Knowledge Management and Communities of Practice around Healthcare Digital Libraries

Patty Kostkova, Jane Mani-Saada, Julius R Weinberg, Gemma Madle

City eHealth Research Centre, Institute of Health Sciences
City University
London, UK
patty@soi.city.ac.uk

Abstract.

The recent explosion of medical information available in digital libraries on the Internet provides users with overwhelming amount of medical knowledge. Although the number of patients seeking health related information online is steadily growing, the great potential of this revolutionary technology has not been fully exploited.
Professionals often cannot find information when and where they need it; members of public are unaware of varying quality of medical information and often seek health advice from unauthorized and misleading Web sites. In addition, little is known about the real impact of medical knowledge provision on clinical care.
Based on our experience with the development of real-world government medical digital libraries in the UK (NeLI and AR DL), we will discuss key issues around knowledge management, healthcare ontologies, quality approval and a new opportunity for online communities of practice around healthcare digital libraries.

1 Introduction

Recent technical advances resulting in a boom in medical informatics, that have enabled new ehealth-related activities, have got a common denominator: the Internet. As June Forkner-Dunn foresees: "the impact of the Internet has largely been unforeseen, and it may have a revolutionary role in retooling the trillion-dollar health care industry in the United States" [1]. However, the Internet can only play this essential role in healthcare if the knowledge provided over this powerful media is made accessible and delivered to the end-users – both healthcare professionals and members of public – in the right form to meets their needs. Therefore, the issues around the knowledge management in healthcare digital libraries and the impact on healthcare service and clinical practice are at the very centre of ehealth research.

In recent years, the ever-increasing amount of medical information available online and the increasing availability of the Internet at work as well as at home has significantly changed the way information are used by health care professionals and by general public. However, despite the desire of better informed patients to take an active role in the treatment process, and the need of professionals to keep improving their

practice according to new results available in digital libraries on the Internet, the reality does not fulfil the expectations.

This paper will outline a number of technical, social and medical issues around medical digital libraries and knowledge management in medicine based on our long-term experience with the development of two government DL projects: National electronic Library of Infection (NeLI), formerly National electronic Library for Communicable Disease (NeLCD), and the Antimicrobial Resistance Digital Library (AR DL), both developed at the City eHealth Research Centre, City University.

The paper is organized as follows. Section 2 will discuss motivations for our research in greater detail, section 3 brings brief description of both DL projects: NeLI and AR DL. Section 4 is devoted to knowledge management issues in digital libraries, such as quality of the provided information, medical ontologies and the search issues. Section 5 discusses creation of online communities of practice around digital libraries as a new phenomenon enabled by the Internet and the impact of Internet and knowledge provision on public. Intelligent agents, used in the development of NeLI to serve the needs of the knowledge, are discussed in section 6. In section 7 we outline related research and section 8 concludes.

2. Motivations

The impact of new healthcare technologies

The introduction of technology into the health services brings a number of major improvements and it is envisaged that the overall impact of ehealth on the quality of care will be significant, however, there are also new issues and problems that need to be addressed.
According to June Forkner-Dunn: “As a group, physicians use the Internet more than do many other sectors of the general adult population. However, physicians have not received sufficient information to convince them that they can provide higher-quality care by using the Internet; indeed, few studies have assessed the Internet's value for improving patients' medical self-management and health behaviour, as well as their clinical outcomes and relationships with health care practitioners. New e-technology formats introduced to the growing consumer movement will drive the next generation of self-care by allowing patients to manage their own health conveniently and proficiently”. In this section, we outline the impact - potential pros and cons of ehealth technologies.

Advantages

Ehealth already has a major impact on organization structures, clinical decision-making and health care practise. In particular, there are number of new issues wide adoption of ehealth would bring:

- significant influence of the work patterns, such as tele-health
- constant availability of the up-to-date knowledge and evidence
- instant dissemination of latest results and outbreak alert notification
- encouragement of best practice deployment and evidence-based care adoption
- potentially improved overall organization and delivery of care
- online professional communities and knowledge sharing
- online patient groups of those with the same conditions
- patient self-management using e-monitoring and empowered patient
- changed patient-physician relationship resulting in patient-centred decision making

However, the obstacles in current heath care settings slowing down or stopping an adoption of new technologies need to be identified, as these factors need to be clearly understood in order to be appropriately addressed in future research and policy definitions.

New problems:

In addition to the existing clearly positive impact allowing a better and higher quality care, there are new issues that need to be addressed in ehealth research. For example, they include issues such as:

1. Trust issue (trust and mistrust of the technology)
2. Security and confidentiality issues (EPR protection)
3. Implications of differential access to the Internet and different user abilities to use computer technology
4. The effect of "digital divide" and the impact on patient health and health care
5. Issues around the quality of information over the Internet
6. Standards – unification of coding and quality standards at national and international levels
7. The impact on the performance could be double-sided: e.g., "mail from patients further burdens overflowing physician schedules" etc.

The Role and Challenges of Digital Libraries

As discussed above, the Internet provides overwhelming amount of medical information. However, healthcare professionals and general public often cannot find the information they need when they need it and if they do the quality may be uncertain. Therefore, the knowledge provision, organization and delivery at the technological, medical and social levels are significantly changing the delivery of care and play a central role in empowering patients who are taking an active role in management of their health.

The role of traditional librarians has significantly changed, as shown at study of Adams and Blanford [2], demonstrating that a librarian acting as an information facilitator implemented within the community could adapt to and change practices according

to individual and group needs that was seen as empowering to both the community and the individual.

The key challenges of medical DL research we have been investigating on the real-world projects: NeLI and the AR DL span across a number of research areas: the quality of medical information, the search and user information seeking behaviour, issues around knowledge management, healthcare ontologies and the underlying technical services (such as agent-technologies in NeLI) implementing the service. Before we move on to these issues, we briefly introduce the aims of the two projects to set the scene for the following discussions**.**

3. National electronic Library of Infection: a Case Study

As mentioned above, our team has been developing two government medical digital library projects: NeLI and its part: the Antimicrobial resistance DL. These projects were used as ideal testbeds for our research into knowledge management, deploying agent-technologies in document management process and evaluation of the impact of these projects. Here, we briefly state the aims of these libraries:

NeLI, a specialist library of the NeLH, is an information gateway and a digital library providing the best available evidence-based knowledge, enhanced with medical quality tags to a wide spectrum of users: clinical experts, public health, general practitioners and general public. The top page is illustrated in Figure 1.

The Antimicrobial Resistance Digital Library, a subset of the NeLI, is providing information about antibiotics and prescribing to raise the awareness of these issues among members of public and to encourage prudent prescribing. The content of the library is organized in FAQs to answer common user questions and gives the links to more detailed resources, as illustrated in Figure 2.

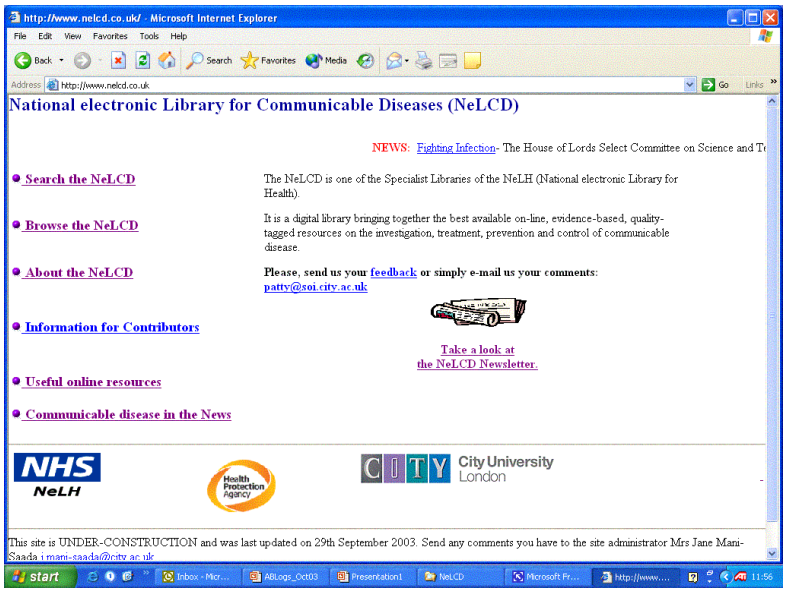

Fig. 1 National electronic Library for Infection

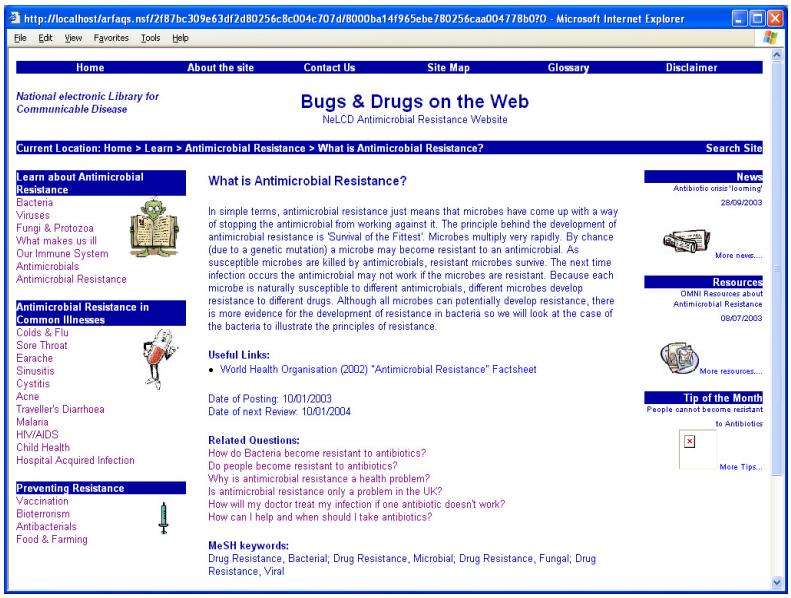

Fig. 2 The Antimicrobial Resistance Digital Library

4. Knowledge Management in Medicine

The knowledge management is a fundamental issue for the design of a digital library. Gray and Brice understand knowledge as the enemy of disease, as described in their recent study [3]. Understanding the problems around data representation – the nature of the data, data modelling concepts and user search behaviour - can ensure that required information will be retrieved in a way to meet users' expectations. In this section we will discuss a number of key issues around knowledge management with respect to the needs of NeLI and AR DL.

Quality Assurance in Healthcare

The problem of quality of health information is a very central one to a successful delivery of information to healthcare professionals and public [4]. The quality of information on the Internet significantly vary and providers and authors are often unknown or unspecified. This is the case of commercial, charity, private and sometimes even government digital libraries. This is of a particular issue for patients retrieving information from unreliable or bias Internet sites and burdening their GPs with obscure requirements or demanding contradicting or harming treatments.

Number of projects providing health information approval schemes, quality check lists and seals of approval offer only partial solutions – these include, National Institute for Clinical Excellence (http://www.nice.org.uk), HON portal (http://www.hon.ch), Organising Medical Networked Information (OMNI) http://www.omni.ac.uk are others. In the area of evidence-based medical quality appraisal the golden standard is the Cochrane collaboration [5]. However, research into public health information seeking behaviour by Eysenbach [6] showed that users often do not look at the "About us" page and seem uninterested in the provider of the web site they are retrieving information from, therefore, assuming that all health information on the Internet is correct.

The problem of information quality of science on Internet with respect the evaluation of the content from users' and librarians' points of view using interactive methods were investigated in great depth by Bargheer [7] who suggested a formal framework for evaluation of scientific material on the web.

In the UK, the National electronic Library for Health (http://www.nelh.nhs.uk), of which the National electronic Library of Infection is a part of, is dealing with the issue of quality by making the level of evidence of all documents available and clearly including only evidence-based documents. Therefore, documents rather than Web sites are approved.

The details of the NeLI quality assurance process is based on Dublin Core metatags describing the online resources, the Reviewers Assessment giving a "bottom line" summary of the quality of the resources available for online discussion. The model of ongoing review process has been set up in collaboration with professionals around communicable disease in the UK. Full details of the quality-tagging and the appraisal process could be found in [8].

Healthcare Ontologies

Despite many ongoing national and international activities in Europe and the US, there is no common agreement on ontology, nor internationally agreed standards in health care adopted by national healthcare systems. There are number of coding standards, data representation standards and common legal and ethical recommendations. For example, there is no common internationally accepted clinical coding scheme – currently, several coding systems are being used by different organizations: MESH, CTLV3/SNOMED and ICD10. Common standards and their medical implementations, such as XML, Health Level 7 http://www.hl7.org/, UML, Z39.50 [9] (specifying an abstract information system with a rich set of facilities for searching, retrieving records, browsing term lists, etc) have not been widely implemented yet. This is not only a UK but an international issue.
Finally, a related knowledge representation project from NLM: the Unified Medical Language System (UMLS) develops and distributes multi-purpose, electronic "Knowledge Sources" and associated lexical programs to enhance systems focused on patient data, digital libraries, Web and bibliographic retrieval, natural language processing, and decision support. UMLS [10] includes a list of vocabularies in the UMLS Metathesaurus.

However, there is a need for harmonizing international standardization initiatives on one side, along with a development of ontology mapping tools allowing interoperability among digital libraries using different standards.

In NeLI, in addition to the MESH coding ontology [11], Dublin Core Metadata initiative (http://www.purl.org/DC) was adopted as it defines a list of fields characterizing an electronic document for cataloguing and search purposes. MESH is a standard coding system widely adopted in UK healthcare libraries and used for Pub Med indexing, while Dublin Core standard allows cross search with other NeLH Specialist Libraries and interoperability with other Internet initiatives, such as Open Archives (http://www.openarchives.org/). The meta-tagging was enhanced with fields to express the quality criteria, level of evidence and the Reviewers Assessment. Full details of these standards and their role in NeLI could be found in [8].

The search for health information

Understanding the issues of user search for health information on the Internet is essential for correct digital libraries design, graphical layout, navigation strategy and site user customisation. However, information seeking habits significantly vary among users and research results suggest that there is a great variety of user search patterns ranging from users seeking information to better understand their condition to patient rather avoiding to receive more information than their GP gave them. 86% of users did not ask anyone about which site to use and those who did preferred friends and family to health professionals and librarians [12]. Most people prefer general

search engines to medical Web portals, however, a study conducted by HON suggests that 70% of users prefer medical professional sites [13].

The key methods for investigating user search behaviour are qualitative and quantitative studies, the former using entry and exit questionnaires, interviews and online surveys; the latter typically investigating web logs that give an insight into quantitative information about each visit to the site, such as; number of hits, domain names, internet provider addresses, date and time of access, web server data, navigation strategy used, number of searches performed, downloads of documents etc. [14, 15]

For NeLI purposes, we have done a brief web log analysis of the pilot site for the period of January 2002 to June 2003. In particular use by hospital-based users was evaluated. Results indicate an increase in activity during the period and an increase in the number of hospital-based users. Hospital-based users were more likely to return to the site, spend more time on the site and to view more pages than other users. Surprisingly, the evaluation study revealed that users tend to browse the site more that search [16]. We are also in a process of collecting exit-questionnaire survey results, however, so far the number of responses is not statistically significant.

5. Online Communities of Practice and the Impact of Digital Libraries

Online communities of practice are one of the recent phenomena, enabled by the availability and affordability of the Internet, that can for-ever change the way healthcare professionals interact, learn and share knowledge. While traditional communities of practice have been widely studied [17], little is known about the key factors and the social impact of their online counterparts.

In particular, the impact of healthcare digital libraries on creation, evolution and sustainability of online communities of practice at national and international level is of very high importance due to the global outreach of medical events, such as infectious disease outbreaks. Recently, we have started investigating factors enabling people to interact effectively without having met face-to-face and discovering the barriers that slow down or prevent this interaction.

Additional research questions we are interested in include: finding out how online communication differs from face-to-face interaction and evaluation the impact of information graphical design and layout in this process. How the creation of online communities of practice around digital libraries change the knowledge update, problem sharing and results dissemination? What are the real-world social and practical obstacles slowing down this process?

The young community of practice we have been involved in creating about the National electronic Library of Infection is currently little more than an online extension

of the face-to-face community of professionals involved directly or indirectly in the project and we are investigating the key factors in this ongoing process, as described by Mani-Saada [18]. Initial research shows that the slow update of the community interaction is a result of the following factors: lack of time for busy NHS clinicians, insufficient quality-appraised content on the library and inappropriate technical support for advanced community interaction. These issues are currently being addressed.

The Impact of Health Information Provision

Providing quality medical knowledge through healthcare digital libraries available 24-by-7 to doctors and patients would be meaningless if there was no impact on public understanding, knowledge and attitude and if this ehealth resource would not improves clinical practice. While the DL evaluation research is focusing on search behaviour, accessibility issues, quality and navigation, little is known about the impact on user knowledge and attitude.

In our research, we have investigated, the usability, knowledge update and attitude change of health care professionals and general public using DLs. These factors we tested and evaluated on a study based on the Antimicrobial Resistance digital library, developed by our team (available soon at http://www.nelcd.co.uk) [19] Based on this very successful study, we are now investigating a general methodology for evaluation of the use of digital libraries, assessing knowledge update by public and change of processional practice based on information available on the Internet, in particular, on the National electronic Library for Communicable Disease (NeLI), http://www.nelcd.co.uk.

The aims of our ongoing research include the methodology for assessing the impact of digital libraries in healthcare and we seek answers to questions like: Does making the evidence available through digital libraries result in any difference in professional practice? Does the accessibility of information make the search for knowledge any easier and what are the key factors in the design of user-friendly e-learning tools, from graphical and the knowledge provision point of view?

Communities of Practice and the Impact of Health Information Provision

Finally, the relationship between these two areas is currently being investigated. Firstly, we believe that healthcare digital libraries and knowledge management of medical information are pointless if they have no impact on online and face-to-face communities, the way health professionals work and interact, and on their clinical practice. On the other hand, communities of practice are rarely evolving spontaneously without a shared information need and a shared domain – there is a need for core shared resource, such as a digital library.

6. Technical Aspects – Intelligent Agents Support

The prototype of the NeLI library (http://www.nelcd.co.uk) has been built using CGI scripts to implement the basic search functionality. The top NeLH site could be found at http://www.nelh.nhs.uk.
Currently we are porting the system to Lotus Domino R5 platform and the new version should be later in 2003.

The prototype of the NeLI library was built around the 10 high-priority areas, identified in a national prioritisation exercise [20], and later populated with a core evidence-based documents with relevance to the infections diseases, syndromes and presentations. Documents in NeLCD are represented in XML (relevant DTD is defined for validation purposes). Common DTD across NeLH will allow extensive document exchange and cross-SL search performed by Information Agents. The separation of the content from style allows flexible manipulation with data, easy modifications of the display format, as well as object-based data representation suitable for data search and document exchange. The documents available at the prototype site are in the editorial process now and the Reviewers Assessments are being received.

Agent Support for Document Dataflow and the Quality Assessment

Lotus Domino built-in agents support is used for implementing the agent functionality supporting the document review process. The description of the agents in NeLI could be found in [21].

There are currently four basic agent concepts in the NeLI. First two, Intelligent Search Agents and Pro-active Alert Agents, are involved in the search process and user profiling and customisation. The later, Reactive Review Agents and Reactive Expiry Agents, are in change of various aspects of the library review process. The NeLI agents architecture is illustrated in **Fig. 1**. .

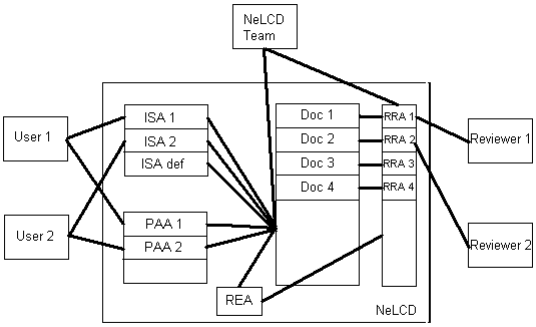

Fig. 1. Agents in NeLI

7. Related Work

While projects and research initiatives relevant to the issues discussed in this paper were described together with the approach or solution adopted in NeLI, in this section we give a brief overview of the key healthcare digital library projects and agent and interoperability standards in healthcare.

Healthcare Digital Libraries

NHS Direct Online http://www.nhsdirect.nhs.uk/ is a government-funded digital library providing basic healthcare information aiming at general public. This is a complementary service to the longer-running telephone service NHS Direct.

Prodigy (http://www.prodigy.nhs.uk/AboutProdigy/ initiative is a broad concept to support general practice in developing the quality of clinical practice in many ways.

Clinical Evidence project (http://www.clinicalevidence.com/) has identified existing clinical evidence and build a tool to access the knowledge to improve the clinicians' decision making. The outreach of NeLI is wider than clinical practise, the existing data sources are not homogeneous but heterogeneous, therefore, advances tools to accommodate the semantics are needed.

Cochrane Library http://www.cochrane.co.uk/ provides the gold standard in appraising clinical evidence. Following highly-critical evidence-based appraisal procedures, these guidelines provide the primary source of information for EB clinical diagnostics and treatment.

Autonomous Agents and Interoperability in Healthcare

Autonomous gents providing various functionality in health care applications have been an interesting area of research in recent years in academia and industry. For example, agent project by Honeywell is investigating applications of autonomous agents in elderly patients nursing [22], agentcities-funded (www.agentcities.net) healthcare project is looking at implementing MAS for negotiating patients visits to specialists according to his or her condition and physical location [23]. Agents-assisted recommendation for screening of cancer patients and other projects were investigated by Cancer Research Fund, UK [24]. However, the NeLCD seems to be the only project using agent technology in medical digital library.
As for the distributed communicate aspect of the library, there are a number related digital libraries providing a collection of cross-searchable documents in the Internet. The Z39.50 [25] standard specifies an abstract information system with a rich set of facilities for searching, retrieving records, browsing term lists, etc. At the server side, this abstract system is mapped onto the interface of whatever specific database management system is being used. The client application is unaware of the implementation details of the software hiding behind the network interface, and it can access any

type of database through the same, well-defined network protocol. On the client side, the abstract information system is mapped back onto an interface which can be tailored to the unique requirements of each user. This provides a well founded universal solution, conceptually similar to the one in NeLH, however, the NeLH is a proprietary database which does not aim to provide universality. The same is the case for the general SDLIP communication protocol [26].
A similar approach, looking at a tree hierarchical topology for communicating agents was investigated by Kostkova as the MAGNET Architecture [27].
Also, commercial Web publishing products, such as developed by Interwoven [28], do not provide the additional autonomous functionality required by the NeLH document quality review and appraisal process, as discussed in [29].
Finally, a related non-agent knowledge representation project from NLM: the Unified Medical Language System (UMLS) develops and distributes multi-purpose, electronic "Knowledge Sources" and associated lexical programs to enhance systems focused on patient data, digital libraries, Web and bibliographic retrieval, natural language processing, and decision support. UMLS [30] includes a list of vocabularies in the UMLS Metathesaurus.

8. Conclusion

In this paper we have outlines the technological advances enabling the recent growth in ehealth technologies, in particular, we highlighted the central role of the Internet and online digital libraries. Based on our experience with the development of National electronic Library of Infection and the Antimicrobial Resistance Digital Library, we have investigated the key issues around knowledge management, quality assurance, online communities of practice and the impact of medical information provision on end users.
These research results contributed to our understanding of the use of Internet ehealth digital libraries and the impact of online communication tools in healthcare that could subsequently improve the design of these systems.

References

[1] Forkner-Dunn J., *Internet-based Patient Self-care: the Next Generation Health Care delivery*. Journal Med Internet Research 2003;5(2):e8

[2] Adams A., Blandford A. *An outreach librarian projects impact upon successful digital library uptake.* In the Proceedings of the 1st Health digital Library workshop (HDL 2003), ECDL 2003, Trondheim, August 2003.

[3] Brice, A. and M. Gray, *Knowledge is the enemy of disease.* Library and Information Update, 2003. **2**(3): p. 32-34.

[4] Eysenbach G. *A framework for evaluating e-health: systematic review of studies of health information and services for patients on the Internet* JMIR Vol 3, Iss 1, January 2001

[5] Cochrane Database. http:// www.cochrane.co.uk

[6] Eysenbach G, Koehler C. *How do consumers search for and appraise health information on the world wide web? Qualitative study using focus groups, usability tests, and in-depth interviews*. BMJ, Vol. 324, March 2002, pages 573-7

[7] Bargheer M. http://www.bibliothek-saur.de/preprint/2003/bargheer.pdf

[8] Kostkova P, G. Madle, J. Mani-Saada, JR Weinberg. *Quality Appraisal of Medical Knowledge in the National electronic Library for Communicable Disease*. Submitted to MedInfo 2004.

[9] http://www.biblio-tech.com/html/z39_50.html

[10] http://www.nlm.nih.gov/research/umls/umlsmain.html

[11] Medical subject Headings. http://www.nlm.nih.gov/mesh/2002/index.html

[12] Fox, S. and L. Rainie, *How Internet users decide what information to trust when they or their loved ones are sick*. 2002, Pew Internet and American Life. p. 47 pages.

[13] Foundation, H.o.t.N., *HON Survey February to March 2001*. 2001: p. 2 pages.

[14] Rozic-Hristovski A., Hristovski D., Todorovski L., Institute J. S., *Users' information seeking behaviour on a medical library website,* J Med Libr Assoc, v90:no.2 (2002), pp210-17

[15] Nicholas D, Huntington P, Williams P *Micro-mining log files: a method for enriching the data yield from Internet log files* Journal of Information Science (in press: Summer 2003)

[16] Madle G, Kostkova P, Mani-Saada J, Weinberg JR. *Evaluating use of a Digital Medical Library: Do Professionals behave differently?* Submitted to MedInfo 2004.

[17] Wenger E. *Communities of practice: learning, meaning and identity*. Cambridge University Press.1998

[18] Mani-Saada J. Madle G, Williams P. *Initial experience with developing communities of practice around the National electronic Library for Com-*

municable Disease. In the Proceedings of the 1st Health digital Library workshop (HDL 2003), ECDL 2003, Trondheim, August 2003.

[19] Madle, G., et al. *Evaluating the changes in knowledge and attitudes of digital library users*. in *7th European conference on Research and advanced technology for digital libraries*. 2003. Trondheim, Norway: Springer Verlag

[20] P. Horby, A. Rushdy, C. Graham, M. O'Mahony, et al. *PLHS Overview of Communicable Diseases 1999.* http://www.staff.city.ac.uk/~jane/ovcd.pdf

[21] P. Kostkova et al. Agent-Based Up-to-date Data Management in National electronic Library for Communicable Disease. In SI: "Applications of intelligent agents in health care", J. Nealon, t. Moreno Ed, in Whitestein Series in Software Agent Technologies, In press, 2003

[22] Karen Z Haigh, John Phelps, Christopher W Geib *An Open Agent Architecture for Assisting Elder Independence.* In the Proceedings of the AAMAS 2002, Bologna, Italy, July 2002.

[23] Antonio Moreno, David Isern. *A first step towards providing health-care agent-based services to mobile users.* In the Poster session of AAMAS 2002, Bologna, Italy, July 2002.

[24] J. Fox. Understanding intelligent agents: analysis and synthesis In the Proceedings of Agents applied in Health Care, 15th European Conference on Artificial Intelligence, ECAI-2002, Lyon, France, July 2002.

[25] http://www.biblio-tech.com/html/z39_50.html

[26] http://www-diglib.stanford.edu/~testbed/doc2/SDLIP/

[27] P. Kostkova, J. A. McCann. *Inter-federation Communication in the MAGNET Architecture*. In the Proceedings of the Grace Hopper Celebration of Women in Computing Conference 2000, Cape Cod, Massachusetts, USA, (2000).

[28] http://www.interwoven.com/products/content_management/key.html

[29] P. Kostkova, J. Mani-Saada, J. Weinberg. *Agent-based Up-to-date Data Management in National electronic Library for Communicable Disease*. In the Proceedings of Agents applied in Health Care, 15th European Conference on Artificial Intelligence, ECAI-2002, Lyon, France, July 2002.

[30] http://www.nlm.nih.gov/research/umls/umlsmain.html