Health Informatics for Paediatric Ophthalmology
Designing Useful, Usable Information Systems

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1 RESEARCH PROBLEM

Electronic medical records (EMRs) are at the core of a recent movement towards evidence-based healthcare in many countries (European Commision 2012, Bluemnthal 2010). In the United Kingdom, there is a target to have a paperless National Health Service (NHS) by 2020 (NHS England 2014). The uptake of EMRs in ophthalmology, however, has been found to lag behind other medical specialties (Chiang *et al.* 2008, Boland *et al.* 2013).

Chiang *et al.* described the features of general ophthalmology that impose unique EMR design requirements and challenge adoption within the field (2011). These include the high throughput nature of routine care, and a heavy reliance on imaging and graphical representation of findings (Chiang *et al.* 2011). As a subspecialty, paediatric ophthalmology is anticipated to encounter these in addition to specific difficulties that reflect its interface with paediatrics and child health (Redd *et al.* 2014).

To facilitate EMR adoption, many have proposed the implementation of a user-centred design (UCD) approach to health information technology development (Texeira, Ferreira and Santos 2012, Martikainen *et al.* 2010). In the United States, all certified EMRs are now required to have been developed following a UCD approach and undergone usability testing (US Department of Health and Human Services 2014). In UCD, the needs of the user and the use environment drive the development of the system (International Organisation for Standardisation 2010). For health information technology, this requires an understanding of clinical information flows and how patient consultations are conducted and documented within medical records. Recent research suggests there are particular challenges in participant recruitment and the conduct of sufficiently in depth research into clinical workflows to support the UCD of EMR development (Ratwani *et al.* 2015). A paucity of literature exploring information flows within NHS paediatric ophthalmology means the application of UCD to EMR development will be particularly challenging for this context of use.

2 OUTLINE OF OBJECTIVES

Broadly, this doctoral research applies and evaluates a user-centred approach to health information technology development within NHS paediatric ophthalmology.

The specific objectives are to: (i) identify how medical record data are and could be used within routine paediatric ophthalmic NHS care and medical research; (ii) define data and EMR design requirements imposed by the identified uses, users and use environments; and (iii) develop and test data capture tools that address these requirements.

3 STATE OF THE ART

Initially, health information technology development was restricted by the technological limitations. However, recent advances mean that, as with other domains, health information technology systems can now adapt to the needs of the user. Design strategies are therefore shifting towards a user-centred approach, to create products that are both useful and usable.

Usability, as defined by the International Organisation for Standardisation (ISO), is the ‘extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use’ (International Organisation for Standardisation 1998). Thus, in order to achieve true EMR-usability,

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an understanding must be gained of who the users of health data are, and for what purposes and where these data will be used, through a user-centred approach.

The ISO standard on ergonomics of human system interaction describes six principles that underpin successful UCD (International Organisation for Standardisation 2010):

- The design is based upon an explicit understanding of users, tasks and environments.
- Users are involved throughout design and development.
- The design is driven and refined by user-centred evaluation.
- The process is iterative.
- The design addresses the whole user experience.
- The design team draws upon multidisciplinary skills and perspectives.

3.1 Users of Electronic Medical Records

The user, as defined by ISO, is any 'person who interacts with the product (International Organisation for Standardisation 2010). Within this doctoral work, in order to satisfy the fifth UCD principle and ensure the whole user experience is appropriately addressed, both the EMR system and the health data it contains are considered part of the product. The definition of an EMR-user is therefore extended to include any person who interacts with the technology or with the resulting health data.

Typically, a variety of qualitative research methods are used to profile potential users and any experience-influencing factors. Within the healthcare setting, informal non-structured interviews can initially identify clinical requirements of an EMR system (Teixeira, Ferreira and Santos 2012, Greenhalgh *et al.* 2010). Additional non-participatory observation can validate these self-reported needs, and help identify those that may not be apparent to the individual users studied (Saleem *et al.* 2015).

There are few examples of such qualitative studies undertaken within paediatric ophthalmology, and thus little literature defining EMR users or specific user requirements. Surveys conducted in the United States have identified clinical priorities of both paediatricians and ophthalmologists (Chiang *et al.* 2013, Leu *et al.* 2012, Spooner 2007). However as usability is defined to depend upon the context of use, it cannot be assumed the findings generalise to practices within the NHS, or indeed to paediatric ophthalmology as a subspecialty.

Further research is needed to understand the exact nature of EMR-user requirements and limitations within NHS paediatric ophthalmology.

4 METHODOLOGY

The multifaceted aims of this doctoral research require consideration of a great range of use contexts and end users. In order to include and explore all user perspectives, a mixed methods approach is applied. The research is divided into three phases: exploratory, to elicit user requirements of a paediatric ophthalmology EMR; a design phase, to iteratively develop software inline with these requirements; and a validation phase, to test the performance of the software against the requirements and assess the suitability of the methods employed.

4.1 Exploratory Phase

4.1.1 National Survey

An online questionnaire has been devised to understand paediatric ophthalmic clinicians' experiences and perceptions of EMR adoption within the NHS. All members (189) listed in the United Kingdom Paediatric Ophthalmology email group are invited to participate in the online survey. Questions consider routine clinical documentation practices, participants' perceived benefits and barriers of EMR use, and, if appropriate, experiences of use. Responses are collected during a two-month period, and subject to univariate statistical analyses using SPSS 23.0.0.0.

4.1.2 Interviews

Paediatric ophthalmic clinicians and researchers are invited to participate in semi structured interviews to further investigate perceptions of the existing health information technology landscape and the information flows between academic and clinical communities. Interviews then explore the user-defined requirements of a paediatric ophthalmic EMR system. Using the nVivo software, qualitative thematic analyses are applied to identify themes in the responses and any differences between user groups.

4.1.3 Time-Motion Study

Qualitative observational data on what medical records are used for, and by whom, are collected in parallel to quantitative time stamps for various predefined clinical activities (for example reading notes, writing notes, talking to patient, examination) in a representative sample of paediaitric ophthalmology outpatient clinics at Great Ormond Street Hospital, London. At the end of each observational session, - following a single clinician for a whole clinic – these data are linked to anonymised demographic and diagnostic data for the patients observed.

Thematic and statistical analyses are used to compare documentation behaviours between the different clinical user groups and the patient groups included in the study.

4.1.4 Medical Record Review

During a three-week period, the paper-based medical notes produced within Great Ormond Street Hospital paediatric ophthalmology outpatient clinics are reviewed. The individual data items written in the notes are identified and grouped into sets, defined as the list of items documented by a single clinician during a single patient consultation. Diagrams are recorded as one data item, for example 'fundus diagram'. Items documented for each eye are recorded as two sequential items; items within each set are ordered as they appear in the medical notes. Similarities between sets are calculated using pairwise sequence alignment techniques, adapted from the Needleman-Wunsch algorithm (Needleman and Wunsch 1970), traditionally applied in genetic sequence analyses. The resulting similarity scores are used to drive the sequence-dependent clustering of sets. A principle component analysis is then performed on cluster membership information, considering the documenting clinician's role and demographic data, and patient demographic and disease data, to explore the factors influencing variations in clinical documentation patterns.

The resulting maximal data set is then aligned with data sets or protocols from existing research studies, to consider the suitability of EMR data for secondary research purposes.

4.2 Design Phase

To apply and test the EMR requirements elicited within this PhD research, a series of data collection tools are being developed as case studies. Software design work focuses on integrating a flexible range of data capture methods, including drawing tools and more standardised drop down menus, text entry or tick boxes, to create electronic forms for the case study scenarios.

4.2.1 Software Development

Software is coded to create web based data capture tools, utilising HTML form and canvas objects, building on existing work within the JavaScript-based open source medical drawing software repository, EyeDraw, from the OpenEyes Foundation (2015). Separate JavaScript modules for each drawing element are written and then compiled, following the EyeDraw workflow.

Working groups, consisting of six to eight clinical experts working within the field, are established via email to review the data capture tools. Feedback is requested on individual tool elements, or complete forms as necessary. Participant opinions are shared amongst the group to encourage discussion and reach consensus on design elements.

4.3 Validation Phase

4.3.1 User Acceptability Testing

The final phase of this research involves users assessing the usability – the effectiveness, efficiency, and user satisfaction, as previously defined – of the data capture tools. Testing is completed online; potential users from across the NHS are invited to undertake tasks using the software. Tasks are designed to replicate real word clinical activities, and the uses of the software prioritised by users, as defined during the exploratory phase of this research. Participants' ability to complete the task is recorded, in addition to the position of every mouse click – the "click flow" – during each task, to measure the effectiveness and efficiency of the software. Participant feedback is invited upon task completion via a combination of Likert items to quantify user satisfaction against the requirements identified by potential users in previous stages of this research, and open-ended free text questions for qualitative comments on the overall suitability of the software.

5 EXPECTED OUTCOME

Upon completion of this doctoral research we hope to have developed and tested a series of software applications suitable, as defined by potential users, for use within NHS paediatric ophthalmic care.

Although we hypothesise the chosen user-centred methodology will produce both useful and useable software, further work will be required upon completion of this research to assess the suitability of the outputs when integrated into the "real world" NHS information system. Hence a secondary outcome of this research will be the provision of an evidence base to guide future software development within the field. This evidence base will provide a description of current clinical practices within paediatric ophthalmology to which comparisons and suitable evaluations may be drawn following health information technology implementation in this environment.

6 STAGE OF RESEARCH

Our national survey identified 7.8% of the paediatric ophthalmic clinicians who responded (*N*=7 of 90) used EMRs for the majority of their paediatric patients. However, 64.4% reported prior experience using an EMR. These individuals with previous experience (*N*=58) were significantly more like to identify 'difficult-to-navigate system designs' (69.0% vs 41.4%, *P*=0.013), 'poor user interface' (62.1% vs 34.5%, *P*=0.015) and 'inability to integrate EMR with other clinical IT systems' (67.2% vs 31.0%, *P*=0.002) as barriers but 'improved communications with patients' (43.1% vs 18.8%, *P*=0.020) as a benefit of routine EMR use. Overall, participants most frequently identified 'software functionalities not meeting clinical needs' as the biggest barrier (25.3%) with the biggest benefit cited being 'increased document legibility' (23.2%), whilst 3.33% perceived no benefit at all.

Therefore, despite the movement to universal EMR-adoption in the NHS, routine use within paediatric ophthalmology is uncommon and more in keeping with uptake in paediatrics (Leu 2012) than general ophthalmology (Boland *et al*. 2013) in other countries.

This initial research indicates there is a great need for a user-centred approach, to identify and align EMR software with clinical needs, overcoming the largest perceived barrier of users. Accounting for such user perceptions throughout the subsequent design phase of this research is more likely to ensure the product overcomes barriers challenging use and delivers the benefits valued by paediatric ophthalmic clinicians.

Additional, more in depth insights from interview and clinical observational data will be combined with these results to define EMR requirements for paediatric ophthalmology, considering both user-defined and user-observed factors as is important in successful UCD (International Organisation for Standardisation 2010). This will complete the first, exploratory phase of the doctoral research. Next software will be iteratively developed and tested against the user-centric requirements, to assess the success of the methodology for EMR development within paediatric ophthalmology set in the NHS information system.

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