

Keywords: Digital libraries, evidence based medicine, patient information

Abstract

This paper presents an overview of several evidence based medicine and patient information studies conducted across the health service over a 4 year period, investigating clinicians', managers' and patients' perceptions of digital resources (primarily digital libraries) in hospitals, PCTs (Primary Care Trusts), NHS Direct and patient groups. The perceived impacts of the different methods employed for delivering health informatics are presented. The findings highlight some generic issues relevant for health informatics in the NHS as well as some specific issues for digital libraries. This paper reviews in more detail the issues of technology implementation ('traditional implementation', 'on the wards' and 'intermediaries within in communities') and the patient's 'information journey' with regard to digital libraries and online resources. Broad guidelines derived from these findings are provided for health informatics deployment.

Background

When hospital information systems were first introduced, it was found that the greatest difficulties in system deployment lay not with technical issues but with the users, their reactions to systems introduction and the need to acquire new skills [1]. Further health informatics research also argues that social and organisational factors can determine the success or failure of healthcare IT developments [2, 3, 4]. Symon et al [3] identified, within a hospital setting, how social structures and work practices can be disrupted by technology implementation. Heathfield et al [2] suggest that this is due to the complex, autonomous nature of the medical discipline and the specialized (i.e. clinician or software engineer) approach to system development. Negative reactions to these systems are often due to inappropriate system design and poor implementation. Wyatt [5], in contrast, argues that poor use of computer technology and the internet by clinicians to answer clinical questions is due to slow, inconvenient access to computer-based clinical knowledge resources. Digital Libraries offer the potential, as flexible information resources, to address these demands [4]. The use and acceptability of these resources has, however, been lower

than expected which could again be due to a poor understanding of the context in which these applications are used [2, 3, 6]. Symon et al [3] found that high status clinicians frequently deviated from formal procedures when a low value was placed on the work activity.

The National electronic Library for Health (NeLH) project is a proposed solution to clinical resource problems within the UK [5]. As well as addressing the needs of clinicians, digital resources also have the potential to positively revolutionize patients' health information interactions by increasing informed health behaviours and effective clinician–patient consultations. However, although positive benefits have been reported [7], so too have frustrations [8] and some serious negative outcomes [7]. Understanding users' perceptions of technology, its deployment and fit with work practices is vital to increasing the acceptable delivery of health informatics.

Method

125 interviews, focus groups and observations were conducted with nurses, doctors, consultants, surgeons, Allied Health Professionals, managers, library and ICT employees in a Provincial Hospital as well as Inner and Outer London Hospitals and PCT. 24 in-depth interviews were conducted with patients (aging from 25 to 81 years), call centre intermediaries (i.e. information and nursing advisors and managers) at NHS Direct and outreach patient librarians in a London PCT.

Four issues guided the focus of questions analysed within all the studies:

- Perceptions of their role within the organisation, and their information requirements (for themselves or the people they supported).
- Perceptions of health service current information practices, social structures and organisational norms.
- The impact of these current practices, structures and norms on information resource awareness, acceptance and use.
- Technology perceptions and how these affect other issues already identified.

The data was collected and analysed using Grounded Theory [9], a social-science method that combines systematic levels of abstraction into a framework (i.e. open, axial and selective coding and identification of process effects) about a phenomenon

which is verified and expanded throughout the study. Compared to other social science methodologies, Grounded Theory provides a more focused, structured approach to qualitative research with its continual cross-referencing allowing for grounding of theory in the data, thus uncovering previously unknown issues.

Results & Discussion

In all the studies, a wide spread of computer abilities and digital library experience was found. The major issues that emerged from these studies relate to usability, awareness and acceptability [10], implementation and the 'information journey' [6]; here, we focus on issues of implementation and the information journey, from both clinical and patient perspectives.

Evidence Based Medicine and its implementation

To start to understand the impact of digital library technologies on clinical practice, three studies have been conducted across different clinical contexts; these studies have highlighted different perceptions of technology associated with different strategies for deploying that technology:

- (1) In one study the '*traditional implementation*' of technology was employed. Individuals initiate interactions for their own needs by accessing a computer in its context (e.g. computer rooms in the library, office or at home) while system authentication procedures, training and ongoing support is provided by librarians based in the physical library.
- (2) In a comparative study, to increase the accessibility of technology, internet accessible computers were placed '*on the wards*' and within communal work places. However, the authentication, training and support were again mainly housed within the library.
- (3) The final study placed library '*intermediaries*' (outreach librarians) within the clinical communities (i.e. multidisciplinary teams and their meetings) to facilitate and support jointly agreed information practice changes due to the introduction of digital libraries. Interactions are instigated by the user, the group and the intermediary, both online and offline, supporting both individual and group needs. Support and training

is also provided within the community by the intermediary, thereby developing an in-depth understanding of the users and groups, and developing relationships within the community of practice between the intermediary and the group.

The results from these studies identified that poorly designed systems, deployed to individuals with poor support, as in study 2, produce a poor awareness of the potential of this technology. Users therefore perceive many health informatics systems as complex and inappropriate for their needs. As one respondent noted:

“It’s like being given a Rolls Royce and only knowing how to sound the horn.”

(Surgeon)

Technology placed within communal work places raised users’ awareness of the technology. However, interactions between this technology and current organizational norms (distinctly hierarchical with divides between practical and theoretical knowledge) produce negative reactions from specific user groups, who felt that current organizational structures and practices were threatened. The placement of web-accessible digital library technology on the wards, in particular, polarised technology perceptions – in particular, creating stronger negative feelings about technology.

“I know there is some friction between the junior doctors and the nurses about who the computers are there for” **(Doctor)**

Computers as a play-thing and a benefit of status were two dominant perceptions identified:

“... but they haven’t got time to sit down and actually play per se.” **(nursing management)**

‘People lower down. Well they would resort to the actual standard text.’ **(nursing manager)**

The physical location of the technology within communal workplaces presented barriers to use, especially for those of lower status.

“Sometimes the computer has been put in a place where it is very obviously in one territory” **(Doctor)**

Conversely, technology implemented within the community which could adapt to, and change, practices according to group and individual needs, as in study 3, was seen as empowering to both the community and the individual.

“It increases the sense that you think, I can find out the answer to this question”

(Consultant)

Through the relationships built up by the clinical librarian, technology usage and work practices developed together and dramatically improved perceptions of and motivation towards ‘evidenced based medicine’ and technology.

“It feels as though there has been an ethos of shared endeavour to get a more pro-active relationship to evidence-based practice and I think without this it will just collapse.” **(Doctor)**

This illustrates some of the challenges facing those deploying technology within clinical contexts; further issues emerged in studies with NHS Direct staff and patients, focusing more on when and how information is used.

Patient information and its deployment

One obvious, but nevertheless often overlooked, finding is that information needs are not static or on one level. The results from our patient studies suggest the decomposition of a ‘health information journey’ into three broad categories: the initiation of an information requirement, information facilitation and contextual interpretation (Figure 1), as described below.

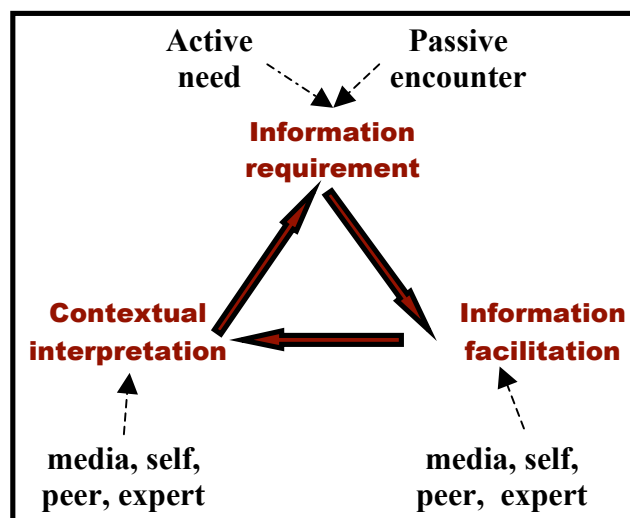


Figure 1: The health information journey

It was found that both active information needs (e.g. ‘I need to know more about my complaint) and passive information encounters (e.g. a news report on the link between HRT and breast cancer) initiated patient’s information requirements.

“because there is a lot of information out there in the media and in the press. People hear about it and they call us because I think they’re worried about it, or they think it’s going to affect them. I mean we certainly have a lot more health alerts than we ever had” **(Health information officer)**

At this stage, though, information requirements can be vaguely formulated. Digital resource designers should therefore understand that patients are not always clear about what their information requirements are, but instead are driven by vague fears.

NHS Direct acknowledge their role as an information guide and facilitator of high quality information from various different sources to increase patients’ knowledge base.

“We sign-post people to the right place.” **(Health information officer)**

Information facilitation is a process of exploring and elaborating requirements and obtaining or providing information. Among those patients who did search the Internet the outcomes of these searches were variable. Successes included one interviewee who twice discovered that friends’ minor symptoms were indicative of something serious. Both subsequently sought medical help resulting in one being hospitalised immediately and the other prescribed drugs for a heart condition. These successes, however, were counterbalanced by reports of failures to find anything useful and the recognition that searching can be “haphazard” and the information “unreliable”. It is interesting to note that many callers to NHS Direct require information facilitation support even if they have direct internet access.

“I’ll say that it’s from a web-site and they’ll say oh well actually tell me where the web-site is and I’ll go and read it myself.” **(Health information officer)**

The patient studies also highlighted a growing need from patients for the interpretation of information in context.

“Because I’ve gradually come to the opinion that they (the doctors) don’t necessarily know what is the best for me as an individual.” **(Patient)**

Contextual interpretation involves understanding the meaning of information in relation to the user's particular case. It was noted that frequently patients tried to push NHS Direct into an interpretive role by asking for either recommendations or diagnosis.

“they call up and say... which is the best one, you know operation, and do you think I should go and have this operation. And we can't tell them that we say 'No you have to discuss it with your consultant, what is the best one for you because with everyone it's going to be different.’” (Health information officer)

Conclusions

The findings from the different approaches to digital library implementation revealed broad guidelines for implementing digital library technology within the health sector and empowering its users:

1. Traditional design and implementation approaches, isolated from communities, produce users – both clinicians and patients – who are either unaware of the technology or perceived it as complex and inappropriate for their needs.
2. Random deployment of technology within communities, with poor design and support, is perceived by many as complex, inappropriate for their needs and a threat to current roles and practices, including the maintenance of clinician–patient relationships.
3. Integrating technology with communities and their practices, and exploiting the skills of information intermediaries, produced increased perceptions of user and group empowerment.
4. Understanding the temporal elements of patients' and clinicians' changing need for and use of information can also help system designers understand different system information requirements.

The studies reported here show that the designers of many online digital resources have not considered the resources' role within the wider context of information work and the 'information journey'. This means that the information is either incomplete or inappropriately directed towards clinicians and patients needs without providing sign-

posts as to where these gaps can be filled. For example, NHS Direct call centres explicitly identify their role as intermediaries in the facilitation of information. However, the poor hand-over and ambiguous roles of other bodies and clinicians means that patients' 'information journeys' are often disjointed. Digital resources could support patients with this gap but do not. Similarly digital resources often do not relay how the information presented fits into the patient or clinicians 'information journey' or where intermediary support can and should be used. This lack of integration means that, for patients and practitioners alike, the position of digital health resources within healthcare remains uncoordinated, awkward and underexploited.

The press are continually referring to problems with patients and technology such as: 'internet print out syndrome' and 'cybercondria'. However, we believe that both patients and clinicians require digital resources that are implemented according to and support their varying abilities and changing needs.

References

1. Harrison, G. S. The Winchester experience with the TDS hospital information system. *British Journal of Urology*, May 1991; 67,5: 532-535.
2. Heathfield, H., Pitty, D. and Hanka, R. Evaluating information technology in health care: barriers and challenges. *BMJ*, 1998; 316: 1959 –1961.
3. Symon, G., Long, K & Ellis, J. The Coordination of work activities: co-operation and conflict in a hospital context. *Computer supported cooperative work*, 1996; 5,1:1-31.
4. Adams, A. & Blandford, A. (2002) "Acceptability of medical digital libraries" *Health informatics Journal*. Sheffield Academic Press. Vol 8 (2). pp. 58 – 66.
5. Wyatt, J. The clinical information access project, New South Wales: lessons from an NeLH precursor. In *Proceedings of Advances in clinical knowledge management*. Presented at ACKM 3, 2000:
www.ucl.ac.uk/kmc/kmc2/News/ACKM/ackm3/wyatt.html
6. Adams, A., Blandford, A & Lunt, P. (in press) "Social empowerment and exclusion: a case study on digital libraries" *ACM Transactions on Computer–Human Interaction (ToCHI)* ACM Press. Draft available from
<http://www.ucl.ac.uk/annb/DLUability/ClinicalDL.html>
7. Potts, H. & Wyatt, J. (2002) Survey of Doctors' Experience of Patients Using the Internet *Journal of Medical Internet Research*. 4(1):e5.
8. Brown, H (2000) View from the front line – Internet printout syndrome, *He@lth Information on the Internet*, The Royal Society of Medicine Press. Issue 13 February 2000 [online at: <http://www.rsm.ac.uk/hii/issue13.pdf>]
9. Strauss, A. & Corbin, J. *Basics of qualitative research: grounded theory procedures and techniques*. Sage, Newbury Park, 1990
10. Adams, A., Attfield, S. & Blandford, A (2004) " Have digital resources taken a

wrong turn on the health information journey” Health digital library workshop
(HDL04) at ECDL04