

# Participatory development via user-involvement - A Case Study about the development of a Web-based Patient-communication system about Methicillin-resistant *Staphylococcus aureus*

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## Abstract

This paper describes the participatory development process of a web-based communication system focusing on disease management, particularly infection control of Methicillin-resistant *Staphylococcus aureus* (MRSA). These infections are becoming a major public health issue; they can have serious consequences such as pneumonia, sepsis or death [1]. This makes it even more important for people to be provided with up-to-date and reliable information. Users of a bilingual communication system (Dutch and German) participated in the development process via a needs assessment, the co-creation of the content and the system via usability tests, and in the summative evaluation of the usage of the system. The system enabled users to search efficiently and effectively for practical and relevant information. Moreover, we found that the participation of the intended users is a prerequisite to create a fit between the needs and expectations of the end-users, the technology and the social context of usage of technology. The summative evaluation showed that the system was frequently used (approximately 11,000 unique visitors per month). The most popular categories include 'MRSA in general' (20%, both languages) and 'Acquiring MRSA' (17% NL, 13% GER). Most users enter the site using internet search engines (Google) instead of the on-site search engine. When they are on the site, they prefer convenient searching via FAQ or related questions. Furthermore, the results showed that the participation of stakeholders is a prerequisite for a successful implementation of the system. To guide the participation of stakeholders we developed a roadmap that integrates human-centered development with business modelling activities.

**Keywords:** *patient education; infectious diseases; participatory development; human-centered design; business modelling*

## 1 Introduction

The participatory development of eHealth technologies is an approach that is used to maximize the fit between the technology, its intended users and other stakeholders like payers, providers, decision-makers and the environmental context in which the technology is used [2-4]. By participating in the development process, the intended users are involved in creating a technology that meets their expectations, while at the same time creating a sense of ownership and trust in the technology to be developed [5-10]. User-involvement in eHealth technologies is highlighted in several studies but is often limited to the design stage: testing the prototypes [11]. In our view, users have to be involved continuously, right from the start of thinking about a certain technology that will support health promotion [4, 12]. User-involvement is particularly important in the case of communication geared towards managing diseases that have an impact on the quality of life [13].

From prior research we know that web-based technologies are valuable because of the capacities to attune the information to users' needs and their mental models about risk-management [14-15]. A second benefit of web-based technologies is that it is easy to provide multi-media instructions (text, graphics, videos) [13]. A third benefit is the opportunity to consult information irrespective of time and place and without having to involve other care professionals; a benefit for people with taboo problems like infectious diseases.

Since infectious diseases like MRSA are ever more prevalent among healthy people, animals, and in raw meat and since infectious diseases can have serious consequences such as pneumonia, sepsis or death, they are becoming a major public health issue [1, 16-17]. Consequently, it is even more important now for people to receive up-to-date, trustworthy and consistent information. In the case of MRSA it is very important that people know what has to be done in the event of an outbreak. However, we know from prior research that patients or members of the general public have limited knowledge about how to manage risk in the case of infections or outbreaks, that misconceptions exist and that most of the information available seems too medical for a lay-person to understand [14].

Apart from informing the general public, it is important to provide those people who are colonized or infected with MRSA with the information they need. Being colonized or infected appears to have a large impact on the carrier's daily life. Since MRSA is very contagious, patients with MRSA have to be hospitalized in isolation, and also take numerous precautions at home, such as maintaining a strict hygiene regime

and avoiding any contact with ill people. Consequently, harbouring MRSA in the home situation has been associated with adverse effects such as anxiety, depression, reduced quality of life, as well as indirect effects such as being denied access to healthcare facilities [18].

In order to decrease anxiety and dispel any feelings of uncertainty among MRSA-carriers (patients with MRSA), it is of vital importance to provide them with reliable, consistent information at all times regardless of where they live or what time of day it is. Previous research indicated that MRSA-carriers perceived current education as deficient and misleading [18]. In addition to this, healthcare providers were perceived as unprofessional since they could not answer relevant questions. Our goals, therefore, were to improve education for MRSA-carriers in the home situation by developing a web-based communication system that meets both cognitive (practical) and affective (personal) information needs and to provide healthcare providers with information that is easy to access and to use. The communication system consists of two parts: one aimed at patients and the general public, the other aimed at health care workers (HCWs). This study focuses on the first part.

The *societal objective* of this study is to develop a web-based system that enables MRSA-patients and members of the general public to efficiently and effectively search for practical and relevant information that can support them in their efforts to cope with the MRSA infection and empower them to take appropriate measures to prevent outbreaks and further complications. This study is part of an international project, MRSA-net (<http://www.mrsa-net.nl>) that aims to control MRSA and facilitate patient safety via cooperation and information sharing for both health care workers (HCWs) and patients or the general public.

The design of most educational resources directed at MRSA-carriers relies primarily on the conventional wisdom of experts, rather than on an evaluation by its intended target group. It is therefore not surprising that MRSA-carriers often miss the point and become confused. To overcome this problem, we applied a participatory development approach, involving the primary target group; MRSA-carriers. We expect that this system will not only be used by this primary target group, but also by a secondary target group that consists of patients' relatives and members of the general public that are interested in, or worried about, MRSA because MRSA is observed more and more in the community (CA-MRSA). In the first stages of our participatory development process, we concentrated on patients, the primary target group, to attune the protocol-based information to their needs. The summative evaluation

includes data from all users; patients, members of the general public and also HCWs.

The *research objective* is to determine the extent to which a participatory development process can be supportive for developing human-centered eHealth technologies as opposed to expert-driven information systems.

## 2 Methods

Participants in the study consisted of patients that had been (formerly) colonized or infected with MRSA. Their contact details were obtained by infection control nurses from various hospitals and public health institutions in the Netherlands. Respondents participated in the process at their own convenience. Data was collected continuously throughout the development, between March 2007 and September 2008. A summative evaluation is being performed on usage data available since the tool's launch in February 2008 up until December 2010. The summative evaluations started in September 2010.

The system's target audience includes patients and members of the general public as well as HCWs. However, as their (information) needs differ, the development process was carried out separately. This study focuses on patient participation, however, HCWs were involved in the development process in a similar way.

The development process described in this study consists of four methods for ensuring the involvement of users (1) contextual inquiry (needs assessment), (2) design via Card Sorting aimed at creating the content and navigation structure of the web-based system, (3) usability testing of the first working prototype and (4) summative evaluation of the usage in practice via log files to assess the pragmatic value of the web-based system.

(1) The contextual inquiry (a needs assessment) started with a systematic analysis of MRSA-carriers' information needs in order to obtain input for the system's content. Semi-structured interviews with 22 MRSA-carriers based on stress- and coping theories [19] were carried out to investigate cognitive and affective information needs. Three types of MRSA-carriers were involved: people with Community Acquired MRSA (CA-MRSA; n=6), Hospital Acquired MRSA (HA-MRSA; n=8), and Veterinary Acquired MRSA (VA-MRSA; n=8). The interviews generated 220 key questions that caused feelings of stress among MRSA-carriers, but remained unanswered by current information providers, while their answers are nevertheless required to cope with MRSA in daily life. The current information is

based on brochures and infection protocols for personnel rather than patients.

(2) Design of the content and structure of the web-based information system via a Card Sort method among 10 of the interviewed MRSA-carriers and Mock-up-prototyping. Card Sorting is often applied as a user-centered method for designing a website's menu structure [20]. Respondents sorted a selection of 100 out of the 220 questions into meaningful groups that eventually served as the system's navigation structure. Subsequently, two mock-up prototypes of the homepage and the search page were created, based on common guidelines for web design and usability [21-22]. We interviewed five different MRSA-carriers to evaluate the prototypes shown on a laptop, and based our choice for the final lay-out of the system on the results. We checked whether or not the information conflicts with the standard precautions for infection control (National MRSA guidelines).

(3) Usability testing of real-time usage. The evaluation was carried out immediately after the first prototype was developed. The first working prototype of the web-based system was evaluated among 18 other MRSA-carriers by means of scenario-testing; a method commonly used to determine website usability [21]. The sample consisted of people that carried CA-MRSA (n=3), HA-MRSA (n=4), VA-MRSA (n=4), people that had been suspected of carrying MRSA and were therefore treated in quarantine in the hospital (n=3), and four representatives of the general public (n=4). The scenario method is of high value, since users are in a unique position to provide early, authentic feedback and it enables the researcher to explore problems encountered while real users work with the website [23]. Respondents carried out scenarios that represented the information needs identified in the needs assessment, while thinking aloud. For example: "*You are colonized with MRSA and you would like to know whether you can visit your ill grandmother. Using the web-based system, can you say aloud what you need to do?*" The results demonstrated how far MRSA-carriers' cognitive and affective information needs were met. The inadequacies that were detected during the scenario-based tests were fixed before the system was officially implemented.

(4) Summative evaluation is performed by analysing the available log files. MRSA-net use has been logged since its launch and we thus have empirical data of more than 2 years of use. This comprises both usage data of activity on the HCW part of the system as well as usage of patient-aimed content. The data on general use are available via the built-in web statistics program (AWSTATS). This data shows the number of visitors, page views, users, entry and exit pages, etc. that have

been logged since March 2008 until the end of 2010. To give an indication of the dataset's size: in 2009, the web-based system (<http://www.MRSA-net.nl>) was visited 154,894 times with on average 4.33 pages viewed per visit.

In addition, specific pages that were accessed have been extracted and compiled in a dataset that offers more precise information about individual user actions: visited content type (general public or HCW, German or Dutch), used search strategy (on site search engine, frequently asked questions, or topic selection), viewed answer, and session duration.

These log files show us how MRSA-net is used and, to some extent, by whom. In other words, these files give us a 'digital fingerprint' [24] of MRSA-net users. Similarly, information accessed on certain topics within MRSA-net can be identified and the extent to which the website fulfils the information needs of its users can be demonstrated through analysis. In this study we focus on the participatory development approach of the web-based system and its usage by patients and members of the general public.

### 3 Results

In this section, the results of the different methods used for developing the web-based system will be presented consecutively.

#### 3.1 Contextual inquiry: needs assessment

Being colonized or infected with MRSA turned out to be a stressful experience. In most cases (52.5%) of stress mentioned, the stress was caused by factors on the affective or personal level (e.g., feelings of stigmatization, fear, depression) and cognitive level (e.g., lack of knowledge). In 20% of cases, MRSA-carriers used emotion-focused coping strategies to deal with the stress, such as venting feelings, seeking social support, or distraction. In 75% of the stressful events, information-seeking strategies were used to cope with the stress. Sixteen respondents (73%) indicated that they had consulted the internet in order to look for MRSA-related information. However, in 83% of cases, the required information was not successfully identified. Other information sources that were consulted included brochures, information leaflets, or healthcare providers (public health institutions in particular).

We discovered 385 incidents of information need, either of a cognitive nature or an affective/personal nature. Cognitive information needs involved:

- General information (122 incidents), such as:

"What is MRSA?", "To what degree can I contaminate others?", "Where does MRSA come from?", et cetera.

- Information regarding the hospitals' MRSA-policy (49 incidents), such as "Why can my father, who is a pig farmer like I am, visit me in the hospital without any protection measures whilst I have to be nursed in isolation?"

Affective / personal information needs concerned:

- Practical information needs (132 incidents), like "Can I still have sex when infected with MRSA?", and "I am a teacher. Should I tell people at work that I am MRSA-positive?"
- Medical information needs (82 incidents), e.g., "Where can I obtain swabs?", "How should I take the antibiotics?"

Surprisingly, we found that the amount and type of information needs differed among the various types of MRSA-carriers: VA-MRSA carriers experienced relatively fewer information needs (84 out of 385 incidents) compared to CA- and HA-MRSA-carriers. VA-MRSA-carriers were served best with information on the hospital's MRSA policy. Carriers of CA-MRSA indicated that they needed both general and practical information, whereas HA-MRSA carriers had medical information needs.

The 385 incidents in which information was expressly required together represented 220 different questions related to MRSA. Since respondents indicated that answers to these questions would definitely help them to cope with MRSA in daily life, we assumed that MRSA-carriers would benefit most from a question-oriented system conform the needs of care professionals [14]. Therefore, we decided to structure the system's content around the identified questions. The answers were based on standard MRSA-precautions, and were complemented by a medical microbiologist who was involved in the research project. The answers were directly communicated to the user in an instructional, imperative style, e.g., "*You* should wash your hands frequently and cover your wounds." All answers were presented in a uniform way according to the following standardized structure: title, short description, comments, sources, and multimedia examples [25]. Users were allowed to decide upon the level of detail of the answer they wished to obtain, because next to the short answer, in-depth elaborative answers were provided, even in the form of sources (e.g., scientific literature, newspaper articles, links to websites for further reading, and explanations of the suggested topics). If possible, multimedia examples (e.g., instructional movies,



pictures illustrating how to adequately apply personal protective equipment) were added as well.

### 3.2 Card sort and prototyping

The Card Sort methods resulted in eleven categories according to which the 220 questions resulting from the needs assessment could be structured. The categories identified by patients were: (1) MRSA in general; (2) Acquiring MRSA; (3) Testing; (4) Treatment; (5) In the hospital; (6) Hygiene and cleaning; (7) Contact with others; (8) Pregnancy and baby; (9) MRSA and my occupation; (10) the Netherlands and other countries, and (11) Contact. Together, categories 1 to 6 and 10 represented cognitive information needs, whereas categories 7 to 9 and 11 met affective/personal information needs. Furthermore, categories also served the needs of the various types of MRSA-carriers: VA-MRSA-carrier's information needs were met by category 5, CA-MRSA-carriers' general and practical information needs were addressed in categories 1, 2, 6, 7, 8, 10, and 11, and the needs of HA-MRSA-carriers were answered in categories 3, 4, and 9.

Compared to general patient information materials, in which a more expert tone-of-voice is used, patients preferred a more practical approach of presenting information. Instead of using medical terms like "decontamination", MRSA-carriers indicated a high level of appreciation for terms that matched their expectations of medical information such as "Treatment" and "In the hospital". Based on the users' information retrieval preferences, the web-based system was equipped with two extra search functionalities next to the categorical search function based on the Card Sort Study: a Most Frequently Asked Questions search and an advanced question-answering system that enabled users to search for answers in their own vocabulary and language (Dutch, German). Feedback on the users' location on the system was provided by means of a breadcrumb trail on top of the page, to enable them to keep track of their location within the system to avoid "getting lost".

Furthermore, a self-learning functionality was incorporated in the web-based system. This function enabled the questions that were looked up most frequently to be ranked higher in the list when the users used the search engine or browsed through the categories. A dedicated content management system enabled the project-team to keep the system up-to-date by adding and deleting questions from patients at any time and at any location. This system also allowed the content to be continually updated based on the needs of patients (they can give feedback via a specific information button) and provided new insights into precautions for infection

control, which is of vital importance because infection control policies are frequently subject to changes. In addition, the content management system enabled the project team to access log files that record general system activity. Questions that were not yet answered by the system could be easily added to the content management system.

We applied a research-based web design and usability guidelines when creating two non-working mock-up prototypes, taking into account the needs assessment results [25]. The mock-up prototypes each consisted of two pages (a homepage and a search page), and showed the system's lay-out and navigation. We asked patients to indicate their preference for one of the two prototypes, and choose the one that elicited the most positive reactions, such as "the convenient structure" (n=3), "the topic MRSA is presented clearly" (n=4), and "the trustworthiness suggested by the logos of the organisations taking part" (n=2). The content that resulted from the needs assessment, and the structure and lay-out that was generated by the design phase, were integrated into the first web-based working prototype. Figures 1 and 2 depict the final version of the web-based system. The system is free and accessible without the need to login. Users can choose between patient or HCW content (see Figure 1, numbers 1 and 2 respectively), to best fit their search. However, switching between the different types of content is possible.

### 3.3 Usability Testing

A usability test of the first working-prototype was carried out. Eighteen (18) patients completed 110 concrete-scenarios, of which 97 (88%) were successfully completed in an average of 131 seconds. According to the respondents, the high efficiency and effectiveness with which they could retrieve information on the system was affected by the following factors:

- **Action-oriented content:** The evidence-based content was presented in a practical manner, which was highly appreciated by the respondents. Since the information on the system represented MRSA-carriers' information needs as identified in the needs assessment, the information was perceived as very relevant, as shown by the following citation: *"If I would click on everything that I wanted to know more about, it would take me an hour and a half!"* Also, the information on the system created feelings of recognition (*"patients like me"*) and reduced feelings of insecurity. For example: *"This information is very important. Had I known about this website at the time I was coping with*



Figure 1: Homepage 1=Entry button for content aimed at the general public (MRSA carriers/patients); 2=Entry button for content aimed at HCWs; 3=Button for the choice of Language (Dutch/German)



Figure 2: Search page 1=Search engine; 2=Categories resulting from the Card Sort Study; 3=Most Frequently Asked Questions; 4=Breadcrumb trail; 5=Structured answer (title, short answer, comments, sources, multimedia examples, and related answers [not visible])

*MRSA, it would have solved so many unclear issues.” Respondents even stated that the system empowered them to take a proactive role in their own healthcare: “I asked the healthcare worker to take screening cultures since I am living on a pig farm and therefore run a high risk of carrying MRSA. If I had not asked for it, the swabs would never have been taken.”*

- **User-generated search structure:** In the majority of cases, the categories (as resulted from the Card Sort Task) were used to search for information to solve the scenarios. Patients appreciated the categorical search function, since it enabled them to orientate themselves towards the information that could be found on the system. Moreover, the fact that each category consisted of several relevant questions around the same topic inspired them to learn more about the theme. However, when patients wanted to formulate a specific query, the search engine was used. The combination of search strategies and continuously visible search functions caused the patients to perceive the system as very efficient: *“The good thing about this website is that it not only enables you to quickly look up a practical question in your own language, but it also gives you the chance to look around and read whatever you think is interesting.”*
- **Multimodal presentation of information (lay-out):** The combination of several types of sources (news, websites, scientific articles) and modalities (videos, pictures) was valued positively. It facilitated the ease with which information was understood and could be applied to daily practice.

Alongside the web-based systems’ benefits, we detected several flaws. First, it appeared that the information was not optimally tailored to the specific information needs of the three groups of MRSA-carriers. The VA-MRSA carriers, in particular, who experienced the lowest information needs during the needs assessment, believed that the information did not adequately fit their needs. They felt that most practical information was addressed to CA- and HA-MRSA carriers, whereas VA-MRSA indicated that they also wanted to know how to cope with MRSA in their daily (work) routine. In response to these problems, one category, “Animals and pig farms”, was added. Secondly, the information structure did not function optimally since respondents did not use the cross-links between questions. They were not aware of this function because they hardly ever scrolled down the page. We resolved these issues prior to the web-based system’s official launch.

### 3.4 Summative evaluations

Since its launch in February 2008, MRSA-net has achieved increasing numbers of monthly visitors. By the end of 2010 it has stabilized at approximately 11,000 unique users of the system per month (both patient/general public and HCW-targeted content). Of these users, 38.7% visited Dutch content, 59.6% visited German content, and 1.7% viewed both types within one visit. Users entered MRSA-net directly using the URL or a link 35,887 times (41%) in 2008; 81,806 times (30%) in 2009; and 107,789 times (30%) in 2010. However, most often users are referred to MRSA-net by an internet-search-engine: 51,519 times (59%) in 2008 (of which 84% via Google); 194,062 times (70%) in 2009 (of which 96% via Google); and 248,518 times (70%) in 2010 (of which 98% via Google). This result is in line with the observation that users often entered MRSA-net on an answer page as opposed to the intended route via the homepage: 23,187 times in 2008, 85,545 times in 2009, and 118,978 times in 2010.

Another result from the summative evaluation that demands our attention is the considerable number of visits that lasted more than 5 minutes and in some cases up to 30 minutes which seems rather long; 6,795 visits (14%) in 2008, 19,914 visits (13%) in 2009, and 30,617 visits (16%) in 2010. During these visits users accessed several (answer) pages. This may indicate that they either had various information needs, or that they could not easily find the information they needed.

To illustrate how users search for information in the patient/general public section of the system, we performed preliminary analyses on the search methods users applied once or more during the space of one visit. Figure 3 illustrates these numbers; the answer pages were accessed directly via an external referral 43,055 times (NL) and 61,374 times (GER), thus via a direct link or search engine. Related questions that are displayed below the answers were used 22,724 times (NL) and 29,866 times (GER) to access answer pages. Further, Figure 3 shows that the categories, (no. 2 in Figure 2) were used 16,023 times (NL), and 25,105 times (GER), respectively, to find information. The Frequently Asked Questions, number 3 in Figure 2, were used 3,991 times (NL), and 12,152 times (GER), respectively. An open search via MRSA-net’s search engine, number 1 in Figure 2, led patients 958 times (NL) and 2,165 times (GER) to the answer pages. In 3,379 (NL) and 4,639 (GER) cases, no search was carried out and no answer was viewed. Usually, these users looked at one or more news messages.

Figure 4 shows the categories that were used for searching information. Between July 2008 and the end



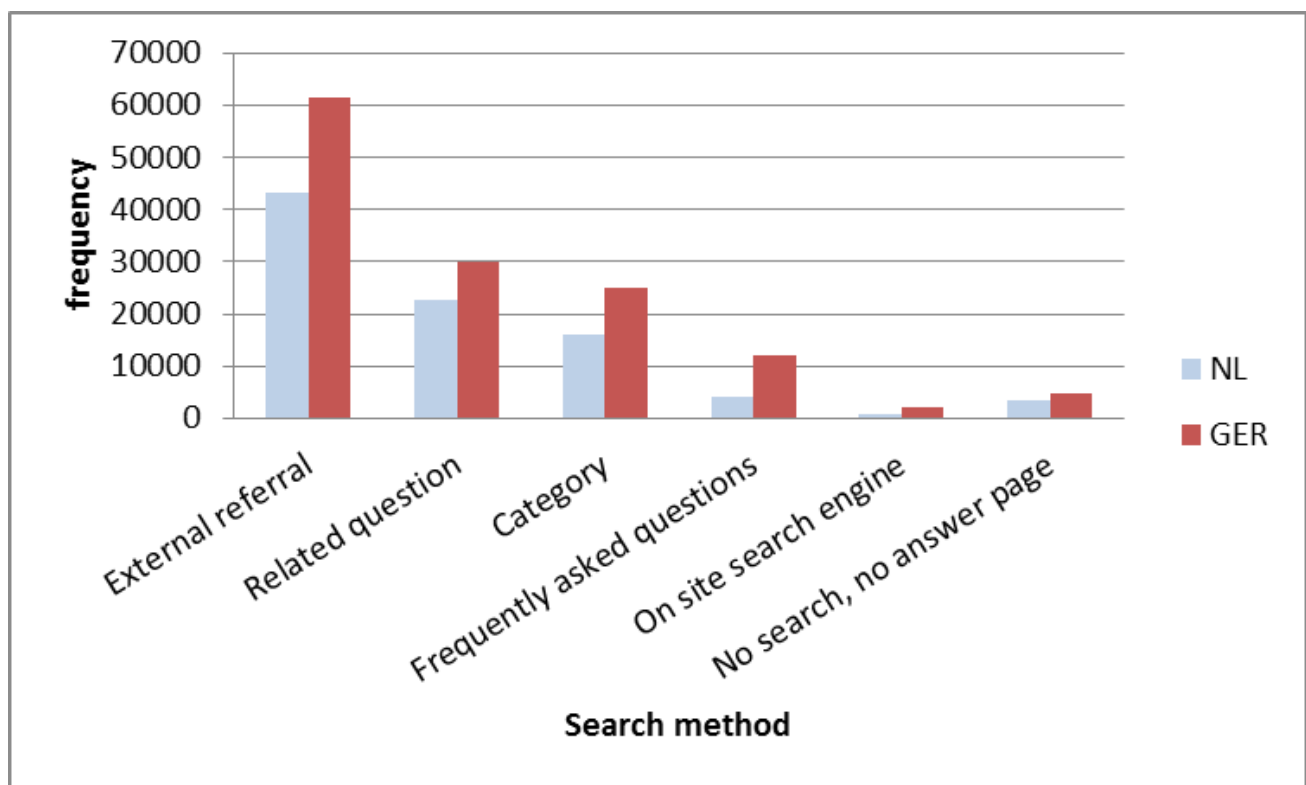


Figure 3: Frequency of search methods used within a visit, in numbers.

of 2010, the categories on the patient-targeted content of the system were used 101,024 times (NL), and 163,547 times (GER). As depicted in Figure 4, the most frequently used categories are ‘MRSA in general’; 20% (NL), 20% (GER) and ‘Acquiring MRSA’; 17% (NL), 13% (GER). Figure 4 further shows that the categories used least often are ‘The Netherlands and other countries/Germany; 2% (NL), 2% (GER), and ‘eContact with a hygiene expert; 1% (NL), n/a (GER).

A first screening of the data further showed that a number of users switch between HCW and patient/general public content within one visit; in 16,842 (6%) visits both content types were accessed. This percentage seems quite low, but considering the fact that a lot of users visit only one page, it can be concluded that a considerable percentage of the users who visit more pages, switch between the content types. This indicates that information aimed at patients and the general public insufficiently addresses public concerns, that patients need more professional information or that the patients (and members of the general public) and HCWs have similar information needs. In other words, that tailoring information towards patients or HCWs is, to some extent, artificial.

## 4 Discussion

Since the advent of the Web, the practice making information available to patients information has gone through a paradigm shift. No longer is the healthcare provider the sole gatekeeper of medical knowledge. Patients and members of the general public have more and more recent medical information at their fingertips, and more time to read it than their health providers [26]. However, the design of most online patient information and education systems relies primarily on conventional wisdom among experts, rather than on evaluation by its intended users. It is not surprising, therefore, that patients often miss the point and become confused; a situation which is often further compounded by their inability to determine the reliability of the information source.

The participatory development process as described above proved effective for attuning the information needs to the patients’ demands and expectations. The study provided us with a user-centered system that enables MRSA-carriers to efficiently and effectively search for practical information, which contributes to the ease of coping with an infectious disease in daily life. Because MRSA-carriers indicated that their information needs were often of a practical nature, we tried to couple information on the web-based communication system to the relevant activity. By ensuring that the

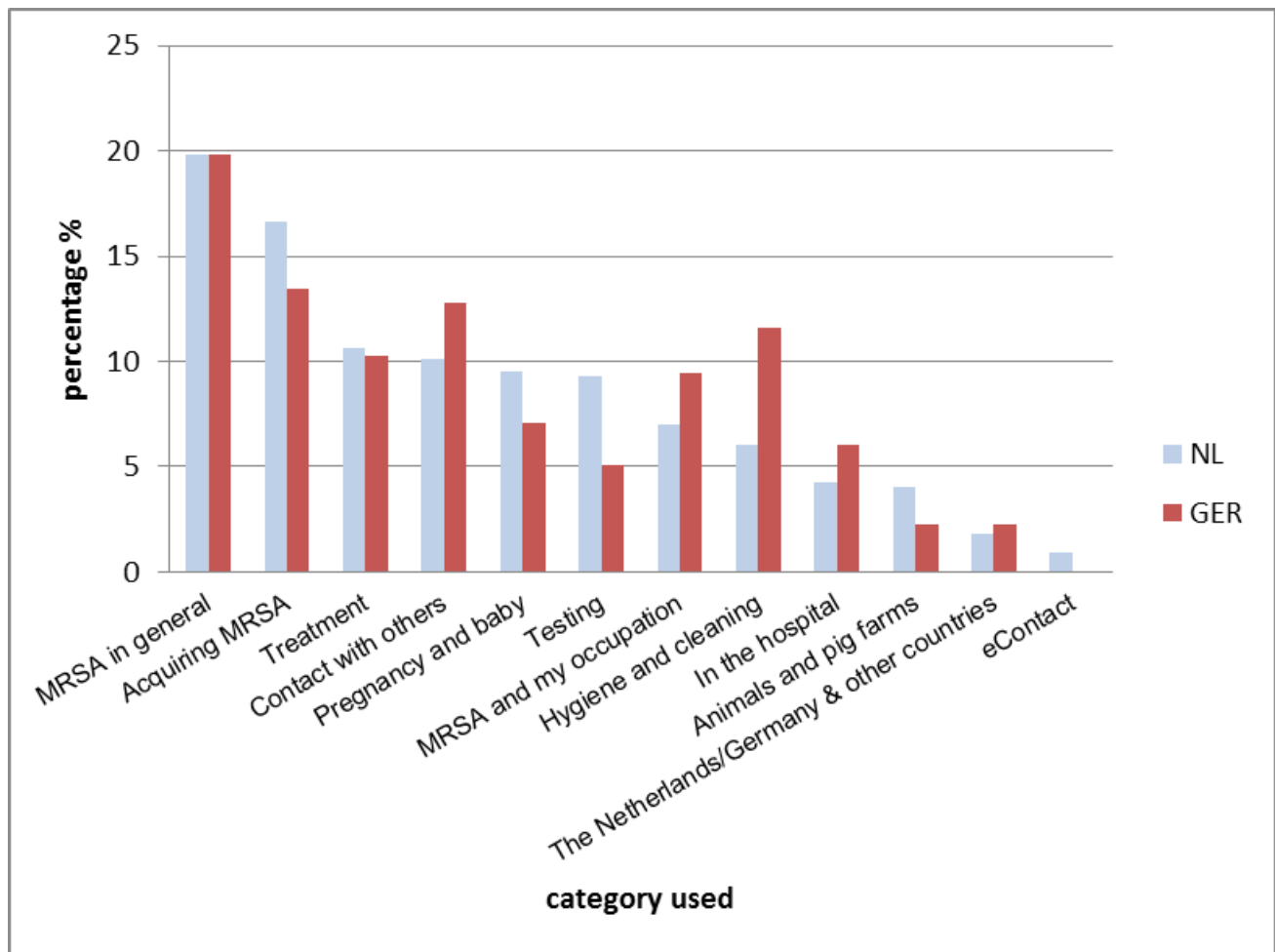


Figure 4: Categories of the system that were used; in percentages.

information is there whenever, and in whichever format he MRSA-carriers want it, we anticipated that good quality information forms the basis for MRSA-carriers to make informed choices about their actions, which fits the concept of Information Therapy [27].

In addition, the internet enables tailored communication to different target groups, which might be beneficial for the three different types of MRSA-carriers (VA-, CA-, and HA-MRSA) that we involved in our study. This study showed that information needs depended on the type of MRSA people carried. By considering the different information needs of various patient groups, the information has the maximum impact on knowledge, attitudes, and subsequent safety behaviour [27]. By including relevant dynamic and visual media, this effect might be enlarged. The content appeared to be of value for a variety of users, including HCWs, patients and the general public given the fact that the system is used frequently and ranks third when searching for MRSA with Google (in Dutch, without applying (paid) search engine optimization). Besides, the web-based system enables self-management, given the fact that the eContact category (consult a hygiene expert if you have any questions) was hardly used.

As our results show, internet search engines, mainly Google, are used to find the system and its contents. "Googling" is thus an important factor for locating or finding a web-based communication system. Google might have replaced the on-site search engine that was hardly ever used because this Googling-strategy is more in line with the users' searching habits. Since internet search engines lead many users to MRSA-net, and using search engines is common when searching for health-related information [28-29], we must ensure that the health information sources we develop (including MRSA-net) are found, and will continue to be found, via these search engines, and that such direct access does not result in important explanatory information being missed. Thus, on-site search engines seem irrelevant when the information is sufficiently indexed by internet search engines. Having a smart navigation structure would seem to be more relevant; one that offers suggestions to users and assists users who spend more time on the site when searching for information. This view is supported by the finding that the "related-question" search method (Figure 3) was the second most frequently applied method.

Although this research project showed many benefits of user-involvement, it also revealed some weaknesses. These concerned the voluntary basis on which MRSA-carriers participated that might have biased the results, together with the small sample size, which possibly impeded generalization of the results to other contexts. To

overcome these limitations, we carried out a summative evaluation via an analysis of the log files to identify whether the usage (questions asked) represents the content structure of the current system. Ongoing analysis will show if new categories emerge, possibly due to the aforementioned selection bias and/or a change in MRSA policy (because of the increase in outbreaks in public health).

Another limitation is that the log files are not reducible to patients with MRSA or members of the general public, due to the freely accessible system where no login is needed for reasons of expanding accessibility without restrictions. The distinction between members of the general public or HCWs may suffer from a similar bias because this separation is based on the self-chosen content type (HCW or member of the general public, numbers 1 and 2 in Figure 1) that users entered. Thus, we cannot be sure that the users who entered HCW content are indeed HCWs. Also, since many users entered the answer pages directly via Google referral, which requires no user type at all to be selected, we can only determine the type of content they viewed, not who they are (HCW/patient). This tailoring of content to user type (HCW or patient/public) may have become redundant. The distinction between HCW and patient information needs may fade in time, caused by the accessibility of medical information on the internet to patients, members of the general public and HCWs.

In any case, the summative evaluation shows the importance of a participatory development approach of a web-based communication system and the need for an advanced navigation system and adaptive and flexible content management system.

#### 4.1 Future research to optimize the MRSA information system

To gain more insights into the actual use of the system, as opposed to intended system use, we plan to carry out the following research activities.

Optimizing the content and the system:

- Validation of the content-structure through log file analysis. By first analyzing which strategy is used most often to access answers on MRSA-net, the rationale of providing a topic structure can be validated or refuted.
- Combining frequencies of topics and answers accessed on MRSA-net with a content analysis through card sorting of questions posed on the system's search engine. This enables us to confirm whether the categories fulfill the users' information needs, whether there are unused categories,

or whether new categories have emerged that are currently not supported by the topic structure and MRSA-net content. This enables us to validate the user-centered methods that were used to create the structure. It is important to keep the content up-to-date, according to users' information needs. The information needs that become apparent from real-life searching practice on MRSA-net, as opposed to the research setting, indicates whether the methods used (scenario-based testing, card sorting) have resulted in good structures.

- Data-mining will be applied to the log files to further search for use patterns and provide a so-called digital fingerprint of the MRSA-net [24, 30]. This information will then be used to find out how the interface needs to be designed and how it should function to serve all users. Since preliminary results show that users search for information in their own domain (public content) as well as professional content, we need to conduct more research into the differentiation of users (professionals and members of the general public) to best serve their information needs and facilitate searching. Possible differences in search behaviour that become evident from the mining techniques will enable us to automatically fine-tune content to users.
- To accommodate different users with different search or use strategies we think that, besides studying current user actions, we need to continuously use this data to optimize the question and answering-system. Based on previous user activity, the system can suggest content that may be of interest and such a strategy seems to fit with our observation that except from (short) Google-referred visits, during visits convenient searching (related questions and FAQ) is applied often. Since patients are often unable to express their need for a specific type of information in a single, self-contained query within the medical domain [31], the search system will allow patients to ask for clarification, make corrections to the system's interpretation of utterances, and ask follow-up questions. Search engines that help users specify their query already show promising results [32]. Consequently, tailoring information and eliciting user input will be the focus of our future research activities.

#### 4.2 Future research to develop other web-based communication systems

Although MRSA-net served as a case study, the methodology can also be used to develop patient education

about all types of infectious diseases, such as ESBL, HIV, hepatitis, etc. and reducing the use of antibiotics to prevent resistance. One of the main findings of this study concerns the usefulness of the methods for participatory development. It can be concluded from this study that the methods used for content design (Card Sort) are valuable because after two years of usage most categories remained intact. This means that the Card Sort method is a useful tool for fine-tuning the information structure to the mental models of patients/members of the general public [14].

However, the results made clear that a participatory development approach involving the end-users is beneficial but not sufficient for the implementation of a web-based information system in public healthcare. Experts (e.g., hygienists) and policy-makers (e.g., National Institute for Public Health and the Environment) initially expressed their doubts about using the system because they were not consulted in the development process. However, after we explained to them that the content does not conflict with the protocols or standards about infection control and after they started using the system, they became staunch advocates of it. From other studies about developing technologies for the healthcare system, it appeared that stakeholder engagement is important for implementing technologies in healthcare [12].

At the moment, the high popularity of the system in the Netherlands as well as in Germany (an award was given to it for being the best cross-border project) indicates that it has legitimacy in the field of infection control. This requires an extension of the system to a public health service, for (local) Public Health Services and primary healthcare facilities (GPs). To incorporate the web-based system in the healthcare organization, for example in Public Health Services or in primary healthcare we have to involve stakeholders other than the primary end-users in order to elicit commitment and trust in a system that has not been developed by the experts themselves. Nijland [31] also demonstrated that stakeholder involvement appeared to be important in the development of sustainable eHealth technologies that are accessible, acceptable and affordable.

This is of interest for future research aimed at "translating" expert-based infection control information into communication systems for the general public and HCWs to help them understand treatment and improve self-management. This is the subject of future research, EurSafety Health Net; the development of an online communication platform to support all stakeholders (patients, payers, policy-makers, care providers) in the care process and to increase cross-border patient safety (<http://www.antibioticstewardship.nl>).

In our future research, we will carry out a multi-



stakeholder assessment to identify the needs to upscale the system to a web-based platform for cross-border patient safety. From other research we know there is a need for a multi-stakeholder, broader-than-the-end-user perspective to ensure that technologies will be implemented in practice [33]. Stakeholder-testing will be performed throughout the development process to a) get a thorough understanding of the context of infection control and patient safety, b) elicit stakeholder needs and values, c) co-create content for the platform. The stakeholders that will be involved in the development and design phases include experts (e.g., National Institute for Public Health and the Environment, European Centre for Disease Prevention and Control), patients, healthcare workers, and the public. Thus, stemming from the results of MRSA-net research, we will involve end-users as well as other stakeholders in the refinement and upscaling of the current web-based system to a patient safety platform for infectious disease management.

To support the participatory development approach, we will use a roadmap for involving users and stakeholders [34]. Figure 5 shows the ceHRes (center for eHealth Research) roadmap [34]. This roadmap integrates Human-Centered Design with business modelling activities to ensure that the development is guided by stakeholder needs and values and can be implemented successfully. We have learned that implementation and evaluation are continuous research activities that start at the beginning of the development process and involve the participation of end-users and other stakeholders. The roadmap is based on eHealth research and a literature review about current models for participatory development.

## 5 Conclusion

To close, the most important conclusions of this study are summarized below:

- Participatory development involving end-users resulted in a promising web-based communication system for health promotion, fine-tuned to users' needs and mental models about health communication. Intended users were content with the presentation and scope of information. The system appeared to be frequently used in both the Netherlands and Germany.
- Participation of users in a development process requires a rethink about the development of eHealth technologies. Instead of an expert-driven approach, the development of eHealth technologies should be considered as a process of co-creation with the users. Strategies are needed based on empirical studies to decide how, when and with what aims users should participate and what the benefits are, given the required time and cost of user involvement.
- The participation of key-stakeholders is needed to ensure the implementation of eHealth technologies in different care settings (public health, primary, or secondary care).
- Development should be accompanied by the continuous evaluation of, and ongoing adjustments to, the way the information is presented based on users' and stakeholders' needs and goals in order to accommodate them optimally. The ceHRes roadmap that was presented and the accompanying instruments will be used in several research projects to determine its value for practice, policy and research. Therefore, we will present it as an eHealthwiki tool [35].

## 6 Conflict of Interests

There are no conflicts of interest.

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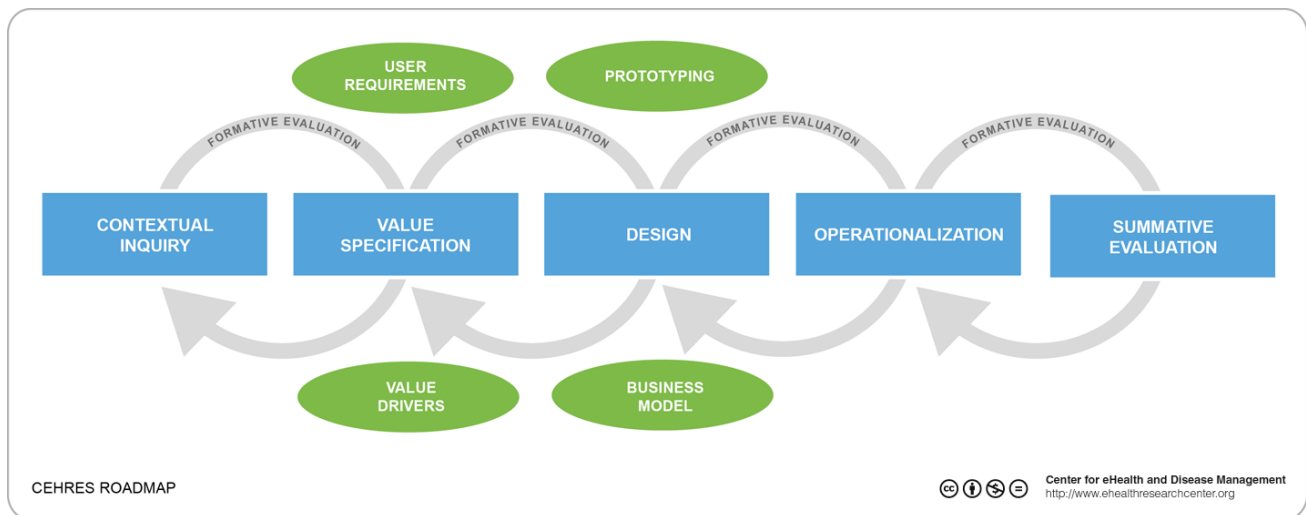


Figure 5: ceHRes roadmap

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