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Refereed papers

The challenge of electronic health records (EHRs) design and implementation: responses of health workers to drawing a 'big and rich picture' of a future EHR programme using animated tools

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ABSTRACT

Background and aim To investigate the use of animation tools to aid visualisation of problems for discussion within focus groups, in the context of healthcare workers discussing electronic health records (EHRs).

Method Ten healthcare staff focus groups, held in a range of organisational contexts. Each focus group was in four stages: baseline discussion, animator presentation, post-animator discussion and questionnaire. Audio recordings of the focus groups were transcribed and coded and the emergent analytic themes analysed for issues relating to EHR design and implementation. The data allowed a comparison of baseline and post-animator discussion.

Results The animator facilitated discussion about EHR issues and these were thematically coded as: Workload; Sharing Information; Access to Information; Record Content; Confidentiality; Patient Consent; and Implementation.

Conclusion We illustrate that use of the animator in focus groups is one means to raise understanding about a proposed EHR development. The animator provided a visual 'probe' to support a more proactive and discursive localised approach to end-user concerns, which could be part of an effective stakeholder engagement and communication strategy crucial in any EHR or health informatics implementation programme. The results of the focus groups were to raise salient issues and concerns, many of which anticipated those that have emerged in the current NHS Connecting for Health Care Records programme in England. Potentially, animator-type technologies may facilitate the user ownership which other forms of dissemination appear to be failing to achieve.

Keywords: electronic health records, healthcare technology design, user involvement.

Introduction

This paper describes the deployment of a prototype demonstration tool aimed at facilitating users' engagement with the design, development and implementation of EHRs. It is not a prototype of an EHR system; rather it is aimed at engaging potential users at

the conceptualisation stage; it aims to tap into members' knowledge that will be useful throughout the design, development and implementation process. Neither is it intended to replace the use of prototype systems and other user engagement techniques; it is rather an addition to these tools and one aimed at organisations with large populations of potential users, such as the NHS.

What is significant about this tool is that it was developed with recognition that successful existing health technologies are, and need to be, interwoven into the ongoing social creation and maintenance of health care, and must support these formal and informal processes: 1-8 overlooking informal processes can have significant implications for work practices and organisational relations, and can lead to subsequent misuse and rejection of electronic patient record (EPR) systems. 6,9-11 Findings from medical records research have shown that there is a need for users to have an opportunity to adopt the EPR and influence its development. 12-14 A key issue is eliciting user involvement across a range of stakeholders, the absence of which has been identified as a cause of system failure in the past. 15-17 There has been a call for technical solutions to facilitate user engagement and empowerment:¹⁸ there is some evidence that this is being attempted for patients, but there is a need for this to be extended to all healthcare professionals and technical staff (including system suppliers) as well. 19

International visions and national contexts

Electronic health records are widely regarded by national governments as the means by which medical work and care delivery can be supported and organised between the variety of organisations and stakeholder groups in healthcare systems.^{20,21} But EHRs face a multitude of challenges previously identified in work on electronic records and health information system research and evaluation studies, as well as the challenge of functioning across contexts.^{5,22–25}

In spite of relatively limited success in implementation at the time of writing, there are significant attempts underway in a number of countries – Denmark, Australia, the USA and Canada – to design and implement various versions of EHRs. ^{9,26–29} Within the UK alone there are separate programmes of work underway in Scotland, Northern Ireland, Wales and England. This paper reports on one part of an EHR demonstrator project which was part of the English Electronic Record Development and Implementation Programme (ERDIP) commissioned by the NHS Information Authority (NHSIA), the forerunner of the current English National Programme for IT. ^{30,31}

The momentum for these initiatives was established by *Information for Health* (1988), which was published by the NHS as a framework for the development of information services for the NHS.³² The aim of the

programme was to promote in-service development and demonstration of best practice and progress towards shared electronic health records '... informing the development of policy and the national implementation programme, and most importantly, helping the wider NHS in its local implementation of electronic records'. ³⁰

National programmes and local developments

The Durham and Darlington EHR (DuDEHR) project was not solely concerned with specific technological possibilities. Its guiding principle was that the EHR must also be informed by the wider practical realities of health and care processes.³⁰ The project employed a range of methods, from architectural modelling to ethnography, to create a 'big and rich picture' of the potential implications of a widespread shared electronic records deployment. These supported the construction of a range of products to elicit users' opinions pre-implementation, rather than post-implementation, and so potentially inform the detailed design and deployment of the then mooted national/ regional EHR programme.³³ This paper reports on one of them: an animated vision (provided by the non-technical animator) of an EHR, henceforth referred to as 'the animator' (described in greater detail in Appendix 1).

Method

In order to address the issue of stakeholder engagement, the project decided to develop a range of tools to facilitate this work. 'Prototypes' and 'probes' are widelyused techniques in market research and increasingly in social research. 34,35 It was therefore thought that the animator could be used in focus groups primarily to elicit potentially useful information for the implementation of EHR. The animator is a tool which through an audiovisual storyboard of four linked scenarios tells the story of an individual patient, Mr Jones. Each scenario uses a mixture of scripted dialogue between the patient and healthcare professional, illustrating from a human perspective the messaging architecture of a potential EHR-envisioned future (see Appendix 1). The scope of the discussions in the focus groups was not confined to the vision presented, but was aimed at stimulating a more informed and creative critique of an EHR future.36

Data collection

In all there were ten healthcare staff focus groups, held in a range of organisational contexts, five in secondary care, three in primary care, one in NHS Direct (the national 24/7 health call centre) and one in an ambulance service. The groups were formed using an open invitation in the healthcare professionals' own workplaces; sessions lasted approximately an hour. Each focus group comprised between seven and 12 participants; they were made up of a range of health professionals, including doctors, nurses and secretaries. They stimulated discussion and debate both before and after the animator presentation (see Appendix 1).

Each focus group had four stages:

- Baseline/pre-animator discussion What participants understood by shared electronic records: an open discussion with the focus group participants of what an EHR was likely to be was undertaken, including what issues they perceived to surround its form, introduction and development. The time taken for this varied from group to group varying between five and 15 minutes.
- Presentation Watching the non-technical animator presentation: a 15–20-minute presentation of the animator in operation was shown to the assembled focus group. This was a 'push and play' preformatted programme designed to illustrate and provoke discussion of the issues surrounding the development of EHRs.
- Post-animator discussion Discussion about the issues of shared electronic records in light of the presentation: a post-presentation discussion of the animator including aspects of the presentation and its depiction (accurate or otherwise) of the health-care scenario, the role of EHR and the views of the focus group upon this. The animator was designed to raise issues, but also allowed the focus groups to develop the discussion with relevance to their own knowledge and experience.
- **Short evaluation questionnaire** This was a short questionnaire of four evaluation questions with an 'Additional comments' box, the results of which are reported elsewhere.³⁷

The role of the focus group facilitator (KNJ) was to promote group discussion among the group; focus group discussions were recorded, then transcribed verbatim. It is in the nature of focus groups that opinions are the result of the group dynamic rather than specific individuals. ^{34,38–40} In light of this we have reported our findings in terms of healthcare sector rather than the specifics of individuals constituting the separate focus groups.

Analytical framework

A coding frame was drawn up and then applied to all the focus group transcripts. ⁴¹ The analysis of the transcribed audiotapes was supported by the qualitative computer analysis package NVivo version 1.3, allowing the systematic retrieval of themes from across the transcripts of all the focus groups. It is standard practice to illustrate topics raised by focus groups with quotations without making other than general claims to consensus, and this is the approach we have adopted here.

Results

The analysis of the data within the transcripts produced a number of themes. The analysis is presented in two parts: baseline and post-intervention. The majority of data were produced in response to the animator in the post-intervention sessions.

Baseline

Few focus group members had any awareness about NHS plans for an EHR, with NHS Direct appearing the most knowledgeable and primary care the least.

'... other than what I have heard from you in the packs of what we're doing, I haven't heard anything from any other sources outside, I can't even recall reading any articles or anything like that to be honest.' (Focus Group 5)

NHS Direct had a clear view of what they wanted an EHR to be while the ambulance service expressed needs rather than perceived solutions. The baseline discussion stimulated some initial reflections, although minimal, on what an EHR could be; for example, primary care members thought patients could have greater ownership of their health records.

Secondary care members had views similar to those from primary care, but additionally thought an EHR could have care pathways within it, potentially entailing increased access to terminals or mobile devices. NHS Direct focus group members raised initial issues that other focus groups raised after only having viewed the animator (such as long-term benefits of shared records).

Post-intervention

The animator produced significant discussion about EHR issues and these were thematically coded as: Workload; Sharing Information; Access to Information;

Record Content; Confidentiality; Patient Consent; and Implementation. These themes are summarised in the sections below.

Workload

Participants were quick to recognise that the implementation of EHR could have significant effects on workload, both positive and negative.

'It's going to impact on the secretaries' workload, it's not going to impact on the GP and consultants because I'll tell you the consultants at the hospital wouldn't put the data in, somebody would be taking it off and putting it on and writing it down for the consultants to read or printing out, they certainly wouldn't have anything much to do with it ... but yeah, I think that the GPs would be very much the same.' (Focus Group 2)

They envisaged that the electronic sharing of information could have the effect of significantly reducing duplication of work: stating that considerable amounts of computer-based information were currently shared by being printed onto paper and sent to other organisations via hand, post or fax. This often led to data being re-keyed or re-entered into the receiving organisation's information system (for example, in the context of primary care discharge, re-keying or scanning of letters and hospital prescriptions from secondary care).

It was also thought that the EHR could have the effect of reducing repetition for patients who were perceived to dislike having to retell their case histories. A further advantage was seen to be that records would contain more complete information.

On the downside it was seen that EHRs could create a range of new recording and data collection tasks for clinicians (potentially) and administrative staff (certainly), including consent and records management in particular. This could lead to significant implications for the redesignation of work within organisations. Participants expressed scepticism about whether NHS organisations were willing, or able, to address such issues as the training needs of staff. The potential presence of more complete records led clinicians to observe that they would need more time to assimilate and collect information.

Sharing information

Sharing information was seen to be at the core of the FHR

'I think very few people would quibble if it's the local hospital, if it's NHS Direct, if it's the district nurses; once you start saying "Well of course, you know this will be available to social services, and that will be available to, you know, other agencies" then that's when you might run into serious problems.' (Focus Group 4)

More information sharing between NHS organisations (such as between primary and secondary care) was seen as a positive development. The group members drew upon various experiences of information sharing, for instance out-of-hours GP services, and thought that major improvements could be made. New information sharing within the boundaries of the NHS was seen as being unproblematic, with NHS Direct group members being particularly able to envision EHRs facilitating developments that were already underway.

Participants expressed concerns about sharing information beyond the boundaries of the NHS. It was universally recognised that information sharing and communication with social services tended to be inadequate and that this had significant impacts on the care of individual patients. Despite the need to support the continuum of care, group members still felt that sharing information beyond the NHS was problematic (for example, concerns were expressed about implications for individuals' welfare benefits). Concerns were: how this would be done, by whom and with what accountability. It was also thought that patients could perceive risks in information sharing beyond the NHS and withdraw their consent to share.

Access to information

The sharing of information, it was noted, implies the practical access to records involving the issue of whom, where and when.

'Yes, certainly potentially and we are now in a situation where we try to delegate a lot more data entry so that it gets done, obviously within a finite time, which means that people do have to have access to potentially sensitive information.' (Focus Group 2)

These practical tasks were a major topic for discussion in the groups and the overall consensus was that these issues were complex in relation to the structure of the NHS with its overlapping boundaries and responsibilities. The dimensions of this perceived complexity were the relationships between technical feasibility, organisational practicality, legality and ethical acceptability.

Part of the story in the animator touched upon the patient being able to access his record. The implications of this stimulated a series of wide-ranging discussions within the groups. If patients could routinely access the EHR, could they become the gatekeeper for access to their records rather than the NHS? If so, at what locations could patients have access? Health service sites such as GP practices and pharmacies would seem obvious, but what about public places like supermarkets or libraries? If access was at the patient's home, would confidentiality from other family members be practicable, especially teenagers

from parents in the case of contraception? What effect could denial of access have to the current working practices of the service? Who would organise, administer and police such detailed access rights? In summary, the issue of access to information generated more questions than answers.

Record content

In close parallel to issues of accessing records was the issue of EHR content; there was a perception that defining record content for use in specific instances in a systematic way was in itself problematic.

'I suppose it depends what information they're going to get, doesn't it, you know if it was, if they just got basics, but then again, what's the basics?' (Focus Group 1)

A number of positive aspects were raised, particularly around the potential to increase the quality and the provenance (particularly the contemporaneousness) of the information.

One of the themes of the story in the animator was the use of a Department of Health National Service Framework (a series of national policy documents specific to conditions or cohorts, outlining standards of good practice) to structure aspects of the record. Overall this was received positively but there were concerns about oversimplification, especially for patients with multiple conditions. Additionally, while the role of national guidance structuring EHRs was seen positively by some, it was felt that there could also be good clinical reasons for not following guidance, and that an EHR would need to support such treatment. The use of national guidance approaches again highlighted the multi-agency nature of care and that information would need to pass through the boundary of the NHS.

EHR content was seen as needing a balance between too much, or too little, information in order to be viable. These sorts of discussions demonstrated a broad awareness of the diversity of information needs of personnel and their activities. Finally, there was no aspect of record content that could not, in some scenario or other, be envisioned as sensitive by participants. It was felt that superficially innocuous information, such as if a patient lived alone, could become sensitive if made more widely accessible via EHR and not restricted to one location.

Confidentiality

On the whole the respondents were particularly sensitive to issues of confidentiality.

'I mean this day and age you can't always have say a staff nurse who has the authority to go and look for something, you have to rely on other people to do that work like the ward clerks, I think that should still be open because I mean anything could have a bearing on the patient's care but I mean we are all bound by confidentiality anyway [sure, sure, yeah] ...' (Focus Group 3)

Discussion of confidentiality displayed a widely-held perception that not only were patients increasingly protective of their confidentiality rights, but that they had concerns regarding outside agencies and reported their health issues accordingly. One concern expressed was that EHRs could lead to increases in non-disclosure of illnesses; another, that some patients, especially older ones, might give their consent too readily based upon a misapprehension of who has access to records and thus failing to achieve 'informed' consent.

In general it was felt that there were legal issues that needed to be addressed regarding the transfer of patient information, with different data fields needing different confidentiality status. However, it was believed that appropriate security and audit trails could technically address the potential problems noted above, and that this could in part ensure confidentiality particularly if reinforced by professional sanctions for abuse.

Patient consent

What emerged as a key discussion area was what sort of consent would be needed: for instance, would a general 'opt-out' of consent be acceptable, or at the opposite end of the scale, should the consent model be based on an 'opt-in' so that patients have to explicitly consent to each data transfer/collection? Particularly problematic was the likely initial requirement, and potentially ongoing requirement, to obtain 'patient consent'.

Consent was seen as further complicated by contextual issues such as patients not wishing to be identified and/or giving false identities at the outset; also unconscious or psychologically unfit patients might be unidentifiable or be unable to consent. On the other hand non-consent also had implications for the safety of NHS staff, especially in the context of mental health care.

'... he says "Oh I don't mind them knowing that" but I mean if it's something ... he might be a drug addict [hmm], he doesn't want it put on, if he refuses and had the right not to have it on his but he is putting other people at risk then [yeah] you know with needlestick injury etc., etc. [yeah] so I think he should have no choice about what goes on his medical history ...' (Focus Group 3)

Workload and resources were key issues; it was felt that primary care trusts and general practices would bear the brunt of these resource and cost implications.

Implementation

There was some scepticism regarding the NHS's ability to implement EHR. There appeared to be a

corporate memory of the promise of systems in the past which were subsequently delayed or cancelled. However, there was an awareness that negative attitudes prior to system implementation could be followed by a positive change of attitude in the postimplementation period. There were also concerns about system failures and of relying solely upon computer technology.

This raised further questions about needing a paperbased backup and the implications this would have on workload and work practice.

'I don't think it will ever replace the paper probably, not that they ever can, I mean there is so much written down ... we will always have to have a backup system anyway.' (Focus Group 6)

While the uniform availability of a unique identifier (the NHS number) was seen as a positive development, the implication taken from the animator of a homogeneous system left some expressing concerns about their freedom to practise and ability to amend erroneous data.

Discussion

Since the ERDIP programme reached its conclusion in 2002, there have been rapid developments in the implementation of large ICT programmes in health care in England and elsewhere. The overall aims of these programmes are the long-term delivery of EHR systems. The issue of user involvement in the design and implementation of healthcare information systems has been of increasing concern for such programmes. This paper has outlined an approach and reported detailed responses of stakeholders to a potential vision of an EHR.

This paper supports previous evidence that indicates the majority of health workers are able to participate in informed debates about EHR given an opportunity.^{23,33} Yet meaningful engagement requires having a 'big and rich picture' of how such programmes could change clinical, administrative, technical and organisational practices and policies. 23,25 Without at least some informed knowledge about the potentially transformational aspects of an EHR it is difficult to see how users can be positively engaged to take full advantage of the significant investments being made, nor how those charged with implementation can make informed decisions about the local requirements of deployment which could lead to the transformation being realised. Currently we observe that the NHS Connecting for Health (NHS CfH) implementation programme (which is structured in five large cross health organisation 'clusters' which cover

the whole of England and over 850 000 NHS staff), the national level Care Record Development Board (CRDB) and the Local Service Providers (LSPs) responsible for the delivery of the systems appear to lack appropriately structured localised opportunities to debate these issues in an informed manner with colleagues, managers and those responsible for local implementations. ^{23,31}

This paper has illustrated that use of the animator is one means to raise understanding about a proposed EHR development, the potential for understanding and potentially preparation for transformational changes. In the discussions following the viewing of the material there was a significant change from the initial baseline discussion to that following a viewing of the animator in terms of the volume, breadth and relative detail of the discussions. For example, the potential for information sharing became much more apparent to the groups, which in turn led to debates about the content of records, confidentiality and patient consent. It is arguable as to whether the groups would have been able to generate such relatively elaborate discussions without the intervention of an animator to stimulate a platform of shared understanding about what was possible in terms of EHRs.

Seven themes emerged from the focus groups' discussions: workload; sharing information; access to information; record content; confidentiality; patient consent; and implementation. Using an animator we were able to get respondents to discuss their concerns and other relevant issues in their own terms without (or at least to a lesser degree) alienating them from their own working practices and understanding of their everyday experiences. Using the animator as a stimulus in focus groups we tapped into the lay understanding of users, grounded the themes from their comments, and began to see how these themes fitted into the more abstract discourses surrounding the policy and technical discourses around EHR.

Conclusions

Currently in England, the means by which large healthcare ICT programmes are currently endeavouring to elicit healthcare professionals' involvement appear inappropriately centralised and focused on clinical staff and/or the opinions of those most interested in the area of health information systems, rather than a wider representative sample of healthcare workers. I Expert users' involvement, be they health workers, informaticians or patients, however warranted their observations on the new system, are not necessarily effective substitutes for ongoing engagement with the wider community. Eliciting involvement

from the wider community can be problematic, not necessarily because of a lack of interest, but often because of a lack of basic knowledge about specific programmes of work and/or opportunities to debate the issues in an informed and participative way.

Using the animator in our focus groups afforded an opportunity to inform the healthcare community that an EHR was being seriously contemplated, and that it would affect organisational and work practices. The animator aimed to be a tool which both briefed the audience and instigated a more informed discussion in the focus groups about the possible introduction of an EHR – in this it succeeded. It is open to question whether other user engagement techniques might have been equally successful, but as a 'push and play' system it would appear applicable to the broad requirements of a large healthcare organisation such as the NHS.

The main advantage that the animator has over prototype-based approaches is that it supports the investigation of members' knowledge of their work practices and organisational knowledge prior to the specification/deployment of hardware and design/ configuration of software. It raises potential issues that need to be considered in a holistic view of design, development and implementation in the context of service development and transformation. It also allows the focus group to be facilitated in order to gather responses from what has been demonstrated in an animator presentation (through a series of scenarios which build a 'big and rich' picture) rather than explaining (or 'selling') a particular technical prototype (which necessarily concentrates on the technical/ process aspects of a system).

For users' concerns to be heard, healthcare professionals and other stakeholders have to be provoked to formulate opinions and given an occasion to voice them. The animator provided a 'probe' to support a more proactive and discursive localised approach, supporting a sense of ownership, which could be part of an effective health worker and wider stakeholder engagement and communication strategy crucial in the implementation of any health innovation programme.³⁵ If such a strategy is successful then the design and development process moves from a merely technical discussion of functionality to the social and organisational implications of healthcare innovation in local contexts, keeping the policy maker and technical expert grounded in the practical concerns and practices of those charged with doing the job of health care. The technique piloted in this project using focus groups supported by an animator could, we suggest, be one way of supporting such strategies.

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CONFLICTS OF INTEREST

None.

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Appendix 1

The 'animator' storyboard: a brief description of a 'big and rich' picture

The animator tells the audiovisual story of an individual, Mr Jones, through four linked scenarios. Each scenario is presented using a mixture of scripted dialogue between the 'actors', a representation of the activity of the various agents and health services and a technical animation of the messaging architecture which shows the processing/exchange of information between the organisations involved.

The first scenario is when Mr Jones phones NHS Direct from home complaining of chest pains. The story tells how he undergoes triage by NHS Direct, and how this is facilitated by Mr Jones having an EHR that can be accessed by the health call centre nurse. The animator illustrates the type of information that would be potentially available through these records and how it is used, not only for triage, but also to transfer patient details to the ambulance crew which the triage nurse has sent to the patient's home.

The second scenario shows the ambulance crew with access to Mr Jones' patient information: information tailored to the requirements of the ambulance crew.

A third scenario follows where the ambulance crew have notified the hospital accident and emergency (A&E) department of their intended arrival and through the EHR have transferred patient details and current treatment details: this has also allowed for the printing of A&E documentation necessary for the care of the patient. The ambulance is then shown arriving at the hospital where the patient is signed over to A&E care.

The final scenario goes back in time six months to a GP consultation where Mr Jones is diagnosed with heart disease and asked if he would like to have his details on an EHR which, it is explained to him, would allow his medical details to be available to various healthcare professionals should they require them.

Focus group participants are encouraged to discuss what they have seen and also to imagine how a similar EHR facility could impact upon their work and what the potential issues surrounding such a facility could be.

