Towards an Internet-based Infectious Disease Management Platform to Increase Patient Safety

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Abstract— An infectious disease communication portal will be developed guided business modeling and Human Centered Design principles. This platform will offer several features such as education, document sharing, decision aids, and outbreak and prevalence monitoring, depending on the needs of the key-stakeholders (caregivers, payers, insurance companies, patients, policy-makers). Data-mining will be applied to logged website use of a previously implemented infectious disease management information website. This will render an understanding of actual use patterns, information need, and search strategies. Preliminary results are presented and implications for further research and platform design are described. These results include: 1. Users most often skip the website's homepage, it is therefore important to support user orientation. 2. Users spend a considerable amount of time searching on the website, a more optimal fit between user and technology is needed. 3. Users switch between information meant for different target groups, information should thus be aimed towards user goals instead of user identity.

Keywords- internet-based communication platform; healthcare associated infection control; information need; patient safety; logfile analysis.

I. BACKGROUND

In this paper, we describe the development of the e-Disease Management Eursafety Health Net platform eDEHN) based on the evaluation of a previously developed and implemented website [1] to promote patient safety. The eDEHN-platform will function as a disease management platform offering several features such as education, document sharing, decision aids, outbreak and prevalence monitoring, and video-conferencing, depending on the needs of the key-stakeholders (caregivers, payers, insurance companies, patients, policy-makers), see Figure 1.

The platform development will be guided by the ceHRes (center for eHealth research) roadmap that integrates business modeling and Human Centered Design [2]. By applying data-mining to the MRSA-net website, valuable information on actual use patterns renders focal points for the development of the new communication platform that shares MRSA-net goals. This summative evaluation can serve as input for the up-scaling of the current website to an infectious disease management platform.



Figure 1. Eursafety Health Net feature overview.

A. Patient Safety

World-wide, patient-safety is increasingly seen as a focal area of healthcare. Due to increases in microbial antibiotic resistance, healthcare associated infections (HAI) form an increasing treat to patient safety [3], [4]. MRSA for example has received much attention in recent years for it is the cause of many HAIs, not seldom with fatal consequences. To fight this problem of microbial antibiotic resistance and subsequent difficult or untreatable HAIs, infection control strategies need to be applied. Since neither people nor bacteria are constrained by national or regional borders, cross border cooperation is needed to ensure effective infectious disease management [5]. Cautious antibiotic use, resistance pattern monitoring, and hygienic measures are among the necessary control measures to fight the spread of resistant bacteria and infections. To inform all actors involved in the care process on the exact measures they should take in case of infectious agents, good information, education, and communication is needed. Patient safety can benefit greatly from efficient communication, education, and information sharing.

B. eHealth technology

To enhance patient safety regarding MRSA, a website was developed using Human Centered Design methods. Information need and structure were identified and labeled scenario-based testing and card-sorting. through Subsequently, website design was tested and adjusted by using mock-ups [6]. Initial tests showed improvement: HCWs were significantly quicker in finding and using information in the internet tool than with paper-based protocols and they were significantly more successful in completing scenario tasks [7]. Likewise, content aimed at the public was created. Patient empowerment was stimulated since the website provides information to answer questions the public (or patients) may have about MRSA.

Since February 2008 MRSA-net can be visited online [1]. It currently pulls about 12,000 visitors per month, mainly originating from its target countries: the Netherlands and Germany. Regardless MRSA-net's success, eHealth technology evolves and successful disease management and infection control ask for a broader set of tools than protocol communication alone. MRSA-net is a starting point, but in our goal of supporting cross border infectious disease management we need to develop the tools HCWs need to control HAIs and deliver safe care.

Cooperation and information is not limited to HCW practice; in infectious disease management patient values cannot be overlooked. Participatory healthcare, healthcare that is organized towards enabling patients to be informed so that they can think and co-decide about the care and cooperate with HCWs, can be realized more easily with eHealth technology. This use of interactive health technology or Medicine 2.0, aims to use technology to involve patients in the care process and offer tools better equipped to meet user needs [8]. Applying eHealth to the broad field of HAI control seems logical and viable.

C. Infectious Disease Management

A variety of antibiotic-resistant infectious agents compromise safety and thus need to be controlled, as stated in World Health Organization fact sheet No. 194 [3]. Increasing patient safety through the reduction and control of HAI in Dutch and German border regions through crossborder collaboration is the goal of MRSA-net's successor: the Eursafety Health Net project [9]. Providing HCWs with knowledge on infection control protocols, facilitating information exchange and monitoring of resistance patterns, as well as creating and enabling public and professional awareness and adequate education is deemed necessary. One of the sub-goals of the project is the development of an ehealth communication platform that facilitates cross-border collaboration on infection control. This platform should support all project partners, HCWs, patients or public in the joint goal of infection control and patient safety. Because successful infection control asks for specific measures taken at different points in the care process, offering timely information and education on infection control is essential. E-learning and e-decision aids are among the tools that eHealth technology has to offer. Also, cross-border monitoring of resistance patterns and antibiotic use can be

realized in internet-based modules. To assess how the communication platform can support such activities, research will be done. Furthermore, to ensure a complete and successful implementation, a business model will simultaneously be created for this eHealth project [10].

D. Business modeling and eHealth development

Besides all good intentions eHealth technologies often lack a full implementation. Reasons for this unsuccessful implementation can be numerous, but a misfit between enduser needs and technology properties are not uncommon [11]. To ensure a good implementation, a thorough understanding of the user, his/her goal or task, and the context in which the application will be used are essential. Involving the users in different phases of the design process is important for researchers and developers. Participatory design, or co-creation, ensures that end-users are kept central throughout the development. The field of Human Centered Design offers methods to inquire users and accomplish userdriven applications [2]. In addition, applying business modeling to healthcare services can generate trust, commitment, and ownership among stakeholders. To illustrate this, MRSA-net design was not based on stakeholder participatory design, but on user participatory design which resulted in some reluctance of important stakeholders to accept and implement the technology [12]. Business modeling tackles this problem of unsuccessful implementation and creates new perspectives on user and stakeholder involvement in creating viable, implementable eHealth technologies [10].

Following the ceHRes roadmap, we aim to develop the eDEHN platform based on the right assumptions and observations regarding its stakeholders and users [2]. In the first phase of the ceHRes roadmap, contextual inquiry, the project is planned and the problem (for which a solution will be developed) is investigated. To ensure that the proposed solution (communication platform with various applications) really supports its users and fulfills a need, the problem (increasing patient safety with regard to infectious disease management) needs to be assessed and understood [2]. The eDEHN platform is currently in the phase of problem analysis: in order to design effective disease management technologies, we need to understand how the technology implemented in the MRSA-net project is used and what information is accessed or requested.

E. Summative Evaluation

Given the initial test results and formative evaluations performed on the MRSA-net website, its prospects were promising [7]. However, as many eHealth designers currently know or are discovering due to more stringent evaluations, actual use may differ substantially from intended use. In a similar way, the intended users may not be the actual users, since freely accessible websites that serve a broad audience can pull many different visitors. Summative evaluation is important because it tells us what information is requested through the MRSA-net website, and how this is done. It tells us what the important areas of interest regarding infection disease management are. Possibly, additional topics of interest surface that need to be addressed to enable HCWs to provide safe care, or address the public's information need and enable patient empowerment.

To illustrate this, one assumption that is valid for MRSAnet's intended users but possibly not for its actual users is that MRSA-net users have a specific question or information need when searching for guideline-based information. However, translating an (sometimes implicit) information need into a well defined search query or recognize the topic of interest can be difficult. Especially when persons are familiar with a subject (as is probably the case with HCWs that use MRSA-net) they may be unable to form effective queries [13]. The so called 'exploratory seeking' may not be supported as well as 'known item seeking' by MRSA-net's question-answer set-up [14].

Further, taking a close look at use patterns can identify information processing problems. Information on MRSA-net contains a question-answer structure: predefined questions translating an information need are matched with protocolbased answers. This structure may be efficient in providing concise, ready to use information for persons seeking socalled procedural information (learning to do) [15]. However, MRSA-net users may find it difficult to process this question-answer structured information when they search for less action oriented information. To what extent the current structure of MRSA-net offers information that users can process effectively depending on their information need will be researched. Again, this will be applied in the new platform by adjusting the content and structure to user goals.

In sum, we apply the ceHRes roadmap by starting with a summative evaluation of MRSA-net. This evaluation also serves as input for the contextual inquiry phase of Eursafety Health Net and renders input for the eDEHN-platform. We start our research by posing the following questions:

II. RESEARCH QUESTIONS

1. How can the platform be positioned on the Internet in terms of accessibility?

2. How can we make navigation and content smart, simple, and tailored to user needs?

3. How can we supply content based on mental models of intended users?

4. Can we enhance the effectiveness in terms of successful information supply?

III. METHODS

A. Dataset (logfiles)

MRSA-net use has been logged and data on general use are available via the web-stats program (AWSTATS) in the content management system. This data consist of visitors, page views, users, entry and exit pages, etc. logged since March 2008 until present. To give an indication of the dataset's size: in 2009, MRSA-net was visited 154,894 times with on average 4.33 pages viewed per visit.

In addition, specific pages accessed have been extracted into a dataset offering more precise information on individual user actions: User type (public or professional, German or Dutch), search strategy (web site search engine entry, frequently asked questions, or topic selection), viewed answer, and session duration are available for analyses.

B. Data-mining, content analysis, and card sort

Data-mining has been used previously to get an insight into use patterns and information need of website users [16] [17]. We decided to apply this method because since its launch, MRSA-net traffic has been logged and we thus have empirical data of > 2 years MRSA-net use. These log files can tell us how MRSA-net is used and to some extent by whom, or in other words, give a 'digital fingerprint' [18] of MRSA-net users. Similarly, information accessed on certain topics within MRSA-net can be identified and the extent to which the website fulfills the information need can be demonstrated through analysis.

To get an insight into MRSA-net use and its performance in meeting user needs, we start with giving an overall picture by reporting general statistics such as visit numbers and frequencies of certain topics accessed and search methods applied (macro-level log analysis).

To assess whether the actual topic structure fits the information need of MRSA-net users and whether new topics need to be addressed, we perform a content analysis on the questions posed via the website's search engine. Per user group (German/Dutch, Professional/Public) we will perform card-sorts with the questions posed on MRSA-net as input to identify new topics. These new topics as well as the 'fit' of the current information structure with actual user information need (number of topics accessed) will be validated subsequently in interviews with members of the MRSA-net target user groups.

Finally, we take a look at the sequence of activities performed by single users through micro mining analysis [17] to gain insight into the way the website is used, what purpose it actually fulfills opposed to initial design ideas, and to what extent user are successful in fulfilling their information goals with the website. For example, a single user who scrolls through many topics on the website may not indicate a user who has one practical (protocol) question, but points towards a user wants to learn more about MRSA control in a broad sense.

In sum, we will combine general log analysis on a macro level, content analysis of open search queries, and micromining analysis to answer our research questions.

IV. PRELIMINARY RESULTS

Although we have not yet terminated our analyses, we anticipate that our research results in more efficient ways of disseminating information regarding infectious disease management and patient safety. Thus, in the development of the eDEHN platform, information structure will be tailored towards user goals and needs based on MRSA-net analysis outcomes. User specific differences in information need and subsequent website use by the different user groups will be used as focal points in the development of the Eursafety Health Net platform to ensure the platform meets user (and stakeholder) needs. 1. Some preliminary findings include the observation that although users are expected to enter the website via the homepage where they are instructed and guided towards the information they need, users most often enter MRSA-net directly on answer pages via bookmarks, hyperlinks, or search engines. For example, it is observed that internet search engines (like Google) stably account for about 70% of all visits. This strategy of (knowingly or unknowingly) skipping the homepage holds implications for the positioning and timing of introductory information; the aims, trustworthiness, and reliability should be always recognizable for users regardless of how they access the information.

2. In addition, user-assisting features such as the breadcrumb trail become useless when users directly access answer pages. This means we should have a clear understanding of when these features are useful and supportive for navigation or user orientation, and apply them accordingly.

3. Another preliminary result that calls our attention is that some users tend to have long sessions (more than 20 minutes) on MRSA-net, accessing a multitude of (different) answers. This may indicate that these users cannot easily find the information they need on MRSA-net or that they have diverse or broad information needs. In both cases, a more optimal fit between user and technology (structure and content) is needed.

4 A remarkable finding is that professionals and public may have similar information needs, or they have no clear ideas about what they can expect when entering via the public professional entry. Users switch between professional and public content, indicating that (professional) guidelines insufficiently address public concerns. For example, a mental health care worker may start searching in public content, but finds out that professional content (guidelines/protocols for MRSA-control in health care facilities) apply to the institution where he/she works too. Thus, they cannot be divided into public or professional easily. Users may not always know which category they belong to, thus information should be aimed towards user goals instead of user identity. In addition, clinical guidelines should provide sufficient information on public-topics in (semi-)professional settings, since HCWs do not provide care in a professional vacuum.

The preliminary results indicate we need a better system for searching, finding, and using information. Eursafety Health Net platform can benefit from further research into information search behavior and dialogue optimization, which will be inspired by the upcoming results of the present research. It will be our challenge to supply information and facilitate communication in ways that keep adjusting and responding to our users' needs. Future research activities include:

• Positioning via stakeholder meetings via needs assessment and co-creation

• Focus groups with key stakeholders to define the features most in need and requirements for the platform

• Interaction, dialogue optimization based on needs assessment, experiments, and data-mining (current research)

• Content management optimization based on datamining (current research) and user tests.

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