My Health: An Online Healthcare Social Network Inclusive for Elderly People

Submission Type: Full paper

Edhelmira Lima Medina  
Computing Institute  
Fluminense Federal University  
Niterói - RJ- Brazil  
edhyly@ic.uff.br

Daniela Gorski Trevisan  
Computing Institute  
Fluminense Federal University  
Niterói - RJ- Brazil  
daniela@ic.uff.br

José Viterbo Filho  
Computing Institute  
Fluminense Federal University  
Niterói - RJ- Brazil  
viterbo@ic.uff.br

Orlando Gomes Loques Filho  
Computing Institute  
Fluminense Federal University  
Niterói - RJ- Brazil  
loques@ic.uff.br

Abstract

Online Health Social Networks (OHSN) are becoming increasingly important in the life of patients by offering them opportunities for helping people to expose and share health situations, experiences and allowing them to form relationships for offering or receiving emotional support. In this work, we investigate how OHSNs can be made more inclusive for elderly people. Firstly, we describe “My Health”, an OHSN developed by our research group, tailored for patients with cardiovascular problems. We then assess how three well-known OHSNs address accessibility guidelines. The results show that not all developers are implementing the current version of the Web Content Accessibility Guidelines (WCAG 2.0). Using “My Health” as a study case, we perform a usability evaluation with the system’s target users after the implementation such accessibility guidelines. As a result, we conclude that conformance to guidelines does not ensures that the users will not have usage and interaction problems.

Keywords

Accessibility, Online Health Social Networks, healthcare, elderly users.

Introduction

Nowadays, the number of patients who use Online Healthcare Social Networks (OHSNs) is increasing (Chou et al. 2009; Swan 2009). These environments allow people to connect with each other surpassing geographical and time boundaries creating virtual communities (Kamel Boulos & Wheeler 2007). In addition, they allow participants to expose experiences, questions, opinions, emotions and even to build relationships in order to offer or receive emotional support (Chou et al. 2009). Examples of successful healthcare virtual communities, based in popularity, i.e. the number of registered users, are PatientsLikeMe (Frost & Massagli 2009), Dailystrength (Landro 2006), Inspire (Doberty 2008), TuDiabetes (Weitzman 2011), Curetogogether (Dhillion et al. 2011) and MedHelp (Chuang & Yang 2010).

There has been a high prevalence of chronic diseases among the elderly population according to the World Health Organization (WHO). Patients living with chronic diseases, besides requiring a detailed monitoring of their health status, need emotional support to deal with their problems, which requires difficult treatments (Dhillion et al. 2011). In this sense, elderly people are expected to be one of the main target users of OHSNs as a tool for promoting the social integration of chronic diseases patients, allowing the establishment of empathy ties between them. Nevertheless, the adoption of new technologies by this segment of the population is not always straightforward mainly due to the physical and cognitive
difficulties that are typically associated with ageing. Thus, for the elderly to take advantage of new technologies and services that can help to improve their quality of life, such barriers must be broken by from the start by the adoption of designing solutions that approach their special needs. In such sense, accessibility plays an important role in a systems’ success (Teixeira 2011).

This work aims at investigating how to make OHSNs more inclusive for elderly people, improving the benefits of their use. To achieve this goal we performed a survey of existing accessibility problems encountered in three different OHSNs. Afterwards, in a case study, we applied the recommendations from WCAG 2.01 to “My Health”2, an OHSN developed by our research group that focus specifically on patients with cardiovascular diseases (Lima-Medina et al. 2014). As the conformance to guidelines does not ensures that the users will not have usage and interaction problems, we also held a usability evaluation with a group of elderly volunteers to detect remaining interface and interaction problems.

**Literature Review**

**Online Healthcare Social Networks and Web Accessibility**

Online Healthcare Social Networks provide an active platform, where patients, families, caregivers, physicians and other health professionals may share ideas, discuss symptoms and debate treatment options. For elderly patients with chronic diseases, who cannot leave their homes frequently, such online communities are especially important. Consequently, there has been a growing interest in studying how these virtual environments affect the health condition of patients, and several research works have been discussing the advantages of e-health communities (Hess et al. 2010, Letourneau et al. 2012, Chuang and Yang 2010, Sarasohn-Kahn 2008). In particular, patients with cardiovascular problems using Social Networks can benefit from positives experiences, such as giving and receiving emotional support, sharing advices and motivation to continue with their treatments (Lima-Medina et al. 2014).

According to the World Wide Web Consortium (W3C), many elderly users have age-related impairments that can affect how they use the Web, such as declining vision, physical ability, hearing and cognitive ability. Such considerations lead to the idea that, in order to provide adequate support for elderly people, OHSNs must provide ways for all users easily accessing its contents and tools. Web accessibility aims at allowing people with disabilities to perceive, understand, navigate and interact with the web. In 2008, the Web Accessibility Initiative (WAI) released a new version of the Web Content Accessibility Guidelines (WCAG 2.0). These new guidelines attempted to address many of the criticisms that were raised about WCAG 1.0. In general, WCAG 2.0 sets four principles, asserting that web content must be Perceivable, Operable, Understandable and Robust. These principles group the available guidelines in a more structured hierarchy than the one proposed in WCAG 1.0.

We conducted an accessibility evaluation of a set of OHSNs following the guidance of WCAG 2.0, in order to identify which aspects are tackled by their user’s interfaces. For that purpose, we selected some well-known OHSNs: PatientsLikeMe, DailyStrenght and Patient Opinion. PatientsLikeMe (Frost & Massagli 2009) has a great number of registered users from North America, India and United Kingdom. The mission of this social network is to offer a space where patients – with various diseases – and health professionals can communicate with each other. One of the most important features in this application is the search mechanisms, which allows users to search topics ranging from information about health conditions, symptoms or treatments, up to users who suffer from the same conditions. PatientsLikeMe promotes the relationship between users, the emotional support of patients and the collection of a rich database on medical information, which is available for studies and research related to the medical area.

DailyStrenght (Landro 2006) focuses on providing discussion groups, each with a well-defined theme. These themes also include other issues outside the health care field: ranging from alcohol withdrawal or

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2 The name in Portuguese is “Minha Saúde”. Accessible at http://www.minhasaude.org/
family problems, to, for example, burns or wounds. DailyStrength allows users to share health information, obtain opinions by health professionals, establish and follow goals set through their profile, among other functionalities.

Patient Opinion (Lupiáñez et al. 2009) is a national feedback website for the UK National Health Service. Users can rate their health service experience, view other ratings, and engage directly with other patients and health providers. Patient Opinion seeks to create honest and meaningful conversations between patients and health services in order to make health services better. Health services use Patient Opinion in three main ways: to plan how to develop and improve services; to understand the choices that patients are making in their health care; and to give doctors, nurses and managers a feel for what patients are saying about the service they provide. The Care Quality Commission receives all published stories and uses them to improve services.

**Usability**

The move from WCAG 1.0 to WCAG 2.0 has not increased the coverage of user problems, as one would have expected. For those problems covered by WCAG 2.0, only 16.7% of the directly relevant guidelines are being implemented on websites [Power et al. 2012]. This is a serious problem for three reasons. First, it indicates that web developers still struggle with creating accessible websites, possibly because their understanding of the guidelines is low or because of a lack of tool support. Second, for those guidelines not implemented, it is not possible at this time to determine if the user problems would be addressed by implementing the directly relevant guidelines. Finally, for those guidelines that were implemented, the implementations failed to solve the user problems. This shows that proposed implementations for solving accessibility problems must be evaluated with target users.

Usability has become an important issue to measure the quality of software. A product or a service performed by a computer, needs not only to be functional and efficient, it also needs to be useable in its entirety. Therefore, following aspects must be considered (Jacko and Sears 2003):

- **Focus on the users** - To develop usable products, the developer must know, understand and work with people that represent the actual and potential users of those products; no one can replace them.
- **For which tasks the product will be used** - If the system functions do not meet the users' goals in their workplace, then the product will not be used properly.
- **The conditions of the users to perform their jobs** - People consider a product "easy to use and to learn to use" based on the time they take to do they want, in the amount of steps required to perform the task and the success that they have to predict the correct action to take.
- **Users decide whether the product is easy to use** - The decision about the product usability is determined by users, not by developers.

Usability tests aim at evaluating the usability of an interactive system from experiences of their target users. These tests can be elaborated through specific questions associated with sets of tasks to be performed. For instance, in Christopher Power et. al. (2012), the authors identified the overall set of user interaction problems divided into three types: problems not covered by guidelines, those covered by guidelines but not implemented and those covered by guidelines with implementations.

**My Health**

The Social Network “My Health” is an online collaborative environment, which provides some healthcare tools and promotes actions for the social inclusion of patients with cardiovascular problems (Lima-Medina 2013). This OHSN, besides having the typical features for storing and managing user profiles, sharing information, relationship and groups, also provides a healthcare plan functionality and a recommendation system. It was developed in partnership with a group of cardiologists from the Fluminense Federal University Hospital.

Our research group, as part of the SCIADS project (Carvalho 2010), developed “My Health” Social Network through different stages until a beta version (prototype) was made available. In the design of “My Health”, a set of popular OHSNs were analyzed to identify some important functionalities, as described in a previous work (Lima-Medina 2013). The functionalities implemented include profiles,
notifications, groups, informational graphics, chats and health applications. In addition, some interaction
features from successful OSNs were considered. For instance: quick publishing on Twitter, instant
message systems, comments and ratings available at Facebook, interface simplicity on Tuenti, and groups
system on Orkut, were also implemented. Figure 1 brings a screen of “My Health” showing a user’s page.

Figure 1: Screen of “My Health” OHSN.

“My Health” is comprised by three modules: Social Management, Health Care Plan, and Friendship
Recommendations. The aim of Social Management module is to manage personal and clinical information
of patients that can be provided through multiple devices with internet connection. Patients can perform
several actions, such as, updating personal data (biography, sex, age, city, etc.) and physiological data
(symptoms, diagnosis, treatments, drugs, exams, etc.); creating topics of interest (posts, blogs, news),
sharing experiences, posting comments and assessing opinions; creating groups and participate in them;
and contacting other patients through groups, private message and invite other users. The Health Care
Plan was created to assist in the control of the patient’s health. It manages the following sets of data:
physiological data (e.g., blood pressure, temperature, weight, heart rate); daily activities (e.g., running,
cycling, walking, eating, sleeping, etc.); emotional states (fine, great, bad, sad); health situations or
symptoms (e.g. fainting, swelling in feet, headache, fatigue, tinnitus etc.); and statistics of all the
information collected above. This data is useful for helping to track the patient’s progress, which can be
visualized in reports and statistical charts. There is also the possibility that patients make invitations to
their caregivers or doctors, so that they can access their statistics and give feedback. It is important to
note that the patients’ clinical data is not publicly visible, i.e., unauthorized persons do not have access to
this data. Finally, the Friendship Recommendations module is responsible for showing a list of patients
that the user could contact during his active session. These patients have similar characteristics in their
profiles, what may improve the level of communication and collaboration among “My Health” users.

The layouts of the “My Health” are based on the bootstrap3 framework, a free collection of tools for
creating web applications. It contains HTML and CSS-based design templates for typography, forms,
banners, navigation and other interface components, as well JavaScript extensions. This framework is
compatible with the latest versions of all major browsers and also supports responsive web design. This
means the layout of web pages adjusts dynamically, taking into account the characteristics of the device
used (desktop, tablet, mobile phone). As patients with cardiovascular problems generally are old people
and have little or no experience in handling computational devices, the design of the “My Health” user’s
interface should meet some specific functional requirements and present some usability features
(Holzinger 2005).

3 Bootstrap: http://getbootstrap.com/2.3.2/.
Methodology

Identifying My Health user’s profile

In order to analyze the impact of a social network in the lives of patients with cardiovascular problems and to identify who are the potential users, we conducted interviews with ambulatory patients from Fluminense Federal University Hospital. For the patients who volunteered, we provided a leaflet explaining how they could register in “My Health” network, what they did directly from their homes.

Interviews were conducted with 91 volunteers who had an age distribution around 60 y.o., i.e., mean=60 and standard deviation=4. Among the respondents, 64 reported that they had a computer at home, 54 had internet access in their homes, but only 29 were familiarized in using computers. These results were used as a filter to select possible candidates to take part of the next step answering a questionnaire.

We only selected users who had access to a computer or a smartphone at home and accepted to participate in “My Health”. Hence, we got 45 users to answer a questionnaire to characterize the user’ profile. From the 45 volunteers who completed the questionnaire, 70% were women. The age distribution remained similar to the interview, maintaining the age of volunteers in 60 and this distribution is shown in Figure 2. Most volunteers (83%) had only completed high school, as can be seen in Figure 3.

![Figure 2: Age distribution of interviewed patients](image)

![Figure 3: Education degree of volunteers](image)

In addition, Figure 4 shows the distribution of volunteers in relation to computer usage time. As can be seen, 36% of the volunteers began to use the computer less than one year ago. Only 6% of volunteers began two years ago, and 46% of the volunteers have been using the computer for three or four years, including for professional reasons. Despite having a computer at home, 20% of the volunteers never used it, suggesting that it belonged to their children or grandchildren.
Another aspect raised is related to internet access. Only 93% of the users with computer at home had internet access. In addition, we collected information about the frequency of use and the tasks usually performed by those with internet access. Figure 5 shows the data related to internet usage frequency. As can be seen, most of the volunteers access the internet several times a week (34%) or several times per day (20%). However, the number of users that almost never access the internet is still high (23%). Figure 6 illustrates the tasks usually performed by volunteers while using the internet, which are: use of electronic mail, chats, Social Networks, games, payments, purchases and searching information. As can be seen, Social Networks are accessed frequently by 55% of the volunteers, sometimes, by 15% and never, by 30%. Regarding the use of chats, 80% of them are using it.
Defining Personas

As a result of these two steps (interviews and questionnaires), we elaborated two personas for the “My Health” Social Network. Persona is a fictional character created to represent the type of social health network user, containing attitude characteristics, behavior and physical characteristics, including any kind of limitations (Jacko & Sears 2003). These personas were used for usability tests.

Persona 1

Anne is a 61 years old retired Systems Analyst, who still loves to use computers. When she was 59 years old, she began to develop cataracts. As she is afraid of surgery, she kept postponing treatment and now she has only 30% of the left eye vision and 50% of the right eye vision. She uses a screen reader program, especially useful when the letters do not have an adequate contrast or when they are very small. In other occasions, she uses magnifying glasses to help her to see the details of images or texts. These tools ensure that her vision limitation does not influence on her computer use, but her doctor advised her that if she did not undergo surgery, she might lose more and more of her vision. Recently she was also diagnosed with a cardiovascular disease. As Anne likes to access the internet she has been researching on the subject and found a social network focused on health. She registered immediately and began to communicate with other seniors who suffered from the same problem, to hear about the treatments these people were receiving. In this social network, Anne can also periodically inform her physical and medical data, such as height, weight, blood pressure, glucose levels, cholesterol, and others, thus helping to tracking her health condition. Anne’s doctor also started to use the same social network to monitor her condition, without having to leave home daily to be examined by him.

Persona 2

Peter is a 63 years old retired man, who started to use computers no more than two years ago. He took a course to learn how to use the internet and also a typing course. Influenced by a grandson, he decided to create a Facebook profile in order to communicate more easily with family and friends. As he is a very curious person, eventually he discovered several useful Facebook features, such as chat and games. He talks with their grandchildren and children by using Facebook. One year ago, Peter almost had a heart attack. This fact made him to become more careful about his health. In an occasion when Peter was in the waiting room of his doctor, he heard another patient say that he was using a health social network that helped him to control his health based on medical data. Peter found it interesting and wanted to know which social network he could use too. When Peter arrived home, he immediately found out and engaged in a social network of such type. In his last meeting with his regular doctor, Peter talked about the health social network to him, who also joined the network in order to better monitoring his patient.
Experimental Results

Accessibility Evaluation

In order to identify how others OHSNs are dealing with accessibility to elderly people, we performed an evaluation based on guidelines from WCAG 2.0. From this set of guidelines we focused on the aspects related to elderly users and those which are most relevant for our OHSN domain. Three specialists of HCI domain performed a checklist of these guidelines in three different OHSNs: PatientsLikeMe, DailyStrength and PatientOpinion. The selected guidelines and the evaluation results are listed in Table 1, where (√) means that a OHSN implements such guideline, (√/X) means that it partially implements it and (X) means that it does not implement it. As a result, we could observe that no OHSN fully implements all accessibility guidelines.

<table>
<thead>
<tr>
<th>Accessibility guidelines</th>
<th>Patients Like Me</th>
<th>Daily Strength</th>
<th>Patient Opinion</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1.1 - Text Alternatives</td>
<td>√/X</td>
<td>X</td>
<td>√</td>
</tr>
<tr>
<td>1.4.1 - Use of Color</td>
<td>√</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td>1.4.4 - Resize text</td>
<td>X</td>
<td>X</td>
<td>√</td>
</tr>
<tr>
<td>1.4.6 – Contrast</td>
<td>√</td>
<td>X</td>
<td>√</td>
</tr>
<tr>
<td>1.4.8 - Visual Presentation</td>
<td>√/X</td>
<td>X</td>
<td>√</td>
</tr>
<tr>
<td>2.1.1 – Keyboard</td>
<td>√/X</td>
<td>√/X</td>
<td>√/X</td>
</tr>
<tr>
<td>2.4.2 - Page Titled</td>
<td>√</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td>2.4.3 - Focus Order</td>
<td>√/X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>2.4.4 - Link Purpose (In Context)</td>
<td>√</td>
<td></td>
<td>√</td>
</tr>
<tr>
<td>2.4.5 - Multiple Ways</td>
<td>√</td>
<td>√</td>
<td>√/X</td>
</tr>
<tr>
<td>2.4.7 - Focus Visible</td>
<td>√/X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>2.4.8 – Location</td>
<td>√</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>3.2.1 - On Focus</td>
<td>√/X</td>
<td>X</td>
<td>√/X</td>
</tr>
<tr>
<td>3.2.3 - Consistent Navigation</td>
<td>√</td>
<td>X</td>
<td>√</td>
</tr>
<tr>
<td>3.3.2 - Labels or Instructions</td>
<td>√/X</td>
<td>X</td>
<td>√</td>
</tr>
<tr>
<td>3.3.5 – Help</td>
<td>√/X</td>
<td>X</td>
<td>√</td>
</tr>
</tbody>
</table>

Table 1. Checklist of the selected guidelines focused on the accessibility for elderly people

We implemented a “My Health” prototype and performed a checklist of accessibility guidelines. This verification consisted of a manual checklist performed by three human-computer interaction specialists. Each specialist evaluated the interface of “My Health” individually. After that, they discussed their results obtaining a consensus. Based on such results, we made improvements in order to address the problems identified. Table 2 illustrates a comparison of before and after the implementation of the accessibility guidelines in the prototype, indicating that we corrected almost all the identified problems. Following the recommendations of WCAG 2.0, the main accessibility improvements we made were:

- Correction of the use of headers h1-h6 to delimit the titles of sections and subsections according to their importance;
- Inclusion and correction of the use of alternative text (alt) in images and non-text content to allow the translation of the content/function of images by screen readers used by people with visual deficiency;
- Inclusion of visual aids (tooltip) in text boxes and links, with complementary explanation of the main functionality;
- Inclusion of multiple font size, allowing users change the size of text according they needs.
- Inclusion of high-contrast layout to facilitate the visualization of people with low vision;
- Improving navigability for the entire social network.

<table>
<thead>
<tr>
<th>Accessibility guidelines</th>
<th>Before</th>
<th>After</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1.1 - Text Alternatives</td>
<td>√/X</td>
<td>√</td>
</tr>
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<td>√</td>
</tr>
<tr>
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<td>√</td>
</tr>
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<td>1.4.6 – Contrast</td>
<td>√/X</td>
<td>√</td>
</tr>
</tbody>
</table>

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Table 2: Checklist of selected accessibility guidelines applied to the “My Health”

**Usability Evaluation**

For evaluating the implementations of WCAG 2.0 guidelines in “My Health” with target users, we elaborated a usability test targeting elderly people to be conducted with the system users. The purpose was to identify features that need improvement and collecting opinions from the potential target users. Initially, we presented to the volunteers the objective of the experiment and requested them to sign an informed consent if they wished to participate. Then we delivered a set of five tasks to be performed on “My Health”. The purpose of these tasks was to explore important features and functionalities in the social network, which are: (1) sign up in the social network to have an account; (2) add a profile picture and expand the circle of friends; (3) publish a public message and make a comment; (4) introduce daily activities and current health status (i.e. headache, fatigue); and (5) send a personalized invitation of friendship.

The experiment was conducted with nine volunteers who did not interact with any social network previously. They were divided into three groups with three volunteers each. The first group, called “pilot”, formed by people with different levels of familiarity with the use of internet, used the prototype of the social network. The second group, formed by people with basic computer skills, and the third, formed by people with advanced skills, used the social network refactored to apply accessibility guidelines updates. The volunteers’ age ranged from 65 and 75 years.

After they finished performing the five tasks, the volunteers answered two questionnaires. The first questionnaire was used to determine the level of user satisfaction when performing tasks. This questionnaire contained six questions related to the realization of the tasks. The answers vary on a scale of 1 to 5, where 1 is few satisfied and 5 is very satisfied. The questions in questionnaire 1 ("My Health" users satisfaction) were:

- Q1 - How comfortable you felt performing tasks on the site?
- Q2 - How easy / difficult was to use the site?
- Q3 - In your opinion, how professional the site look like?
- Q4 - How satisfied are you in accomplishing the tasks on the site?
- Q5 - How satisfied are you about the physical effort (number of steps) necessary to perform the tasks?
- Q6 - How satisfied are you with the language and jargon used on the site?
The second questionnaire was used to identify potential problems in the communication quality of the social network. It contains 10 questions subdivided in four topics: Layout, Terminology Learning and Features. The answers vary in a range from 1 to 10 representing the degree of quality for each item, with 1 being the worst score and 10 being the best score. The questions were related with:

- Q1 - Texts readability
- Q2 - Content organization
- Q3 - Logical Screen sequence
- Q4 - Consistency of terminology used on the site
- Q5 - Consistency of messages position on the screen
- Q6 - Utility of messages errors
- Q7 - How easy was learning to use the site?
- Q8 - How easy was to remember the names of functionalities on the site?
- Q9 - Speed of site response
- Q10 - Level of site noise

Figure 7 shows the results obtained for each group in relation to the first survey. As can be seen, the user satisfaction level in all questions was positive. However, when analyzing the results of the second questionnaire, shown in Figure 8, we can see some shortcomings pointed out by users (Q1, Q3, Q6, Q7 and Q8), where some of them are independent of computer proficiency. As can be seen, the users had
some difficulties during the reading of texts (Q1) due to the font size. Another complaint was the windows sequence (Q3), mainly in the care plan section. In addition, the error messages were not clear to the user (Q6). In relation to learning (Q7 and Q8), volunteers reported initial difficulty in using the resources provided by the social network and in remembering the features available. In addition, it was observed that the volunteers had difficulty only in the realization of the first task, which is the registration task in the social network.

Conclusion

This paper presented a study of current accessibility state in Online Health Social Networks. In addition, we applied the main WCAG 2.0 guidelines to ensure accessibility to elderly users in the “My Health” Social Network. In combination, a usability test was conducted with volunteers over 65 years to detect users interaction problems on the website.

The evaluation results show that not all developers are implementing the current version of WCAG. Moreover, a case study with a “My Health” prototype revealed that even when the guidelines are implemented, there is no indication that people with disabilities will get rid of usability problems. Further work in this area is both relevant and much needed. This work has provided stimulus for future works.

The results of this study may indicate that it is time to move away from the problem-based paradigm for web accessibility, where our primary goal is to eliminate problems encountered by users. Taking a lesson from usability research, web accessibility research must define a much broader set of design principles, based on user data, that focuses on the use of OHSNs by people with disabilities – not just on the problems they encounter. Only when those design principles are clearly understood, we can look at proposing rules and heuristics that web developers can apply to assess their success in creating OHSNs that people with disabilities can use and profit well.

Future Work

As improvements to be done in “My Health”, we intend to include the suggestions raised by users, such as adding a section that tells symptoms of common diseases, expand the clinical information collected by the social network, insert animations on the site and improve the error messages. In addition, we intend to continue to address the problems of accessibility and create a tutorial about how to use the social network to minimize the initial difficulty of use.

Acknowledgements

The authors would like to thank CNPq, CAPES and FAPERJ for partially funding this work, in addition to the volunteers who participated in the studies.

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