would urge international medical societies in their respective specialties to lead on achieving these objectives. We concur with the conclusions of Bleich and Slack that ‘the key to enthusiastic acceptance [of IT] is computing that is easy to use and helpful to doctors, nurses, and other clinicians in the care of their patients’.⁷³ In addition, we argue that the IT systems must not be built on the old hierarchical models but rather on a bottom-up approach.

Enterprises such as the EEPD project have the potential to improve the quality both of electronic and of paper records and are exemplars of possible conduits for achieving international standardizations. The advantages of such an approach have been implicit in the text; however, the disadvantages are not so well rehearsed as to eliminate any unexpected emergent properties that may arise when communities work together. This is where webscience⁷⁴ comes into its own. It is the authors’ vision that in utilizing the Internet and the wisdom of the crowd, the aphorism ‘the whole is greater than the sum of the parts’ will overcome the current problems in delivering an electronic maternity health record and lead to genuine improvements in patient outcomes.

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