RehabNet – A social network for the deployment of online rehabilitation

By

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Thesis

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Abstract

Social network sites (SNSs) have gained much popularity and attention of academic and industry researchers intrigued by the opportunities they give people to reach others in an easy and timely manner, to exchange and share various kinds of information. As recognition of this fact, there has been a growing attention over the last years in the development of health social networks and their impact on the people. However current health social networks suffer different limitations related with their functionality and usability. Furthermore, the majority of these health social networks only meet present information about treatments and symptoms, and do not are designed for health professionals and researchers. This work presents the implementation of a health social network which aims at filling existing gaps, allowing people to have a direct interaction with the health professionals and the possibility to participate from home in training activities and research studies to improve their recovery. Additionally, offers health professionals and researchers the possibility to create and deploy new types of trainings and assess the impact in the recovery of people. Surveys and usability tests were performed to validate the conceptual and design ideas.

Keywords

Social network sites (SNSs), Patients, Health Professionals, Researchers, Remote monitoring, At home training, Survey, Usability.


Resumo

Sites de redes sociais ganharam muita popularidade e atenção de investigadores acadêmicos e da indústria intrigados com as oportunidades que eles dão às pessoas para comunicar com outros de uma maneira fácil e em tempo oportuno, para trocar e partilhar vários tipos de informação. Como reconhecimento deste facto, tem havido uma crescente atenção nos últimos anos no desenvolvimento das redes sociais de saúde e no seu impacto nas pessoas. No entanto redes sociais de saúde atuais sofrem de diferentes limitações relacionados com a sua funcionalidade e usabilidade. Além disso, a maioria dessas redes sociais de saúde só apresenta informações sobre tratamentos e os sintomas, e não são projetados para profissionais de saúde e investigadores. Este trabalho apresenta a implementação de uma rede social de saúde com o objectivo de preencher lacunas existentes, permitindo que as pessoas tenham uma interação directa com os profissionais de saúde e a possibilidade participar desde casa em actividades e pesquisas para melhorar a sua recuperação. Além disso, oferece aos profissionais de saúde e investigadores a possibilidade de criar e implementar novos tipos de exercícios e avaliar o impacto na recuperação de pessoas. Foram realizados questionários e testes de usabilidade para validar as ideias conceituais e de design.

Palavras-chave

Sites de redes sociais, Pacientes, Profissionais de Saúde, Investigadores, Monitoramento remoto, Treinamento em casa, Questionários, Usabilidade.
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Chapter 1. Introduction

Movement disorders are a group of conditions and syndromes affecting the ability to produce and control bodily movements. It seems simple and effortless, but normal movement requires an astonishingly complex control system. Disruption of any portion of this system can cause a person to produce movements that are too weak, too forceful, too uncoordinated, or too poorly controlled for the task at hand. Unwanted movements may occur at rest, intentional movement may become impossible. Abnormal movements are symptoms of underlying disorders. Disorders or conditions that may cause abnormal movements include: cerebral palsy, choreoathetosis, encephalopathies, essential tremor, inherited ataxias, parkinson disease, psychogenic disorders, restless legs syndrome, spasticity, stroke, tourette syndrome, wilson disease [1]. Inside this group of movement disorders, stroke is one of the main causes of adult disability in high-and-middle-income countries with about 16 million first event stroke incidents per year [2]. Despite this project it is designed for all the people with movement disorders, it is more focused on stroke survivors because the high economic and social cost [2].

The process of recovering from a stroke usually includes hospitalization treatment and continued at home rehabilitation. Because stroke survivors often have complex rehabilitation needs, progress and recovery are different for each person. Treatment for stroke begins in a hospital with "acute care". This first step includes helping the patient survive, preventing another stroke, and taking care of any other medical problems. Spontaneous recovery happens naturally soon after the stroke, and some abilities that have been lost usually start to come back. This process is quickest during the first few weeks. Rehabilitation helps the person keep abilities and gain back lost abilities to become more independent. It usually begins while the patient is still in acute care. For many patients, it continues afterward, either as a formal rehabilitation program or as at home individual rehabilitation services. Many decisions about rehabilitation are made by the patient, family, and hospital staff before discharge from acute care [3].

There are several kinds of rehabilitation programs:

**Hospital programs** – These programs can be provided by special rehabilitation hospitals or by rehabilitation units in acute care hospitals. Complete rehabilitation services are available. The patient stays in the hospital during rehabilitation. An organized team of specially trained professionals provides the therapy. Hospital programs are usually more intense than other programs and require more effort from the patient.
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**Nursing facility programs** - As in hospital programs, the person stays at the facility during rehabilitation. Some provide a complete range of rehabilitation services, with specially trained professionals, machines and therapies to improve the patient rehabilitation. Others provide only limited services, with less trained professionals or machines during rehabilitation.

**Outpatient programs** - Outpatient programs allow a patient who lives at home to get a full range of services by visiting a hospital outpatient department, outpatient rehabilitation facility, or day hospital program.

**Home-based programs** - The patient can live at home and receive rehabilitation services from visiting professionals. An important advantage of home programs is that patients learn skills in the same place where they will use them [3].

Each of the above programs has advantages and disadvantages, and do not cover the total aspects of a person with special needs. Hence, both the economical and the psycho-social impact of stroke emphasize that we need to find more effective diagnostics, treatment and rehabilitation approaches.

ICT based new approaches to stroke rehabilitation have appeared in recent years, such as Virtual Reality, Telemedicine among others. Telemedicine has been defined broadly as the use of telecommunications technologies to provide medical information and services [4]. Technically, this encompasses all aspects of medicine practiced at a distance, including use of telephone, fax, and electronic mail technology, as well as the use of interactive full-motion integrated video and audio that brings together patients and providers separated by distance [5].

One of the approaches that are emerging in telemedicine is social network sites. These platforms provide a fast and easy way to reach large populations in variety of ways, with great diversity of services and in a short time. Among the services that can be used in health social networks are messages, chats, videos, forums besides contents like calendars, games, among others. This work contributes to the creation of a novel method in the area of telemedicine by using a social network that allow patients to recover at home but with direct interaction with other patients, health professionals, contributing to the validation of at home based therapies.
Chapter 1. Introduction

1.1. Motivation

This thesis has the following motivations:

- The necessity to provide a more accessible recovery program for people with movement disorders.
- The necessity to provide tools to reduce both economical and social costs for the patients and families.
- Allow patients with movement disorders to train different activities without getting out of their home.
- Allow the health professionals to follow the progress of their patients after hospital discharge.

1.2. Contribution

The main contribution of this thesis refers to the creation of a social network that allows people to recover at home with direct interaction between patients and with health professionals. By addressing this current limitation of rehabilitation programs, our project contributes to improve the communication between patients, health professionals, researchers and other practitioners. Additionally this thesis also contributes to:

- Create a platform to validate different methods of rehabilitation for patients with movement disorders and their acceptance and utility for patients, health professionals and other practitioners.
- Provide a novel tool to improve the quality of life of patients and their families by allowing at home training and reduce associated costs with transportation and increased dependencies of patients.
- Identify limitation of current rehabilitation programs and reuse the solution for future developments.
Chapter 2. State of the art

This chapter includes the state of the art of social network sites, and their use on health, by discussing how they emerged and their history.

2.1. Social networks

Social networking has become an everyday word and a common method of communication for many people. Although the concept dates back to the 1960 (with University of Illinois Plato computer-based education tool) the mass adoption of this phenomenon only emerged after the advent of the internet [6]. Social networking is done through social network sites, and since the launch of SixDegrees.com in 1997, hundreds of networks ranging from blogs, to dating and socializing sites, to glorified classified systems have spurred online [6]. Social networking sites are defined as web-based services that allow an individual to (1) construct a public or semi-public profile within a bounded system, (2) articulate a list of other users with whom they share a connection, and (3) view and traverse their list of connection and those made by other within the system. The nature and nomenclature of these connections may vary from site to site [7]. Currently social networking sites reach 82 percent of the world’s online population, representing 1.2 billion users around the world (figure 1). Even more illustrative of social networking’s emergence is the amount of time people currently engage with it. As a percentage of the time people spend online, social networking activity has more than tripled in the last 6 years. In October 2011, social networking ranked as the most popular content category in worldwide engagement, accounting for 19 percent of all time spent online. Nearly 1 in every 5 minutes spent online is now spent on SNS [8].

Figure 1 - The rise of the global social networking audience between 2007 and 2011. Adapted from [8].
The growth of social networking is a global cultural phenomenon. Despite significant differences in government, infrastructure, availability of Internet access and cultural practices around the world, social networking is growing in every single country. A look at individual markets shows the penetration of social networking sites, ranging from 53 percent in China to 98 percent in the United States (figure 2). Regardless of how open or closed a society may be, it is safe to assume that more than half of local online populations are engaging in online social networking, making the practice comparatively ubiquitous around the world.

The high user engagement on social networks across global regions demonstrates it is universal appeal. For each region, the total time spent by users on Social Networking grew by at least 35 percent over the year 2011, reflecting it is growing pervasiveness across the board. In Latin America, Europe, and the Middle East-Africa – three very culturally different regions – Social Networking accounted for at least 24 percent all time spent online [8].

![Percentage of Online Population Using Social Networking around the World](image)

*Figure 2 - Percentage of online population using social networking around the world. Adapted from [8].*

To fully comprehend the state of social networking today, one must understand how Facebook – the largest player by virtually any metric – drives the behavior of the category as a whole. Consider that Facebook is the third largest web property in the world, trailing only Google Sites and Microsoft Sites. In October of 2011, Facebook reached more than half of the world’s global audience (55 percent) and accounted for approximately 3 in every 4 minutes spent on social
networking sites and 1 in every 7 minutes spent online around the world. While Facebook is the leading social networking site in the vast majority of countries, it is not the leader everywhere – yet. In the beginning of 2010, Facebook was the category leader in 30 of the 43 markets (figure 3). Since then, it has taken the lead in 6 additional markets, spanning Asia, Latin America and Europe [8].

![Facebook's Ascent in Recent Years](source: comScore Media Metrix, Worldwide, January 2010 – October 2011)

Figure 3 - Facebook’s ascent in number of visitants in recent years against other social networks.

Adapted from [8]

Anyone with children might be under the impression that social networking is a “kids’ activity.” Several years ago, there was some truth to that. However, in the last 18 to 24 months, that has changed completely. Social networking reach in older segments has all but caught up, to the point where it is now quite similar across age groups. In fact, users 55 and older represent the fastest growing segment in social networking usage (figure 4). Even more striking, in regions such as North America and Latin America, Social Networking reached at least 93 percent of online users age 55 and older. Another group showing significant gains are males. Although males still lag in terms of reach and engagement with social networking, they exhibited a nearly 10-percentage point increase in reach from July 2010 to October 2011. As social networking is integrated into other online behaviors such as online video viewing, the slight differences we see today may completely evaporate [8].

Looking for the case of Portugal (figure 5), the percentage of online population visiting social networks (96-percent), it is possible to see that almost people that uses internet uses social networks, with Facebook having the more percentage of visitors. One significant aspect is the difference between males and females visiting social networks, and this difference increases with the age of the users.
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Males and users 55+ represent the fastest growing segment in social networking.

Figure 4 - Social networking penetration among worldwide demographic groups between July 2010 and October 2011. Adapted from [8]

Figure 5 – Analysis of social networking in Portugal. Upper left - Percentage of online population using social networking in Portugal. Upper right – Top 5 social networks by unique visitors and average minutes per visitor. Lower left – Social networking demographic reach. Lower center – Average engagement with social networking. Lower right – Top 5 social networks by unique visitors. Adapted from [8]
Chapter 2. State of the art

2.2. Social Networks in Health

About 20 percent of the content generated by internet users mentions health in some way [9]. According to Pew Internet Research, 60 percent of connected people use internet as their first source of information about health-related matter [9]. Due to the high percentage of the world’s online population social networks is one of the biggest online locations for searching about health care. Health social networks are those websites providing users the opportunity to access, share, and contribute to health resources at a number of different levels. Health social networks form around shared interest in a specific health conditions like obesity or cancer; a specific area of health care like children’s medicine or hospice; or health information in general. The key characteristic of an online health social network is interaction that can support sharing knowledge and/or providing emotional support for individuals dealing with health-related questions and problems affecting them or other people they care about. Health social networks like CarePages (www.carepages.com), PatientsLikeMe (www.patientslikeme.com), and CureTogether (www.curetogether.com), increase significantly the amount of health-related information and avenues for social support that patients can access compared to what most traditional, offline social networks provide. Individuals can and do use these expanded cognitive and emotional resources in ways that impact their health-related decisions. Research on the online health community PatientsLikeMe has shown that such a community can serve as a platform for members to share personal health information and use that shared information to seek and offer advice and foster relationships. Research shows apparently positive information-seeking behavior by patients, though as in the case of social networks overall, such relationships are still not fully understood [10].

Online health social networks are an extension, not a replacement, of patients existing social networks. Patients and members of their traditional social networks may interact in online health social networks as well. Patients immediate friends and family may use online health social networks as a supplemental channel through which to communicate with patients and provide additional knowledge and support. Online health social networks may provide patients with social support from individuals who are geographically distant but emotionally and experientially close to the patients. New acquaintances made through online health social networks may become part of traditional social networks as they choose to enhance their relationships by meeting face to face.

Health professionals are not excluded from online health social networks, either. Within appropriate professional boundaries, health professionals may find constructive ways to
engage with their patients in the online context as well as in the traditional contexts of office visits and face-to-face treatment in health care facilities. Through online health social networks, health professionals may learn sooner about patient conditions, complaints, or behaviors; this knowledge may more fully inform diagnoses and prescriptions. For example, in a remote rural community, a patient with a particular form of stroke or undergoing a particular treatment may not have regular face-to-face contact with people in his/her small and geographically isolated community with who he/she can share knowledge and experiences about those specific health issues. A rural health professional may not have regular face-to-face social interaction with fellow professionals to discuss medical issues, new research, or the practical implications of new health insurance regulations [10].

2.3. Services provided by health social networks

This section has an in-depth review of the services provided by health social networks: information sharing and emotional support, health professionals questions and answers (Q&A), quantified self-tracking and clinical trials access.

2.3.1. Information sharing and emotional support

The basic services offered by the majority of health social networks are a mix of information sharing and emotional support at no cost to registered site users. Some health social networks may emphasize more one area, such as information and research citations (for instance: OrganizedWisdom) or social connection and support (for instance: DailyStrength). Websites may auto-populate general information from Internet health resources such as Wikipedia articles and PubMed links. In addition to the general information, patients may be able to enter qualitative and quantitative data about their own conditions, symptoms, treatments and overall experiences for a more accurate exchange of information between them. Emotional support, social support and patient empowerment are a consequence of information sharing and important components of health social networks, available both implicitly and explicitly. Implicitly, emotional support is experienced by seeing that there are others with similar conditions. Implicit emotional support is also felt by being a community member, participating in the process of creating a personal profile and recording health information, seeing how other non-medical professionals describe the same conditions and symptoms and finding out what remedies others have tried (Figure 6). Emotional support is also offered explicitly in some health social networks through user interaction. Site members may have the ability to
comment on forums, publicly or privately message each other, give each other advice and transmit lightweight social greetings, such as hugs, as shown in excerpts from DailyStrength’s activity feed (Figure 6). This type of communication is available on this kind of social network because it is a way to attract other users, even patients’ immediate friends and family may use it to understand the kind of problem or treatments that a person close to them undergo. The impact of patient information sharing and emotional support is thought to be quite positive but is not fully understood yet. PatientsLikeMe has conducted some research, finding that “patients who choose to explicitly share health data within a community may benefit from the process, helping patients engage in dialogues that may inform disease self-management” [11].

2.3.2. Health Professionals Questions and Answers (Q&A)

The information sharing and emotional support between patients allow them to know and interact with people with the same type of problems, but do not give the patients the same type of assurance that a health professional can give. That is the reason why other service is offered by several health social networks (for instance: MedHelp, WellSphere, MDJunction, ehealth forum, iMedix, WeGoHealth) such as the ability to pose questions to health professionals. Questions and answers are usually displayed publicly unless the patient marks them as private. Posing questions may be free or fee-based, for example at MedHelp, it is $22 to pose a question to a physician directly and free to post a question in the medical communities where peers or professionals may respond. The websites generally have health professionals profile pages where they complete information about their expertise, background and affiliations, with links to previous question responses on the site and possibly their medical blog entries (Figure 7).
This transparency and willingness to interact helps to project the image of health professionals. Many health professionals are willing to answer questions, learn sooner about patient conditions, complaints or behaviors, recommend next steps and possibly provide a preliminary and diagnosis. Even this basic mechanism of lightweight health professional-patient interaction could help ease burdens on health care systems. One may think that physicians would not take part for legal, reputational and other reasons but the key point is that they are willing to participate and, may find reputational enhancement and other benefits.

2.3.3. Quantified self-tracking

Besides information sharing and emotional support, and health professionals Q&A, another type of service offered by some health social networks (for instance: PatientsLikeMe, CureTogether, MedHelp, SugarStats) is quantified self-tracking. The self-tracking functionality consists of easy-to-use data entry screens for condition, symptom, treatment and other biological information. The information can then be seen in a graphical display, possibly with views by individual, aggregated population or custom groups. For example, Figure 8 shows a detailed patient profile from PatientsLikeMe including disease progression, prescription drugs and symptom tracking for a 37 year-old male who has had amyotrophic lateral sclerosis (ALS) for six years, and Figure 9 shows an aggregated view of the top treatments tried by the CureTogether endometriosis community. Individual tracking data, medications and other relevant information can be printed from the websites to expedite interaction at in-person health professional visits.
Chapter 2. State of the art

Figure 8 - PatientsLikeMe ALS profile charts example. Upper left – Progression of the patient condition. Middle left – Prescription drug and the reasons that had taken a drug. Lower left – Primary symptoms and the severity of them. Adapted from [12]

Figure 9 - CureTogether patient-entered treatment statistics, with the number of people that tried a particular treatment and if had or not an improvement. Adapted from [12]
Self-tracking information is further incorporated into the PatientsLikeMe site by mapping the data to a graphical representation of the patient as shown in Figure 10, a stick figure shaded with different colors per symptom severity and disease stage so anyone looking at the profile can assess the patient’s status immediately. Figure 10 depicts two patients with amyotrophic lateral sclerosis (ALS), one with arms onset (top diagonal line) and one with bulbar onset (bottom diagonal line), tracking their condition progression by year and decline in Functional Rating Scale (FRS). The site’s collaborative filtering allows users to find “patients like me,” which is important since similar patients are the most relevant ones for providing and sharing information.

![Figure 10 - PatientsLikeMe peer disease tracking over time with graphical images of patient. See text for further information. Adapted from [12]](image)

### 2.3.4. Clinical trials access

Another type of service offered by some health social networks is information regarding clinical trials (for instance: PatientsLikeMe, Inspire). The presence of health social networks makes traditional clinical trials more efficient through the availability of large searchable online databases of patients with health history and condition information. Pharmaceutical companies, industry analysts, policy architects and other interested parties can assess demand and market size directly from health social network websites. PatientsLikeMe and Inspire are at least two health social networks offering access to clinical trials at present, selling anonymized data to pharmaceutical companies, universities and research labs. For example, in May 2008, Novartis recruited clinical trial participants from PatientsLikeMe estimating that they were able to speed up their 1,200-patient study of a new medicine for multiple sclerosis by a few months. In another instance, PatientsLikeMe contacted 1,500 amyotrophic lateral sclerosis (ALS) patients for another research project and received 50 DNA samples (3.3%) [12]. The yield might not seem high but the time and cost savings in identifying, screening, contacting and obtaining responses from relevant patients is significant.
In addition to lower-cost patient recruitment, there are three other ways that health social networks are improving the quality of clinical trials. First, the depth of information generated through large online patient communities creatively interacting and monitoring their conditions with quantitative tracking tools can lead to new findings that give a better understanding of the underlying conditions. PatientsLikeMe in-house research staff is publishing some of these findings, such as the identification of non-motor symptoms of Parkinson’s disease in younger sufferers. Second, health social networks provide a feedback loop to the clinical trials process. For example, PatientsLikeMe patients noticed and suggested corrections and improvements to the graphical display of data in ALS clinical trials [12]. Third, online health tracking in conjunction with clinical trials means that patients can make their experience feedback available as a public resource. Self-run clinical trials and structured self-experimentation is emerging as patients may no longer have the inclination to wait for formal research findings and pharmaceutical company-sponsored clinical trials, and can possibly fill the medicine gap for orphan diseases and other conditions that do not make good business cases in the existing pharmaceutical model. Patients can review research literature and other remedy suggestions on their own and try them, tracking the results in a rigorous manner, sharing the information and running non-traditional clinical trials themselves. In one example, a PatientsLikeMe patient, newly diagnosed with rapidly progressive and young-onset ALS gathered 250 patients to self-experiment with lithium per a research paper he had found. The self-run patient study results were preliminary and found that the use of lithium did not slow disease progression. The example highlights many elements of the new power and role of patients, their ownership of the health care process and the attendant contentious legal, ethical, methodological and other issues. [12] Inevitably, fraud is likely to arise or may already exist in health social networks as there are significant economic incentives for drugs and other treatments to have high patient usage statistics and favorable reputations. The bona fide peer community may be one of the most helpful resources in detecting and policing fraud due to the deep knowledge of patients regarding their conditions and remedies, and their time spent on the websites.

2.3.5. **Summary**

A list of health social networks is presented in Table 1, organized into three categories: patient-focused general multi-condition websites, patient-focused cause-specific websites and health professionals-focused social networks. Most patient-focused health social networks offer the basic level of service, emotional support and information sharing, for a variety of
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medical conditions. About half also offer the second level of service, some sort of Q&A with health professionals, and a few offers the third and fourth levels of service, quantitative self-tracking and clinical trials access.

There is little doubt that the growth of the Internet and social networks has opened up and continues to widen possibilities of accessing health information and processing such information to impact health outcomes. Currently the majority of health social networks offer as key characteristic the interaction that can support sharing information and/or providing emotional support for individuals dealing with health-related questions and problems affecting them or other people they care about. This service allows patients to know people with same kind of problems and exchange details about that problem, or other aspects, such the health professional or treatment used to solve the problem. The impact of patient information sharing and emotional support is thought to be quite positive but is not fully understood yet. If it can be used to help the patient emotionally and help to self-manage their situation, it can also lead to a bad treatment like choosing a drug that is not the indicated to that particular problem.

Table 1: ES&IS stands for emotional support and information sharing, Q&A represents health professionals Q&A, QS means quantified self-tracking, CT represents clinical trial access and N&I signifies for networking and information.

<table>
<thead>
<tr>
<th>Name</th>
<th>Focus</th>
<th>Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>General health social networks</td>
<td></td>
<td>ES&amp;IS</td>
</tr>
<tr>
<td>PatientsLikeMe</td>
<td>500+ conditions, ex: ALS, MS, HIV/AIDS</td>
<td>✓</td>
</tr>
<tr>
<td>CureTogether</td>
<td>175 conditions, ex: endometriosis, migraine</td>
<td>✓</td>
</tr>
<tr>
<td>MedHelp</td>
<td>General: tracking, physician Q&amp;A</td>
<td>✓</td>
</tr>
<tr>
<td>Inspire</td>
<td>Over 1,000 health and wellness groups, journaling</td>
<td>✓</td>
</tr>
<tr>
<td>DailyStrength</td>
<td>600+ conditions</td>
<td>✓</td>
</tr>
<tr>
<td>OrganizedWisdom</td>
<td>60 conditions, referenced research citations</td>
<td>✓</td>
</tr>
<tr>
<td>WellSphere</td>
<td>50+ communities, ask an MD feature</td>
<td>✓</td>
</tr>
<tr>
<td>MDJunction</td>
<td>750+ conditions, physician listings and marketplace</td>
<td>✓</td>
</tr>
<tr>
<td>EhealthForum</td>
<td>Physician Q&amp;A;1.2M questions logged on site</td>
<td>✓</td>
</tr>
<tr>
<td>HealthChapter</td>
<td>General: 715 groups</td>
<td>✓</td>
</tr>
<tr>
<td>Trusera</td>
<td>General: 23 main topic areas</td>
<td>✓</td>
</tr>
<tr>
<td>iMedix</td>
<td>General, support and answer response</td>
<td>✓</td>
</tr>
<tr>
<td>Wellescent</td>
<td>General</td>
<td>✓</td>
</tr>
</tbody>
</table>
Q&A allows the patients to make questions to health professionals. This service is very powerful but lacks on direct contact between the patient and the health. Self-tracking allows patients to have a graphical representation of their evolution on conditions, symptoms or treatments but can be a little confusing if it has a lot information or complex information to present to the user. Another service that some health social networks offer is information about clinical trials, because of the large databases of patients with health history and condition information. This service is very useful to pharmaceutical companies, industry analysts, and other interested parties. This has the advantage of giving a quick feedback of some clinical trials to the patients, and gives them the opportunity to use some findings before a formal research and pharmaceutical company-sponsored clinical trials. The advantage also can turn into a disadvantage because fraud can appear with significant economic incentives for drug tests and other treatments. To conclude it is possible to see through table 1 that currently none of the health social networks offer the four services described above and only a minor part offer the maximum of two services to the users. Hence it is needed the creation of a health social network that can offer the possibility of information sharing and emotional support as the current offer, but can take a step offering the patient a direct contact with the health professionals and give them the opportunity to follow their progress during the treatments and, if available, allow the patients to participate in new treatments computer based at home trainings or treatments.
Chapter 3. Functional analysis of existing systems

The growth of internet, and specially the social networks along with the economic problems around the world made people search new ways of managing their health. Currently much of the people worldwide use internet and consequently health social networks as their first source of information about health-related matters. The health social networks evolved so much that people make their decision of consulting a physician after analyzing all the information available online. Currently the major health social networks offer a variety of features that includes emotional support and information sharing, physician Q&A, quantified self-tracking, clinical trial access, networking and information, but none of them offers all the services in an integrated manner. In the Annex I are the features offered by each one of the major health social networks. In the following analysis only CureTogether, DailyStrength, EhealthForum, Inspire, MedHelp and PatientsLikeMe are considered because offer more services to the users. Figure 11 & 12 show the features available and the percentage (%) of health social networks that offer them.

![Features](image-url)

Figure 11 - Main features offered by health social networks
Figure 12. Features offered by health social networks and the number of them that use a particular feature.
Chapter 3. Functional analysis of existing systems

Sign up, Home, Profile and Friends

To access the contents of some websites the user needs to make a sign up, which is a way to register a user with website and to avoid the creation of spam. In Figure 11 it is possible to see that the all the health social networks analysed (CureTogether, DailyStrength, EhealthForum, Inspire, MedHelp and PatientsLikeMe) offer the possibility to sign up. The majority only ask the user name, email and password to do it, only PatientsLikeMe and MedHelp offer the possibility to choose what type of user you are: Patients, Doctor or Researcher. After completing the process of registration, the user can enter the website, where he is redirected to his Home page. The home page is the first page that is displayed after the log in and serves as index to other sections on the website. In the home pages of the analyzed health social networks, there are common features that are available such as the profile, friends, messages and to search something. The profile feature normally contains personal or work information. All the health social networks analyzed have this feature where the user can view and edit their basic information. The member/friends feature allows the users to see other users that are registered in the website, and to have some type of relationship with them. This feature is available in the six health social networks analyzed and offers the possibility to search a person, add a user as a friend, send a private message to another user and send an email to invite others to join the site.

Support Group/Forums and Blog/Pages

The support group/forums feature is a discussion area on a website. In this area the user can start some threads, and reply to other people’s threads. This feature is not offered by all but CureTogether. In here the user can view the existing support groups/forums, their information, search what is for their best interest and start or participate in discussions. All the health social networks analyzed that offer the support group/forum feature have the same options available except for my groups/forums that is only available in Inspire. A list of the members of the topic/forum that is available only in Inspire and DailyStrength. The blogs/pages feature is a collection of posts that appears in reverse chronological order. This posts can composed by only words, as well as audio, video or embeddable objects. This feature is available on 67% of health social networks analyzed, not being available in CureTogether and PatientsLikeMe. There the user can view the blogs/pages, or search their information and post replies.
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Treatments, Symptoms and Experts answers

The treatments feature is a page that allows the users to see the different types of treatments for different conditions. The feature is available in all the health social networks analyzed. This feature is immediately visible in DailyStrength and PatientsLikeMe, in the other networks the user needs to make a search or find it through forums or blogs. In here the user is able to view or search for treatments, know more about them and in DailyStrength and PatientsLikeMe can add a treatment to their status. The symptoms feature is a page that allows the user to see what condition corresponds to different symptoms. This feature is also available in all the health social networks analyzed, but only immediately visible to the user in PatientsLikeMe. In here the user can view or search symptoms, their information and add a symptom to their status. The feature “experts’ answer” is page where the patients can post questions to health professional about conditions, treatments and symptoms. This is available in DailyStrength, EhealthForum and MedHelp. In there the user can view and search questions of their interest. If he/she does not find the answer to his/her question, he/she can post a question that then can be answered by an expert or by someone with experience in the matter. The question may or may not be answered by an expert because there is not a direct connection between the user and the health professional. However a user of the health social network can post a comment to help solving the problem. Only MedHelp have the feature to find a health professional.

Research and Trackers

The trackers feature allows the users to record and review some data about their health. This is available on CureTogether, DailyStrength, MedHelp and PatientsLikeMe. Trackers of weight and sleep are available in 50% of the health social networks. Exercise tracker is available only on CureTogether and MedHelp. Finally, DailyStrength offers a health event calendar where the user can to view the past, current and the future events made by the website. The research feature allows the user to find clinical trials that can help with their condition. This is available in Inspire and PatientsLikeMe, but only immediately visible in PatientsLikeMe. However it is possible to find clinical trials on Inspire after making a search. In PatientsLikeMe “clinical trials” feature the user enters his/her their condition, age and gender and it is possible to see clinical trials that match with the data. In addition, in PatientsLikeMe the user can view videos of presentations about a great variety of health issues and researches that were made by PatientsLikeMe that involved registered users. Finally in publications that feature the site the
user is redirected to Google scholar where he can see publications that mentions the PatientsLikeMe website.

**Conclusion**

After this analysis it is possible to see that there is a great similarity in the features offered, such as home, profile, friends, treatments, symptoms and even support groups/forums services, available in five out of six health social networks analyzed. But when taking a deep look at the services (Figure 12) such as treatments, symptoms, experts answers, trackers and research it is possible to see that the services offered are limited. Among health social networks that offer information about treatments and symptoms, only MedHelp offers the possibility to make questions to experts and have quantified self-tracking. MedHelp does not offer the possibility to participate on new clinical trials or have direct contact with the health professionals. While some health social networks are included in the Figure 12 as offering some services, many times the users need to make searches to find them, like symptoms or clinical trials.
Chapter 4. Assessing the needs of end users

In the following we will investigate what the best way to host information about the features that we saw as essential and see what are the biggest aspects needed by the patients, researchers and health professionals to enable a better interaction between them. This chapter includes the study that was approved by the SESARAM (Annex II) with doctors, physiotherapists, speech therapists, occupational therapists and patients. From the state of the art we have seen that successful projects are those with greater user interaction. To evaluate the satisfaction and expectations of the health professional and patients with the support services an inquiry was made. For this analysis were considered all the people that were being treated in the service of Physical Medicine and Rehabilitation of the Dr. Nélio Mendonça Hospital and the doctors, physiotherapists, speech therapists and occupational therapists. A total of 54 inquiries were made between the 11th of December 2012 and 8th of January 2013 and can be found in Annex III.

4.1. Patients needs

Were made 18 inquiries of the 54 to an average age of 52.6 years old, 8 of them were male and 10 female, with different scholarship (Table 4) and diagnosis (Table 5). The patients questionnaire was composed by 19 questions, which 14 of them were multiple choices, and the other 5 open answers. Most of the questions to the patients were made to let them chose from multiple choices to facilitate the answering. Patients were asked about computer usage (question 1 through 3); usual means of transportation and communication (questions 4 through 7); best way to interact with health professionals (questions 8 through 11); content and usage of the forum (questions 12 and 13); level interest, and positive and negative aspects of the approach (questions 14 through 19). The goal was to understand the need and costumes of the patients. In the following the answers given to each question are analyzed.

Demographics - Patients

<table>
<thead>
<tr>
<th>Gender</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>10</td>
</tr>
<tr>
<td>Male</td>
<td>8</td>
</tr>
</tbody>
</table>

Table 2 - Gender distribution of the patients
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<table>
<thead>
<tr>
<th>Age</th>
<th>Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>20 – 29</td>
<td>2</td>
</tr>
<tr>
<td>30 – 39</td>
<td>2</td>
</tr>
<tr>
<td>40 – 49</td>
<td>2</td>
</tr>
<tr>
<td>50 – 59</td>
<td>5</td>
</tr>
<tr>
<td>60 – 69</td>
<td>4</td>
</tr>
<tr>
<td>70 – 80</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>18</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age</th>
<th>Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>20 – 29</td>
<td>25,5</td>
</tr>
<tr>
<td>30 – 39</td>
<td>33</td>
</tr>
<tr>
<td>40 – 49</td>
<td>43</td>
</tr>
<tr>
<td>50 – 59</td>
<td>54,4</td>
</tr>
<tr>
<td>60 – 69</td>
<td>64,5</td>
</tr>
<tr>
<td>70 – 80</td>
<td>71,6</td>
</tr>
<tr>
<td>Total</td>
<td>52,6</td>
</tr>
</tbody>
</table>

Table 3 - Age distribution of the patients that answered the inquiry

<table>
<thead>
<tr>
<th>Education</th>
<th>Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elementary ed</td>
<td>3,6</td>
</tr>
<tr>
<td>Secondary ed</td>
<td>11,1</td>
</tr>
<tr>
<td>Higher ed</td>
<td>15</td>
</tr>
<tr>
<td>Total</td>
<td>9,9</td>
</tr>
</tbody>
</table>

Table 4 - Scholarship distribution of the patients

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Stroke</td>
<td>9</td>
</tr>
<tr>
<td>Cervical fracture</td>
<td>1</td>
</tr>
<tr>
<td>Traumatic spinal vertebroplasty</td>
<td>1</td>
</tr>
<tr>
<td>Brachial plexus injury</td>
<td>1</td>
</tr>
<tr>
<td>Guillain Barré syndrome</td>
<td>1</td>
</tr>
<tr>
<td>Low back pain</td>
<td>5</td>
</tr>
<tr>
<td>Total</td>
<td>18</td>
</tr>
</tbody>
</table>

Table 5 - Diagnosis distribution of the patients

**Question 1:** “Do you use a computer? How many times a day?”

In Figure 13 it is possible to see 50% (9/18) of the patients use the computer at least 1 hour per day, and that below 55 years old are the ones who use it more frequently.
Chapter 4. Assessing the needs of end users

**Question 2.** “Do you use internet? How many times a day?”

In Figure 13 - Hours of usage of the computer by the patients separated by age it is possible to see 44% (8/18) of the patients use the internet at least 1 hour per day, and that below 55 years old are the ones who use it more frequently.

![Hours of usage of the PC](image1)

**Figure 13 - Hours of usage of the computer by the patients separated by age**

![Hours of internet usage](image2)

**Figure 14 - Hours of usage of the internet with the patients separated by age**

**Question 3.** “Do you use social network (facebook, twitter, etc.)”? 
38% use social networks. This represents that 87% of the patients that use internet. All that use social networks use them 1-3 hours a day (Figure 15).

**Question 4.** “How often do you need a consultation from a doctor/therapist?”

Patients need to see the doctors or go to therapy mostly (77%) at least 2 days per week. No difference was focused in the answer depending on the patient age (Figure 16).

**Question 5.** “How much time do you spend on consulting a doctor/therapist since leaving home?”
Chapter 4. Assessing the needs of end users

The total of time that each patient spend between leaving their houses and seeing the doctor or having therapy depends on the place where they live and the mean of transport they use., but is mostly between 1 and 4 hours. Most patients (66%) spend more than 2 hours (Figure 17).

![Time spent in treatment and transportation](image-url)

**Figure 17** - Time that the patients spent in treatment, including the transportation.

**Question 6.** “What is the distance between that you travel to have a consultation?”

The distance between the patient’s home and their health care is between 1 and 10 km for 67% of the patients. The maximum distance reported by patients was 40 km.

**Question 7.** “What means of communication normally uses to communicate with doctors/therapists?”

The answers show that besides the medical appointments, only the phone is used and very sporadically, mainly to make the appointments (Figure 18). None of the communication channels that involve a computer is used.
Figure 18 - Means of communication normally used by the patients to contact the health professionals

Question 8. “Rate the potential of each mean of communication for their potential?”

With the graphic it is possible to see the potential that each means of communication has for the patients. To the patients the medical appointments will continue to be extremely important in the future, but only one of the patients thinks that Internet, Forum or a Chat has no potential 5% (Figure 19). Patients give extreme relevance to personal appointments but also much relevance to all the rest.
Question 9. “What is the relevance you give to be frequently follow-up by the doctors / therapist?”

94% of the patients (17/18) considered that is extremely important to be followed frequently by a doctor or therapist, and one said that was very important.

Question 10. “How often would you like to receive evaluations from doctors / therapists?”

More than 50% of the patients would like to receive evaluations from the doctors/therapists at least one time per week, in order to knew their progress.
Question 11. “What is the importance of having remote evaluations?”

In this question we find differences between age groups (patients that have more than 55 years old). Of the 18 patients, 12 (66 % of them) think that it is important to have direct contact with the health professionals even if they are not face to face. This was predominant in younger patients (<55 years old) (Figure 21).

Question 12. “What content should be in the forum? You can select more than one!”

The answers show that patients think that the forum should contain information about treatments above all (77%), with the advices coming in second place (50%) (Figure 22).
Chapter 4. Assessing the needs of end users

**Figure 22** - The content that should be on the forum

**Question 13.** “How do you think the forum should be used? You can select more than one!”

The Figure 23 shows that for patients the part that includes researches is not as important (38%), the essential part is to have a direct contact among patients (77%), and between the patients and health professionals (77%).

**Figure 23** - By whom the forum should be used

**Question 14.** “What were the 2 aspects you liked more? Why?”

In this question patients provided open answers, and the results are very different. 5 of the patients (27%) said the most interesting thing is the possibility to have a direct communication through the forum or messages. 4 (22 %) said that the all idea is interesting, 4 (22%) said that do not know how to use the PC. 2 (11%) appreciated to have access to information about treatments. 1 (5%) said the only fact to use the PC and to have exercises is very good, and other 2 (11%) did not know.
Question 15. “What were the 2 aspects you liked less? Why?”

8 out of 18 (44%) said that did not find anything that they did not like, 4 (22%) said that do not know how the use the PC. 4 (22%) said that did not know. 1 (5%) said that the time available may not allow the use of the site, and another (5%) said the forum may not be a good idea because it is public.

Question 16. “What aspects are the most confusing for you, if you had some?”

Patients said that did not find anything confusing about the topics that were explained (61%). 33% said that did not know and another (5%) said the need to use the PC.

Question 17. “Aspects that would improve or add?”

44% of the patients answered that did not have anything to add or to improve. 33% said that did not know. 11% said to have an agenda to make appointments. 5% said that should have music, another 5% said that should have information about treatments.

Question 18. “What is your level of interest in using the tool presented even is not a user of the internet or social networks?”

Figure 24 show that patients bellow 55 years or less have great interest in using this toll whereas older patients were not so interested. Even two patients above 55 reported interest in using it, even if they did not know how to use a computer.

![Figure 24 - Level of interest in using the tool presented with the patients separated by age](image)

Question 19. “Any additional comments you would like to leave?”

15 of 18 of patients (83%) did not have anything else to report. 1 said that the idea was good. Another patient said that should have video/audio material, and another one said that wanted to learn to use the PC.
Chapter 4. Assessing the needs of end users

Conclusion

The 18 patients that participated in this survey had an average of 53 years old and an average of 10 years of study. These were representative of the target population of our system. The answers show that at least 50 % of them use the computer and have some experience using the internet and social networks. Therefore, these patients are potential users of our system. The majority of the patients visit health professionals twice a week and 66% spend more than 2 hours when in each appointment. Besides the medical appointments the 56 % of the patients use to phone to communicate with the health professionals, but only occasionally and normally to make an appointment. This means that still exists room for improvement in this area, with the use of systems like ours to streamline and optimize the interaction between the patients and the health professionals. Only one in eighteen patients think that Internet, Forum or a Chat will not serve as a mean of communication between them and the health professionals. Patients answered that would like to receive regular evaluations by health professionals, and 66 % of them value the importance of having remote evaluations. So these patients view systems like ours as a way to complement face to face interactions. Most patients think that forum could be useful, and should contain at least information about treatments and advices. Patients consider that the forum should be used between patients, and between patients and health professionals, leaving aside the communication between health professionals and researchers. To sum up we could see that 61 % of the patients showed interest in using the tool presented, even when they did not know how to use a computer.

4.2. Health professionals needs

The questions to the 36 health professionals, divided by doctors (13, with average age of 39.8 years old), physiotherapists (15, with average age of 40.9 years old), speech therapists (4, with minimum age of 45.8 years old) and occupational therapists (4, with average age of 41 years old). The health professional inquiry was composed with 24 questions, where 18 of them were 5-point Likert scale and the other 6 were open answer. The health professional were asked about computer usage (questions 1 and 2); usual information needed from the patient and means of communication (questions 3 through 5); level and way of update about new therapies and treatments (questions 6, 7 and 14, 15); best way to interact with patients (questions 8 through 14); content and usage of the forum (questions 17 and 18); level of interest, positive and negative aspects of the approach (questions 19 through 24). The goal
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was to understand the health professional needs, habits and availability to use this type of tool to interact with patients. In this section the answers given to each question is analyzed. The questions that use Likert scale will be evaluated quantitatively with a value between 1(none) and 5(extreme).

Demographics – Health professionals

<table>
<thead>
<tr>
<th>Specialty</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctors</td>
<td>13</td>
</tr>
<tr>
<td>Physiotherapists</td>
<td>15</td>
</tr>
<tr>
<td>Speech therapists</td>
<td>4</td>
</tr>
<tr>
<td>Occupational therapists</td>
<td>4</td>
</tr>
</tbody>
</table>

Table 6 - Health professionals that answered the inquiry

<table>
<thead>
<tr>
<th>Age</th>
<th>Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>20 – 29</td>
<td>27,2</td>
</tr>
<tr>
<td>30 – 39</td>
<td>34,9</td>
</tr>
<tr>
<td>40 – 49</td>
<td>46</td>
</tr>
<tr>
<td>50 – 59</td>
<td>52</td>
</tr>
<tr>
<td>Total</td>
<td>40,0</td>
</tr>
</tbody>
</table>

Table 7 - Age distribution of the health professionals

<table>
<thead>
<tr>
<th>Gender</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>25</td>
</tr>
<tr>
<td>Male</td>
<td>11</td>
</tr>
</tbody>
</table>

Table 8 - Gender distribution of the health professionals

Question 1. “Do you use internet? How many times a day?”

Only 5 of the 36 (14%) health professionals do not use the internet at least 1 hour per day, meaning that 86 % of them have experience using the computer and internet.

Question 2. “Do you use social network (facebook, twitter, etc.)”?

The answers show that 50 % uses at least one hour the social networks and the other 50% uses less than one hour or do not use at all.
Chapter 4. Assessing the needs of end users

Question 3. “What kinds of questions are "mandatory" in an appointment?”

The majority said that the questions more asked are: Age; What brings the patients to that consultation; Level of pain; Type of medication that are using; Definition of the objectives.

Question 4. “What means of communication normally uses to communicate with patients?”

All of them choose the face to face type and 50% said that uses the phone but only sporadically. None of the communications that involves the computer is used.

Question 5. “Rate the potential of each mean of communication for their potential?”

With the graphic it is possible to see the potential that each mean of communication has for the health professionals. 33% of health professionals think that internet, forum or chat has few or less possibility to be a mean of communication between them and patients (Figure 25).

Potential of each means of communication

![Graph showing potential of each mean of communication](image)

Question 6. “What is your level of knowledge about new therapies / technologies?”

Health professionals have at least some level of knowledge about new therapies and technologies. Only 2 of 36 (5%) of health professionals have little knowledge about new therapies and technologies (Figure 26). The average in our Likert scale was 4,03 out of 5, meaning that they have a great level of knowledge about new therapies and technologies.
Question 7. “What is the need you feel to look for new treatments or investigations?”

Health professionals feel a need to search for new treatments. They do not have a service that keep them updated about new investigations (Figure 27). In the Likert scale that was defined the average was 4,44 out of 5, meaning that they feel a need very high to find new treatments.

Question 8. “What is the relevance you give to frequently follow the patients?”

Health professionals find at least very important to follow the patient, while the percentages at column other is because for some it depends on each case (Figure 28). In the Likert scale that was defined the average was 4,00 out of 5, meaning that is extremely important to follow the patient frequently.
Chapter 4. Assessing the needs of end users

Question 9. “How often would you like to receive notifications of the patients’ evolution?”

Most of the health professionals prefer to have notifications about the patient at least one time per week, and 10 of 36 (27%) of the health professionals choose the option “Other” because depends on each case. There is a contrast between the doctors and the therapists because the different therapists follow more frequently a patient than the doctors (Figure 29). In the Likert scale that was defined the average was 2.22 out of 5, meaning that option preferred is at least one time per week.

Question 10. “What aspects would you like to follow from patients?”

In this questions health professionals provided open answers, and reported that would like to know how the patients feels, if there was changes in is condition, if the patients is doing the exercises, how is doing with the thing at home and job, if the treatment is helping.

Frequency of notifications that would want to receive

Figure 29 - Frequency of notifications that would want to receive
**RehabNet: A social network for the deployment of online rehabilitation**

**Question 11.** “How useful would be if family members had access to evolutions of patients?”

Figure 30 shows that the answers are aggregate between some and extreme. The doctors are the ones that presents more disparity, including the column other that is because two of them questioned the ethic of the others having access to the patients medical condition. In the Likert scale that was defined the average was 3,5 out of 5, meaning that to the health professionals the family members having access to the patients developments has some importance.

![Utility of the family members having access to patients developments](image)

**Figure 30 - Utility of the family members having access to patients developments**

**Question 12.** “What is the importance of having direct communication with the patients?”

75% of health professionals answered that was extremely important to have a direct communication with patients, 22 % said that was very important and 2% said that has some importance.

**Question 13.** “Importance of having remote appointments?”

Only 6 out of 36 (16%) of the health professional choose the options much or extreme, that is because all of them, including three physiotherapists that choose the option other, said that only trying they could have a definitive answer (Figure 31). The answers were based by the habit and need that health professional have to be with patients face to face. In the Likert scale that was defined the average was 3,05 out of 5, meaning that to the health professional is somehow important to have remote consultations with the patients.
Chapter 4. Assessing the needs of end users

**Importance of having remote consultations with the patients**

![Graph showing the importance of remote consultations with patients](image1)

*Figure 31 - Importance of having remote consultations with the patients*

**Question 14.** “What is the amount of patients that you think may benefit from this site?”

This graphic (Figure 32) is so distributed because great part of the health professionals says that the age of the patients and their limitations would not allow the use of this technology. In the Likert scale that was defined the average was 3,00 out of 5, meaning that the average answer was some of the patients can benefit from this site.

**Amount of patients that can benefit from this site**

![Graph showing the amount of patients that can benefit from the site](image2)

*Figure 32 - Amount of patients that can benefit from this site*

**Question 15.** “What is the importance that you give to receive information about new research?”

75% of health professional answered that is extremely important to receive information about new researches. 25% said that is very important.
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**Question 16.** “What is the importance of participating in new researches?”

67% (24/36) of the health professionals answered that it is extremely important to have the possibility of participate in new researches, 22% said that is very important. 8% said that is some important, and 3% said that has few importance and gave the lack of time as justification.

**Question 17.** “What content should be in the forum? You can select more than one!”

Figure 33 shows what content should be in the forum, separated by each specialty. The majority of each specialty said the forum should contain all the possibilities. In total at least 72% of health professional said that the forum should contain all the options.

![The forum should contain](image)

**Question 18.** “How do you think the forum should be used? You can select more than one!”

The answers are almost consensual (Figure 34), with 8% (1/13) of the doctors choosing the forum should not exist. All the speech and occupational therapists choose all the options, and the doctors and physiotherapists choose almost the options, with especially attention to the relation Patient-Doctor that is acceptable by majority of them (at least 85%).
Chapter 4. Assessing the needs of end users

Question 19. “What were the 2 aspects you liked more? Why?”

In this question health provided open answers, and as result the number of aspects was different with 30% of the health professionals saying that like all about the idea. 25% said the forum is the most important aspect. 22% referred the importance of having a new method to have contact and to monitor the patients. 14% said the fact to have access to new information and researches about treatments. Another 8% said that did not know what was positive.

Question 20. “What were the 2 aspects you liked less? Why?”

13 out of 36 (36%) of the health professionals said that did not find any negative aspects. 36% said that the technological barrier and the age of patients would limit the adherence. 14% said that the limited time to be in front of the computer would be the problem. 8% said that should have supervision, and another 5% said that the fact to have remote consultations was the thing that they did not like.

Question 21. “What aspects are the most confusing for you, if you had some?”

61% of the health professionals said that did not find anything confuse. 14% said that is still very abstract. 11% questioned how will be possible if the hospital do not have computers to all in the hospital. 8% said that the confusing will be for the patients that are older and another 5% said the most confusing part is how will be the ethic part, with people having access to information about other patients.
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**Question 22.** “Aspects that would improve or add?”

69% of the health professionals said that did not have anything to add or change. 16% said that should be made considerations in order to have the approval of the commission that controls the data. 8% said that only after trying could have anything to add or change. 5% said the site should have a simple language and layout to help the less experienced users to access it.

**Question 23.** “What is your level of interest in using the tool presented even is not a user of the internet or social networks?”

Figure 35 show the level of interest in using the tool, presented with the doctors/therapists separated by specialty. The percentage that has few or none interest in using the tool presented is very low. Actually 31 out of 36 (86%) have at least some interest in using the tool. In the Likert scale that was defined the average was 3,31 out of 5, meaning that the health professionals have much interest in using the site.

![Level of interest in using the tool presented](image)

**Question 24.** “Any additional comments you would like to leave?”

97% said that did not have anything to add, and 3% said did not want to be in the front of the computer.
Chapter 4. Assessing the needs of end users

Conclusion

It was possible to see that at least 50% of the health professionals know how to use the computer and the internet. Therefore these health professionals are potential users of our system. The information required by health professionals does not vary, independently of their specialty. Besides the face to face appointments, 50% of them use the phone as method of communication with the patients. Only 33% of the health professionals believe that internet, forum or chat has little potential as a mean of communication with patients. This shows that 66% of health professionals are open to use new means of communication to improve the interaction between them and the patients. The health professionals have good level of knowledge about new therapies and technologies but they have a great need to find new treatments. Interestingly, in some questions made to the 36 health professionals the answers varied depending on the specialty. The majority of health professionals said that is very important to follow frequently the patients, but the frequency of notifications that would want to receive about the patients and the relevance of family members having access to patients developments varies depending on the specialty. The importance of having remote consultations was controversial for the health professionals because they would need to try out our system first to evaluate it. They still feel the need to see the patient face to face, and consider this type of tool as a complement and not as a substitute of appointments. They think some of the patients could benefit from this tool, and they would want to receive information and participate in new research studies. The majority of the health specialists think all the options (FAQ, Information about treatments, articles, advices) should be available in the forum, and should be used by all types of users. Therefore the forum can be considered an important feature to trade information and discuss a variety of topics. The level of interest in using the tool is high, with 86% of the health professionals having at least some interest in using it. In the following chapter we will use the information collected in the last two sections to define the requirements of our system.
Chapter 5. System development

Currently the health social networks offer a variety of services, but none of them have complete package of offering emotional support and information sharing, health professional Q&A, quantified self-tracking, clinical trial access and networking and information. That said it is imperative to make use cases and software requirements analyses to help in the software design process. Within this analysis the uses cases, functional and non-functional requirements are described. Functional requirements represent the intended behavior of the system while non-functional requirements specify criteria that can be used to judge the system. Based on the information acquired through the state of the art analysis and the surveys, the following subsections describe the necessary use cases and requirements for the RehabNet system.

5.1. Use Cases

5.1.1. What is Use Cases

Multiple use cases definitions can be found, but the term use case was introduced by Ivar Jacobson. A use case is a description of a series of interactions that an individual actor initiates with a system. An actor is a role played by a user (Figure 36). A use case is thus a general way of using some part of the functionality of a system. [13]

Rouse [14] defines a use case as a methodology used in system analysis to identify, clarify, and organize system requirements. The use case is made up of a set of possible sequences of interactions between systems and users in a particular environment, and related to a particular goal. There are three basic elements that make up a use case [15]:

- **Actors**: Actors are the type of users that interact with the system.

- **System**: Use cases capture functional requirements that specify the intended behavior of the system.
• “Goals: Use cases are typically initiated by a user to fulfill goals describing the activities and variants involved in attaining the goal.”

5.1.2. RehabNet Use Cases

Actors Description

The system has three different actors, that being, patients, health professionals and researchers, but the first case it is about a new user:

New user – As a new user he can to the sign in with the RehabNet and be able to enter their personal data and choose the type of user before doing the validation.
Patient – As a patient, the user will be able to access their profile and change the information in it, to use the agenda, forum and the messages. He can accept be followed by a health professional and participate in researcher with trainings.

Figure 38 - Patients Use Case
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Researcher – As a researcher, the user will be able to access their profile and change the information in it, to use the agenda, forum and the messages. The researcher will be able to create, edit and remove researches and trainings.

Figure 39 - Researcher use case
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**Health professional** - As a health professionals, that are designated with the word Doctor, he have the same features that a researcher but will be able to follow patients, and to add patients to events.

![Doctor use case](image)

**5.2. Functional Requirements**

In this section we integrated all requirements into one single specification list. In this list S will indicate requirements derived from the state of the art analysis, P from the patient survey, and H from the health professionals survey.

**5.2.1. Registration requirements**

1. Users must be able to sign up with the RehabNet. (S)
2. Users must be able to choose what type of user will be between Patient, Health professionals or Researcher. (S)
3. Users must be able to insert their personal data, such display name, username, password, email, gender, birth day, country. If the user chooses Health professionals must put their medical number. (S)
4. Users must be able to register and/or log in through Facebook or Google. (S)
5. Users must be able to activate the option remember me. (S)
6. Users must be able to recover their password. (S)
5.2.2. Visualization requirements

1. Users must be able to view the updates of the social network as they log in. (S)
2. Users logged in as researchers must be able to access my home, settings, profile, agenda, members, forums, trainings, and researches. (S, H)
3. Users logged in as patient must be able to access my home, settings, profile, agenda, members, forums, and trainings. (S, P)
4. Users logged in as health professionals must be able to access my home, settings profile, agenda, members, forums, trainings, and researches. (S, H)
5. Users must be able to select the content of the page My home by choosing from the widgets available. (H,P)
6. Users must be able view and change their own settings such password, email, notifications, and account statistics. (S)
7. Users must be able to view and change their profile, having the ability to change their photo, username, birthday, gender, nationality and condition. (S)
8. Users logged in as health professionals must be able to establish relationships with patients, by following them. (S, H, P)
9. Users logged as health professionals must be able see their list of patients that are following. (S, H)
10. Users logged in as health professionals must be able to establish relationships with others health professionals or researchers, by adding them as friends. (S, H, P)
11. Users logged in as patients must be able to establish relationships with other patients, by adding them as friends. (S, H, P)
12. Users must be able to accept friend requests from others users. (S, H, P)
13. Users must be able to communicate with their contacts. (S, H, P)
14. Users must be able to see, add or delete events to their agenda. (S, H, P)
15. Users logged in as health professionals must be able to add patients that are following to an event, and that event should be added to patients agenda. (S, H, P)
16. Users must be able to upload and share digital contributions with their contacts. (S)
17. Users must be able to control who can see what part of their profiles fields through privacy settings. (S)
18. Users must be able to search for a member by name. (S)
19. Users must be able to search for a member by user type (S)
20. Users must be able to create, change or delete their topics in the forum. (S, H, P)
21. Users must be able to choose the access level of a new forum. (S, H, P)
22. User must be able to see public topics of discussion in the forum. (S, H, P)
23. Users must be able post, edit, delete or like comments in topics of the forum. (S, H, P)
24. Users must be able to see my topics or all topics in the forum. (S, H, P)
25. Users must be able to view, create or delete messages from their messages box. (S, H, P)
26. Users logged as researchers/health professionals must be able to create new trainings, including the title, description, type of training, type of playing, image and game that they want to upload. (S, H)
27. Users logged as researchers/health professionals must be able to view a list of all trainings. (S, H)
28. Users logged as researchers/health professionals must be able to view, play or delete their own trainings. (S, H)
29. Users logged as patients must be able to view a list of all trainings. (S, H, P)
30. Users logged as researchers/health professionals must be able to create new researches. (S, H)
31. Users logged as researchers/health professionals must be able, in the first step of a new research, to insert the title, description, duration, frequency, and define the access level of that research. (S, H)
32. Users logged as researchers/health professionals must be able, in the second step of a new research, to choose for what patients the research is indicated, by having the option to send to all patients, to choose from demographics field such as country, condition, gender, or range of age. The health professionals have the additional option of selecting from the list of their own patients. (S, H)
33. Users logged as researchers/health professionals must be able, in the third step of a new research, to select the training or trainings for that research. (S, H)
34. Users logged as patients must be able receive messages to participate in new researches. (S, H, P)
35. Users logged as patients must be able to accept to participate in new researches. (S, H, P)
36. Users logged as patients must be able to view a list with the trainings that they accepted. (S, H, P)
37. Users logged as researchers/health professionals must be able to view a list of all researches. (S, H)
38. Users logged as researchers/health professionals must be able to view a list of their own researches, and have an option to delete a research. (S, H)
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39. Users logged as researchers/health professionals must be able to view the results of the researches and export them. (S, H)

5.3. Non-Functional Requirements

1. The system should have the capacity to recover lost data from the last operation made in case of energy failure.
2. The system should not take, in max, 8 seconds per consultation or interaction made.
3. The system should have a good storage capacity.
4. The system should promote the integrity and consistency of the data base independently of the occurrences on the site.
5. The system should allow multiple users to use the system simultaneously.
6. The system must have identification and passwords for different types of users: system administrator, doctors, researchers and patients who have access to the system.
7. The system should maintain the privacy of their users.
8. The system should be portable, meaning that must run with different type of operating systems and different web browsers.
9. The system should guaranty that is running 98% of the time.
10. The system should allow any user to access without restriction to their functionalities.
11. The system should maintain a good operation, by not causing delays when used by multiple users.
12. The system should maintain an historic of the operations made.

5.4. RehabNet mockups and Evaluation

The specified served as a guide to the make initial mockups of the system to present to the end-user. In this chapter we will include the design and the tests that were made to potential users of the system. These mockups are made to test design ideas, to examine content, aesthetics and interaction techniques in perspectives of designers, customers and users. The idea is to cut down on the complexity of the implementation, eliminating parts of the total system. Tests were made using a personal computer and can be found in Annex II. Mockups were made using the balsamiq mockups software (Balsamic Studios, USA) that is a graphical user interface mockup builder application that allows arranging pre-built widgets, and to tweak and rearrange easily. Due to software limitations, it was not possible to fill in data. For that reason the text input was already filled in the mockup tests. A total of 9 tests were made
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with 3 researchers, 3 computer technicians, 2 doctors and the last one a software engineer (Table 9). In these tests users were asked to perform some tasks while we kept track of how long it takes to be answered. They were informed to do whatever comes naturally. They were told to think aloud, and give any suggestions. A mistake is considered when a user does not perform a task as expected/pictured.

<table>
<thead>
<tr>
<th>Specialty</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Researchers</td>
<td>3</td>
</tr>
<tr>
<td>Computer technicians</td>
<td>3</td>
</tr>
<tr>
<td>Doctors</td>
<td>2</td>
</tr>
<tr>
<td>Software engineer</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 9 - Profession of the users

Previously we have defined the need of providing RehabNet user with the following features: Sign-up, Home, Profile, Members, Messages, Forums, and Researches. In the following we present the initial prototype implementation of each of them. In this section the number of mistakes and the number of times users failed to conclude a task.

**Question 1.** “To use the social network it is necessary to do the registration. Please access the content of the prototype as a researcher “

The next three figures show the steps that a user see when doing the task. In Figure 41 it is possible to see the front page of the mock-up where the users have the option to choose between register, log in, lost password and also the Facebook or Google option.

Figure 41 - Front page of the mock up
In Figure 42 it is possible to see the form of registration where the users could choose the type of profile they wanted in the mock-up.

![Registration form](image1.png)

**Figure 42 - Registration form**

In Figure 43 it is possible to see the front page after the log in as a researcher, where the user could have the first contact with the options available in the mock-up.

![Initial researcher page](image2.png)

**Figure 43 - Initial researcher page**
The number of mistakes was 17 that is considered high when they were asked to access the content of the site as researchers. All the users made the same error, not finding the button register and not choosing the type as researcher. All the tests were failed, because none of the user concluded the task in the limit of time considered. In order to fix this situation the layout in the first page of the site was changed. It has information about the RehabNet social network and the type of users that are available to register. Another change is the possibility to do the registration in the front page without making more steps. The home page after the log in was changed to give access to more information.

**Question 2.** “Please find a way to send a message to another user”

The next two figures show the steps that a user see when doing the task. In Figure 44 it is possible to see the messages page, where the user could compose a message, view their inbox messages, delete them and access the sent messages.

![Messages page](image)

*Figure 44 - Messages page*

In Figure 45 it is possible to see the user have the option to choose who is going to receive the message, the subject, and the text that he wants to send.

The number of mistakes was 5, with 2 of the 9 (22%) users making the same mistake, by not choosing compose message. The number of times that the time expired was 2 (22%). A user had doubts about the meaning of toggle all. To avoid that mistake the name compose a message was changed to create a message. The button with toggle all was changed to select all and the side bar was changed from the right side to the left to be clearer to the users.
Question 3. “Please manage your messages”.

In Figure 46 is possible to see the received message page where the user can view the message, delete, mark as read and reply.
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The only error was made by one user that only viewed the messages and did not delete any of them. To avoid that the button for delete was changed for the word delete in front of each message. The side bar was changed from the right side to the left to be clearer to the users.

**Question 4.** “Please create a new research to investigate the effect of a new activity for left leg on elderly. After see the results”

The next two figures show the steps that a user see when doing the task. In Figure 47 is possible to see the page of my researches where the users have the chance to create a new research, edit, see the results or delete a research.

![Figure 47 - My researches](Image)

In Figure 48 it is possible to see the options that the users have to create a new research, with the option to choose the details and if want to use a current activity or to create new one.

The number of mistakes was 8. 3 out of 9 (33%) user made the same error, which was not choosing new activity. The number of times the limit of time expired was one (11%) (Figure 49). In order to correct the high volume of mistakes the format of creating a research was changed. The name my researches was changed to researches. The activity was changed to training and was added as separated bar on the main menu. The researches now are divided in 3 steps. In step one it is the research information, with the title, description, request medical evaluation and the access level. The step 2 it is the research patients, where it is possible to add patients to a research or do a demographic selection. The step 3 is where the selection of trainings is made.
Create a new research and see the results

Figure 48 - New research page

Figure 49 - Create a new research to investigate the effect of a new activity for left leg on elderly. After see the results
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**Question 5.** “Please search in the forum a topic of recover from a stroke at 40 years. If it is not created yet, make a new topic for it”

In Figure 50 it is possible to see the forums page where is possible to create a new topic, choose a current topic to view it or to make a comment.

![Figure 50 - Forums page](image)

In Figure 51 it is possible to see the options that the users have to create a new topic in the forum. Have the option to insert the title, the content of the topic, the tags, if can be commented, who have the access to view it and to save or preview it.

![Figure 51 - New topic page](image)
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Only was a mistake, which was a user not selecting immediately, create a new topic. The user recommended to change to new forum.

**Question 6.** In this question was asked to the user to add another user as a friend.

The next two figures show the steps that a user see when doing the task. The Figure 52 show the members page where the users could see the current users, or search for one, or click on a member to see their profile or add as a friend.

**Figure 52 - Members page**

In Figure 53 is possible to see the profile page of a different user. In here is possible to add the see the user details, add the user as a friend, report user and send a message.

**Figure 53 - Other user profile page**
The number of mistakes was made by 5 out of 9 (55%) of the users, meaning that 4 of them did not make any error. The mistake that was common to 3 was not choosing the correct profile of the user. The number of times that the limit of time expired was two. To fix that situation, follow patient or add user, depending on the type of user was added in the members feature.

Add a user as a friend

![Add a user as a friend](image)

Figure 54 - Add a user as a friend

The Figure 55 serves to show the own profile page that the user have access, where they could edit photo, edit profile and see the current profile data.

![Profile page](image)

Figure 55 - Profile page
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Conclusion

The usability test revealed some of the imperfections of the design. In the front page the form of the buttons and their position was a problem, as the fact of register and lost password being in the same level. In the register form, the selection of the profile type and the space used was considered not ideal by the users. Therefore the front page and the register form were changed for the final mockup. The fact that was not allowed to follow a patient was referred so the follow patients’ was added in the final mockup. In the forums the fact the only thing mentioned by the users was the fact of the sidebar being located in the right side when creating a new topic. That bad location was changed not only in that page, but in all that had the same problem. In the messages page the form of the delete button in front of each message was considered as bad, so that was removed. The name compose a message was not the best so was changed to create a message. In order to correct the high volume of mistakes the format of creating a research was changed. The activity was changed to trainings and was added as separated bar on the main menu. In the trainings it is possible to the health professionals and researchers to upload new trainings, to choose the name of the training and the focus type. The researches now are divided in 3 steps. In step one it is the research information, with the title, description, duration, frequency and the access level. The step 2 is the research patients, where it is possible to add patients to a research or do a demographic selection. The step 3 is where the selection of trainings is made. The usability tests supported the overall design and functionality of the site, and revealed a number of design and implementations issues that were addressed in the next implementation. Given that the overall design was generally accepted, we decided to implement these changes directly on a functional site.

5.5. Prototype development

From chapter 4.1 up to 4.3 we established, through the requirement analysis and mockups, the needs and a design to provide the RehabNet users the features that are more in line with their necessities. In the following we present the candidate open source social networks and why Elgg was the chosen one. Further we present the changes that were made to the engine and platform to correspond to the final desired product.
5.5.1. Top open source social networks

As introduced in the state of the art social networks have been growing exponentially and there are no signs of slowing down. As a result of such exponential growth, the number of content management systems (CMS) dedicated to building social networking websites has greatly increased over the years. Thanks to their ever-growing number, some good old fashioned competition has spurred many social networking CMS into providing professional platforms of the highest quality. Yet at the same time, of poor CMS have also flooded through hoping to nibble on a slice of the gigantic social networking pie [16]. Here we present six of the best open source social networking CMS that are currently available for download and customization.

1. The OxWall CMS is an unbelievably flexible and easy to use PHP/MySQL social networking software platform. Its flexibility allows for an extremely easy way to change the way it works using Oxwall plugins. These plugins are complete units of functionality that can be used for various purposes. It takes special care about core and plugin compatibility, so any updates are easy to maintain. Oxwall offers an unseen level of efficiency when you need a full-featured, working site. Oxwall is used for a wide range of projects starting from family sites and custom social networks to collaboration tools and enterprise community solutions.

2. BuddyPress is an open source social networking software package. It is a plugin that can be installed on WordPress to transform it into a social network platform. BuddyPress is designed to allow schools, companies, sports teams, or any other niche community to start their own social network or communication tool. BuddyPress inherits and extends upon the integral functional elements of the WordPress engine including themes, plugins, and widgets. As it is built on WordPress it is written using the same primary technologies: PHP and MySQL.

3. Mahara is an open source e-portfolio system with a flexible display framework written in PHP. Mahara, meaning 'think' or 'thought' in Te Reo Māori, is a user centered environment with a permissions framework that enables different views of an e-portfolio to be easily managed. Mahara also features a weblog, resume builder and social networking system, connecting users and creating online learner communities. Mahara is a Linkedin clone script for career social networking. It has all the aspects to build a portfolio based website for members for career based social networking. The Mahara CMS provides users with blogs, a resume builder, a file manager and a view creator - a tool to help users create arrangements of their content in a particular way for others to see.
Chapter 5. System development

4. XOOPS is an extensible CMS that allows you to build sites based on your needs. It is a web application platform written in PHP for the MySQL database. You can first start off as a personal blog and expand later to include social networking, forum and much more via the use of appropriate modules. Its object orientation makes it an ideal tool for developing small or large community websites, intra company and corporate portals, weblogs and much more. Yogurt is the particular module that allows you to build a social networking site with XOOPS. You can setup your personal album of pictures, videos from YouTube, mp3 files, add your list of friends, a public wall for messages (scraps), to create communities (tribes) and many more useful features. XOOPS and Yogurt are based on php and work well in the LAMP environment.

5. LovdbyLess is a free open source social network platform built with Ruby on Rails. LovdbyLess offers you social networking solution that has everything you need to build your community. Some features of Lovd by Less include blogs, photo gallery with captions, site search for friends, activity update and user-to-user messaging. Other things that are built into the software include Flickr and YouTube integration. One thing good about Lovd by Less is that it is easy to use and contains most of the applications that you need. For those who prefer Ruby on Rail rather than php, this would be a good alternative.

6. Finally Elgg is an award-winning open source social networking engine that provides a robust framework on which to build all kinds of social environments, from a campus wide social network for your university, school or college or an internal collaborative platform for your organization through to a brand-building communications tool for your company and its clients. Elgg is a nice social network script written in php and mysql with login option with Facebook and twitter. Wirebox feature lets its users to shout what is on their mind, just like Facebook and his friends get updated. It was awarded with 'best open source cms award' in 2007. Elgg operates on a LAMP (Linux, Apache, MySql and Php) environment and it is easy to install and configure. With php knowledge, you can get your social networking site up and running in no time [17].

5.5.2. Elgg Social Networking

After analyzing the current open source social networks the choice was to use the Elgg platform. This is an open source platform for building social websites, especially social networking sites. That sentence may require some parsing, so it is possible to start with the fact that it is free open source software (FOSS). This means that are free to use it however the user wants, free
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to modify it, and free to redistribute it. Its development is managed by the nonprofit Elgg Foundation and developers from all over the world contribute code to make Elgg better.

Elgg is used to build social websites. It has social networking in its DNA and provides all the social features mentioned in the preceding section. Think of the buzzwords that are associated with social media: blogging, sharing, tagging, friending, or tweeting. Elgg does all of that. Elgg is a platform that provides the building blocks for creating great social websites. While it is possible to install Elgg and immediately begin using it as a social networking site, most of the users want to customize it. Those who are not developers can download plugins to change the look and feel or add new capabilities. For the developers, almost every part of Elgg can be customized by writing new plugins. The Elgg platform is divided into two parts: a core engine and the plugins that extend that engine. The engine contains the basic building blocks needed for a social website. It also provides the framework for developers to create new social tools through plugins [18].

The Elgg platform offers these features:

- **Powerful Data Model**: Elgg provides a powerful data model making the creation of different entities simple, yet flexible.
- **Activity Streams**: The granular activity stream API ensures your plugins can push the required content to your users.
- **Plugin API**: Elgg’s powerful plugin API offers the possibility to build and add required features.
- **User Management**: Elgg handles user management and relationship requirements.
- **Access controls**: All objects in Elgg can have access control level applied making granular access permissions possible.
- **Web Services API**: Expose functionality through the REST API by building a plugin and then either publish the API for other developers to build clients or provide your own [17].

The Elgg platform comes with a number of built-in features. Among these are the Avatar, Dashboard, Friends, Groups, Profile and Widgets. Beyond these Elgg comes with optional plugins such as Blogs, Bookmarks, File repository, Message board, Private messaging, Pages, Activity and Microblogging [19]. After the installation of Elgg, it is possible after the first tour to notice that exists a user area and a separated administration area. Each area has its own theme. Figure 56 is a sample of the default theme with each component labeled.
In the default theme the topbar is located at the top of the page and is used for navigation. The site name or logo is located below the topbar in the header. A site menu for navigating to Elgg’s different tools is also in the header. Most pages in the default theme have two columns with the content in the wider column. The narrow column on the right has a menu specific to a particular area of the site. For example, on a blog page the sidebar menu has links for viewing and interacting with blogs. At the bottom of the page is the footer. It often contains another site navigation menu or links to site specific pages such as a contact form or a privacy statement [18].

5.6. Final Prototype

5.6.1. User Interface

The built-in features that Elgg platform brings can be enough to begin using it as a social network site, but to have the type of health social network desired it needs to be changed and improved. As the initial mockups revealed some imperfections of design, the first thing that needed to be changed was the user interface. The appearance and feel of Elgg is controlled by the theme. Elgg comes with a default theme, it is not a separate module that can be uninstalled, but it is built into the engine. To change the theme to match the user’s feedback
on the mockups was necessary to install a new plugin called purity three theme [20]. This plugin overrides the default theme, and his installed has another plugin. After installing it was necessary to change parts of the theme such as the home page (Figure 57).

![RehabNet - The Social Network that allows you to recover and exchange information about health care](image)

**Figure 57 – Home Page of RehabNet**

The user interface is different of the mockups to improve the design and usability. In the top right is the login place holder, where the user can enter the email and password to access the features of RehabNet. There is an option to remind the credentials of the user and other to recover the password. Bellow in the left side is a description of the social network and the features that each type of user (Health professional, Patient, Researcher) can find. In the right side is the registration form where the user can enter their personal information and select one of the three types of user to register, and use the features that are offered in the RehabNet. As previous stated there are three types of users (Doctors, Researchers and Patients). This functionality was developed using the plugin profile manager [20]. After installing the plugin was necessary to define what the types, fields and privileges of each user. This functionality is what separates the content and privileges for each type of user as specified on the use cases.
5.6.2. Standard social features

The RehabNet includes some standard social features such as messages, forums, messages and agenda. In Figure 58 it is possible to see the messages page where the user can manage and create new messages. This feature comes with the bundled plugins of Elgg. Beyond the changes in the layout, the name to a new message changed to create a message and the sidebar moved from the right to the left side. It was added the possibility to view the new connections requests that were made to him through the plugin friend request [20].

![Figure 58 - Messages page](image)

The Elgg platform came with blog feature that was changed to correspond to the forum needs for RehabNet. The Figure 59 shows the forum page where the user can create a new topic, see the latest comments and topics already created by all, own or connections. It is possible to comment, edit and even delete own topics. As suggested by the usability tests in the mockups the sidebar moved to the left.

The members features (Figure 60) it a default Elgg feature, but was changed to present the users by type and to be a two way relationship, because by default was not necessary to accept a request from another user to be friends. To add this functionality it was used the plugin friends request as template. It is possible to search other members by name. If a user is a patient he as the possibility to send connection request to other patient or researchers but is unable to send it to doctors. The doctors have the possibility to follow a patient and send connection requests to other doctors or researchers. If a patient accepts a follow request by a doctor, he is added to the tab my patients on the doctors profile, and the doctor is added to the tab my doctors in the patient profile. The fact that a patient accepts to be followed by a doctor is used on the agenda and in the researches, because allows doctors to add a specific
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user to an event or research. The researchers can add any user as friend. The add/follow button was added after the usability test in the mockups.

Other feature that was added to RehabNet was the agenda (Figure 61) using the plugin event calendar [20]. This allows the users to create events and set the location, description, set the day/time, and add a reminder. It is possible to see the own calendar and the friends calendar. If a public event is created by a friend it is possible to add to the user own calendar. A custom
functionality was added that allows doctors to add an event to patients agenda if he is following that particular patient.

![RehabNet](image)

**Figure 61 - Agenda page**

### 5.6.3. Advanced RehabNet features

The main focus of our thesis is to allow doctors and researchers to deploy trainings and researches that allow patients to do recovery work even when they are not in therapy. To allow this was created two sections from scratch. The first one is the trainings where the users registered as doctors or researchers can upload their own games, either by uploading a file or grabbing the url of other game that they consider important. The Figure 62 shows all trainings page where the user can see the trainings that are available, when and by whom they were upload, the description of each training and the game focus. There is a difference in what appear on my trainings tab for doctors or researchers (Figure 63) and what appears to patients (Figure 64). To doctors or researches this page allows them to see their own uploaded trainings and delete them. They can play the training to test it. To patients the tab my trainings is where is located the trainings they accepted to participate on a research. When they click in the training, a new page is open where the patients can play the selected training (Figure 65). The trainings plugin has the feature that can catch results from games developed or modified directly for our platform. Our platform is able to catch results from games that send the results and time from each time that game is played. Beyond catching those two variables, it saves the user and date the game is played to then present in graphs (Figure 71 - Results page).
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Figure 62 - Trainings List

Figure 63 - My trainings page for doctors or researchers
Figure 64 - My trainings page for patients

Figure 65 - Training page with external game
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The second section that was created from scratch was the researches. This feature allows the doctors and researchers to create new researches using trainings that were previously uploaded. To create a new research the user has to complete the form (Figure 66) where he should enter the title, description, duration and repetitions. The second step allows the doctor and researcher to select what patients should receive notifications of the new research. They have the option to send to every patient on RehabNet or to choose by demographics where they can filter patients by country, condition, genre or age. The doctors have another option that could choose from the list of patients they are following (Figure 67). The final step (Figure 68) of creating a research is where the users can select the training to add. In here the list of all training is presented and they can limit the trainings by the selecting one of the checkboxes in the type of training (Motor, Memory, Language or Executive functions). He can limit the trainings by the selecting one of the checkboxes in the type of training. When the process of creating a new research is complete the patients that were selected or match the criteria defined receives a message. In this message is the title, description and the creator of the research. The patient has an option to take part on the research and when he accepts, the training that is connected with the research is added to My trainings tab of that patient.

Figure 66 - Create research step 1/3
As it happens in the trainings the researches is divided in by two lists. The Figure 69 is the all researches page where the user can see the researches that are available, when and by whom they were uploaded, the description of each research, and the results of the research. This feature was not available with Elgg and was necessary to create from scratch and is connected with the trainings plugin.
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Figure 69 - All researches page

The Figure 70 is my researches page and is exactly like the all trainings but allows the user to see their own uploaded researches, their results, and delete them.

Figure 70 - My researches page
Chapter 5. System development

To present the patients’ results of the research we create the results page (Figure 71). In here the only creator of the research can export the results to excel or pdf, and see two graphs, one based on score and date and other based on time and date. To implement the exportation was used the libraries mpdf [21] and phpsxcel [22]. To implement the graphics was used the highcharts library [23].

![Results page](image-url)

Figure 71 - Results page
Chapter 6. Conclusions

The goal of this thesis was the development of a new social network for the deployment of online rehab content which can contribute to bridge the existing gap between health professionals, researchers and patients. For that we studied the state of the art to understand what is currently available and to find satisfactory solutions to help us implement our idea. Then we did a field study with 54 subjects (36 professional experts and 18 patients) to understand their needs and how they would use this technology. Results showed that 86 % of the health professionals, and 61 % of the patients, have at least some interest using our tool. Once the user requirements were defined, a mock up implementation was made and tested with 9 subjects (2 health professionals, 3 researchers, 3 computer technicians and 1 software engineer). Finally, a working prototype was implemented using Elgg platform as basis and adding new features such different types of users, possibility to upload trainings, and create researches. The main contributions are the novelty of the solution; two fields studies for user requirements and design validation; working prototype.

The conclusion of any research work always leaves a door open to future studies, so this thesis is no exception. As stated in the previous chapters, the World Wide Web and specifically the social networks are growing exponentially with no signs of slowing down. Inside the social networks, the health social networks are a niche that is being very developed recently, so ongoing and future work on this prototype will depend on the direction of them and the availability of all participants, especially the health professionals and patients and their willingness to try new methods of rehabilitation. Additionally features and improvement of the content available in terms of treatments and conditions for the users is a reachable. Although is already possible to easily produce results from the researches, the graphical area still needs some refinements in terms of presentation. Due to the short amount of time to develop this prototype, some chosen solutions were not the best in order to solve some problems. Related with the trainings and researches, the prototype only supports the option to play online trainings. Further work can include the option of having trainings on the user machine allowing them to play locally, and doing the upload of the results after. This prototype is part of a more complex work that is a neuroscience based interactive system for motor rehabilitation, will be continuously developed.
References


[11] J. Frost and M. Massagli, "Social uses of personal health information within PatientsLikeMe, an online patient community: what can happen when patients have access to one another's data.,” Journal of Medical Internet Research, 2008.


ANNEX I. Major Health Social Networks

In this annex it is possible to see the features that are offered by each one of the major health social networks.

Figure 72 - Daily Strengh features
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Figure 75 - Inspire features

Figure 76 - CureTogether features
ANNEX II. Ethics Document

TÍTULO:

Plataforma social online para médicos, pacientes e investigadores efetuarem o seguimento, monitorização e reabilitação baseada em computadores

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A) Introdução

Défices a nível cognitivo/motor podem ocorrer devido a uma variedade de doenças. Pacientes com este tipo de défices requerem reabilitação especializada e prolongada, o que conjuntamente com os elevados valores de incidência, tem um grande impacto nos sistemas de saúde, pacientes e seus familiares. Consequentemente, surge a necessidade de encontrar novas técnicas de reabilitação que permitam estimular o processo de recuperação e possibilitem uma reabilitação continuada e personalizada para explorar ao máximo o potencial de recuperação de cada paciente.

Na última década, novos conhecimentos sobre os mecanismos de recuperação para pacientes com défices cognitivos e/ou motores e o rápido crescimento de tecnologias de reabilitação desencadearam o aparecimento de novos métodos computadorizados, como a telemedicina. Uma das abordagens que está a sobressair da telemedicina, porque está a ter um crescimento exponencial, são os sites de redes sociais. Estas plataformas oferecem uma forma rápida e fácil para chegar a uma grande parte da população com grande diversidade de serviços num curto espaço de tempo. Entre os serviços que podem ser usados nas redes sociais de saúde estão as mensagens, chats, vídeos, fóruns, além de outros conteúdos como calendários, jogos, etc. No entanto, a maior parte destes sistemas estão direcionados para a pesquisa e não para a interação entre pacientes, médicos e investigadores. Para preencher esta lacuna, o presente projeto colaborativo pretende desenvolver um novo sistema interativo computadorizado para a reabilitação e interação entre pacientes com défices motores/cognitivos, resultado de doença e envelhecimento, médicos e investigadores. O sistema proposto incorporará tarefas para troca de informação, mensagens, fóruns, calendário de atividades, criação de novas investigações e atribuição de exercícios entre pacientes, médicos e investigadores.

Esta investigação interdisciplinar tem impactos esperados a nível científico, tecnológico e social, nomeadamente: contribuirá para o avanço do conhecimento relacionado com processos de reabilitação; contribuirá para o desenvolvimento de novas tecnologias para a reabilitação; possibilitará a comunicação direta entre pacientes, médicos e investigadores; e permitirá aos hospitais, pacientes e investigadores ter acesso a novas soluções para atenuar as sequelas decorrentes de problemas motores e/ou cognitivos e melhorar e reduzir os custos dos serviços.
B) METODOLOGIA

Cerca de 20% do conteúdo gerado pelos utilizadores da internet menciona a saúde de alguma forma. De acordo com o Pew Internet Research (Fox, S., Jones, S., 2009), 60% das pessoas conectadas utilizam a internet como a sua primeira fonte de informação sobre assuntos relacionados com a saúde. Devido à elevada percentagem da população mundial que acede à internet, as redes sociais são um dos maiores locais online para procura de informação acerca da saúde. Redes sociais de saúde são sites que fornecem ao utilizador a possibilidade de aceder, partilhar e contribuir para o maior número de informações de diferentes formas. Estas redes são formadas à volta de uma condição específica de saúde como a obesidade ou cancro. A principal característica de uma rede social de saúde é a interação que pode suportar a partilha de conhecimentos e/ou fornecer suporte emocional para pessoas que lidam com questões e problemas relacionados com a saúde que os afetam ou afetam pessoas que são muito próximas.

Redes sociais de saúde podem oferecer suporte social e emocional aos pacientes que estão geograficamente distantes. Novas amizades feitas através destas redes sociais podem se tornar parte de uma amizade tradicional em que os pacientes encontram-se frente a frente. Por exemplo, numa comunidade rural remota, um paciente com défice motor/cognitivo ou a fazer um tratamento particular pode não ter contactos regulares frente a frente com pessoas na sua pequena e isolada comunidade que possam partilhar conhecimento e experiências sobre essas específicas questões de saúde. Um médico rural pode não ter uma interação frente a frente regular com colegas da mesma área para discutir questões médicas, novas investigações, ou implicações práticas acerca de um novo seguro de saúde. É por isso importante contribuir para o desenvolvimento de sistemas computadorizados que permitam reabilitar, monitorizar e trocar informações acerca da evolução ao longo do tempo de défices motores/cognitivos.

i. OBJETIVOS

Este projeto propõe o desenvolvimento de um sistema computadorizado baseado numa rede social online que permita aos seus utilizadores (médicos, pacientes, investigadores) interagirem entre si, tornando mais fácil a troca de informação acerca de problema relacionados com a saúde. Esta ferramenta pode estreitar as distâncias existentes entre pacientes, médicos e investigadores e rentabilizar o tempo destes utilizadores ao permitir uma comunicação direta entre os mesmos, sem estar frente a frente. Além disso, as funcionalidades deste tipo de sistema permitem que cada tipo de utilizador tenha acesso a informações que lhe serão transmitidas sem ter que fazer uma pesquisa na web. Finalmente, a utilização de um meio computadorizado permite registar durante um grande período de tempo as avaliações clínicas dos pacientes permitindo assim fazer estudos retrospectivos. Além disso, a simplicidade do sistema e o facto de ser online possibilitará que os pacientes, médicos e investigadores tenham acesso ao mesmo em qualquer lugar com ligação à internet, podendo assim aceder ao mesmo remotamente.
II. INSTRUMENTOS DE RECOLHA DE DADOS

Serão realizados questionários e testes de usabilidade do sistema informático. Verificar Anexos.

III. AMOSTRA

Pretende-se recrutar 25 pacientes que precisam de reabilitação e estejam a ter tratamento no Serviço de Medicina Física e Reabilitação e até 25 médicos ou terapeutas em total de várias áreas (reabilitação física, cognitiva, fala) que estejam a trabalhar com os pacientes anteriormente descritos. Os pacientes e médicos serão devidamente informados dos objetivos, relevância e pormenores do estudo e tratamento, e serão convidados a participar no estudo de forma voluntária. Todos os pacientes e médicos que aceitem participar no estudo devem dar o seu consentimento informado verbal e escrito segundo o modelo em anexo. Os pacientes e médicos podem em qualquer momento interromper de forma voluntária a participação no estudo.

IV. DESENHO E PROCEDIMENTOS NA RECOLHA DE DADOS

Existirão duas fases para investigar o impacto da tecnologia proposta na recuperação dos pacientes. Na primeira fase serão realizados questionários aos médicos e pacientes sobre as funcionalidades desejadas no sistema. Enquanto na segunda fase os pacientes e os médicos poderão dar feedback acerca do sistema já implementado através de testes de usabilidade. Seguem os pormenores do protocolo proposto.

Critérios de Inclusão (para pacientes)

1. Pacientes em processo de reabilitação física e cognitiva;
2. Capacidade cognitiva suficiente para a compreensão do sistema;
3. Escolaridade ≥4ª classe ou saber ler e escrever;
4. Idade: 18-65 anos;
5. Cooperação, motivação e voluntarismo para participar neste estudo.

Critérios de exclusão

1. Afasias severas e/ou défices cognitivos que interfiram com a compreensão das tarefas e/ou comunicação com o paciente;
2. Desordens da visão que possam afetar a utilização do computador (por exemplo, hemianopsia, diplopia, etc.).

V. TRATAMENTO E ANÁLISE DE DADOS

Os resultados deste estudo serão apresentados de forma explícita através de tabelas e gráficos. Em termos da descrição de dados, as variáveis categóricas serão apresentadas em valores absolutos e/ou porcentagens; as variáveis quantitativas serão apresentadas através da média e desvio padrão. Legislação e ética
VI. FORMA DE DIVULGAÇÃO DOS RESULTADOS

Legislação e ética

Para poder atingir os objetivos do projeto, é necessário estar de acordo a legislação e requisitos éticos no âmbito da realização de ensaios com humanos, assim como com a regulação da proteção de dados e da tecnologia a ser utilizada. Este projeto realizará actividades (estudos de usabilidade e ensaios clínicos) que envolverão: a recolha de dados com humanos, o processamento de dados pessoais e observação de pacientes. A aplicação da legislação e regulações devidas serão asseguradas antes, durante e depois da execução do projeto. O projeto aqui detalhado está em conformidade com a legislação e regulações aplicadas em Portugal e na Europa. Os profissionais envolvidos neste projeto têm experiência nesta área de investigação, tendo no passado coordenado e realizado ensaios clínicos resultantes de colaborações entre instituições universitárias e hospitalares.

O projeto está em conformidade com legislações Europeias, tais como:

- A Carta de Direitos Fundamentais da União Europeia (em particular, o Artigo 3º - direito à integridade das pessoas e o Artigo 8º - protecção dos dados pessoais);
- Declaração de Helsínquia;
- Diretiva 2001/20/EC do Parlamento Europeu do Conselho de 4 de Abril de 2001 relativamente à uniformização de leis, regulamentos e disposições administrativas dos Estados Membro no que diz respeito à implementação de boas práticas clínicas na realização de ensaios clínicos com produtos médicos para uso humano;
- Diretiva 95/46/EC do Parlamento Europeu do Conselho de 24 de Outubro de 1995 relativamente à proteção de indivíduos no que diz respeito ao processamento e mobilidade de dados pessoais;
- Tratado da União Europeia: Artigo 6º;
- Carta de Direitos Fundamentais de 7 de Dezembro de 2000.

O projeto está em conformidade com legislações Portuguesas, tais como:

- Artigo 35º da Constituição da República Portuguesa – utilização da informática;
Proteção de dados

Este projeto estará em conformidade com os seguintes procedimentos no que diz respeito ao tratamento de dados pessoais:

- Os dados não serão recolhidos sem autorização. Antes do recrutamento, todos os voluntários serão informados verbalmente e por escrito sobre os pormenores do ensaio a ser realizado, incluindo qualquer risco envolvido. Todos os pacientes assinarão um Consentimento Informado (em anexo) antes da participação no ensaio;
- Nomes, datas de nascimento e outros dados sensíveis e passíveis de identificação serão encRIPTados para proteger a privacidade do paciente e dos dados recolhidos;
- A informação recolhida será utilizada apenas para o propósito do projecto e não será retida para outros fins;
- Nenhuma informação pessoal será tornada pública ou cedida a terceiros;
- Serão aplicados controlos técnicos estritos para garantir que a informação não seja disponibilizada inadvertidamente a organizações de marketing direto ou outras terceiras entidades.
C) Bibliografia de Suporte


D) ANEXOS

I. Documento de informação ao sujeito da investigação

DOCUMENTO DE INFORMAÇÃO AO SUJEITO DA INVESTIGAÇÃO

NOME DE ESTUDO: ____________________________________________

INVESTIGADOR: _______________________________________________

CONTATO: Telefone_____________________Email_____________________________

Foi-lhe pedido para participar num estudo de investigação no âmbito de desenvolvimento de Tese de mestrado para a Universidade da Madeira. Estará envolvido na recolha de informação para ajudar a compreender melhor como os pacientes podem interagir numa rede social. A participação neste estudo significa que a informação sobre si e a forma como usa a rede social será recolhida e analisada juntamente com as informações recolhidas de outras pessoas que realizarão o mesmo teste. As respostas individuais que fornecer serão confidenciais.

QUAL É O OBJETIVO DESTE ESTUDO?

Pacientes com problemas de mobilidade e de capacidade cognitiva tem limitações na realização de atividades e na sua qualidade de vida. O objectivo deste estudo é a avaliação dos benefícios da utilização de REDE SOCIAL DE SAÚDE. Tecnologias interativas para reabilitação e troca de informação permitem ao paciente ter uma comunicação direta com outra pacientes ou médicos sem ter que se deslocar da sua área de residência.

O QUE É QUE ESTE ESTUDO ENVOLVE?

Ser-lhe-á pedido para responder a questões e realizar testes de usabilidade numa rede social. As perguntas permitem avaliar o seu bem estar físico geral, a interação com o computador, a interação numa rede social.

Todos os inquéritos levarão cerca de 30 minutos a completar.

A informação recolhida será armazenada juntamente com as informações de outras pessoas com as mesmas condições de saúde.

A QUEM É PEDIDO PARA PARTICIPAR NESTE ESTUDO?

Você foi selecionado para participar neste estudo pelo facto de apresentar um determinado quadro clínico como consequência de um AVC. Serão envolvidos 25 pacientes e 25 médicos/terapeutas.
EXISTEM RISCOS NESTA PARTICIPAÇÃO?

Não existem riscos para a sua saúde, pois o procedimento consiste na utilização de um computador e realização de inquéritos de avaliação.

EXISTEM BENEFÍCIOS POR PARTICIPAR?

São ainda pouco conhecidos os benefícios de utilização de REDES SOCIAIS DE SAÚDE pode gerar. Poderá não receber nenhum benefício imediato por participar neste estudo. No entanto, a informação recolhida no estudo beneficiará no futuro pessoas com défices motores/cognitivos.

QUEM TERÁ ACESSO À MINHA INFORMATION?

O seu nome não será identificado em quaisquer relatórios ou base de dados. Todos os relatórios e materiais pertencentes a este estudo serão mantidos confidenciais. Contudo, não podemos garantir confidencialidade absoluta. A sua informação pessoal poderá ser revelada se solicitada pelas vias legais. É também possível que os resultados deste estudo sejam divulgados e/ou publicados no futuro. Neste caso, a sua identidade será confidencial e não será revelada na divulgação. No final do estudo todos os relatórios serão destruídos.

Este estudo obedece a regulamentos nacionais e internacionais (tais como a Declaração de Helsinki ou Código Deontológico) aplicados à investigação com seres humanos. Todas as pessoas envolvidas neste estudo respeitarão a intimidade e privacidade do paciente. O processo clínico é confidencial. O nome e outros dados pessoais não serão partilhados ou distribuídos a não-autorizados (Directiva 95/46/EC, Lei 67/ 98 – Lei da Proteção de Dados Pessoais).

EXISTEM CUSTOS ENVOLVIDOS?

A sua participação não envolve quaisquer encargos ou despesas da sua parte, com exceção do tempo necessário para a participação no estudo.

QUAIS SÃO OS MEUS DIREITOS?

A sua participação neste estudo é inteiramente voluntária. Pode recusar participar neste estudo ou desistir em qualquer altura. Se decidir não participar, isto não afetará o seu futuro tratamento ou direitos de saúde e direitos legais.

QUEM POSSO CONTACTAR SE TIVER ALGUMA QUESTÃO OU PREOCUPAÇÃO?

Se tiver alguma dúvida sobre os seus direitos como participante pode contactar Sergi Bermúdez i Badia ou Artur Vieira.
Testes de usabilidade – Médicos e Pacientes

Os testes com utilizadores servem para validar o sistema desenvolvido pelo projecto ou identificar problemas de usabilidade existentes recorrendo a um grupo de utilizadores (pacientes e médicos) que navegará no site. Estes testes permitem identificar potenciais problemas de usabilidade e observar o comportamento dos utilizadores durante a navegação no site, bem como perceber o motivo pelo qual escolhem seguir determinados caminhos no website em detrimento dos caminhos considerados “normais”.

Alguns dos benefícios e vantagens dos testes de usabilidade em relação a outro em relação a outro tipo são:

- O comportamento dos utilizadores pode ser observado e comparado com os outros utilizadores que realizam a mesma tarefa;
- A compreensão das dificuldades sentidas pelo utilizador pode ser alcançada através do registo das verbalizações durante o teste.

Basicamente, aquilo que procuramos saber com a realização de testes de usabilidade é se:

- Os utilizadores foram capazes de realizar as tarefas em causa?
- A informação relevante foi encontrada?
- Quanto tempo demorou?
- Os caminhos seguidos foram os mais eficientes?
- Os utilizadores sabem o que estão a fazer?
- Que problemas encontraram?

Para tal os utilizadores terão ao seu dispor um portátil e um rato em que poderão fazer os testes de usabilidade.
Consentimento informado

DOCUMENTO DE CONSENTIMENTO INFORMADO

Entendo que toda a informação derivada do estudo _______________ _________________ é propriedade de _________________ _________________.

Dou o meu consentimento para que dados anónimos a meu respeito possam ser guardados e processados por _________________, para fins de avaliação científica. Li (foi-me lida) a informação mencionada acima. Entendo o significado desta informação, e as minhas perguntas foram satisfatoriamente respondidas. Tive tempo suficiente para decidir sobre a participação neste estudo. Venho por este meio consentir a minha participação e consentir na recolha, uso e revelação de informação. Irei receber uma cópia deste documento de consentimento informado assinada e datada.

_______________________________________ __________________
Assinatura do participante

_______________________________________ __________________
Nome do Representante legal -Se aplicável

_______________________________________ __________________
Nome do Investigador
Autorização do uso da imagem

DOCUMENTO DE AUTORIZAÇÃO DO USO DA IMAGEM

Eu _______________________________________, venho por este meio autorizar o uso da minha imagem no âmbito do/a _________________ para ser publicado/apresentado no/a _________________ a ser.

Funchal, _____ de _____________ de 201___

________________________
Nome
ANNEX III. Usability Questionnaire

III.1. Health Professionals Questionnaire

<table>
<thead>
<tr>
<th>Profissão (especialidade)?</th>
<th>Idade?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sexo?</td>
<td>Masculino</td>
</tr>
<tr>
<td></td>
<td>Feminino</td>
</tr>
</tbody>
</table>

1. Costuma utilizar a internet? Quantas vezes ao dia?
   - Nunca
   - 1-3 horas
   - 3-5 horas
   - 5-7 horas
   - 7 ou mais horas

2. Utiliza as redes sociais (facebook, twitter, etc)? Quantas vezes ao dia?
   - Nunca
   - 1-3 horas
   - 3-5 horas
   - 5-7 horas
   - 7 ou mais horas

3. Que tipo de perguntas são “obrigatórias” quando de uma consulta?

4. Que meios usa habitualmente para a comunicação com os pacientes?
   - Visitas/Consultas
   - Telefone
   - Internet
   - Forum
   - Chat
   - Outro: ____________________________

5. Classifique cada um dos meios de comunicação quanto ao seu potencial:
   - Visitas/Consultas?
     - Nada
     - Pouca
     - Alguma
     - Muita
     - Extrema
   - Telefone?
     - Nada
     - Pouca
     - Alguma
     - Muita
     - Extrema
   - Internet?
     - Nada
     - Pouca
     - Alguma
     - Muita
     - Extrema
   - Fórum?
     - Nada
     - Pouca
     - Alguma
     - Muita
     - Extrema
   - Chat?
     - Nada
     - Pouca
     - Alguma
     - Muita
     - Extrema

6. Qual o grau de atualização que tem acerca de novas terapias/tecnologias?
   - Nenhum
   - Pouco
   - Algum
   - Muito
   - Extremo

7. Qual é a necessidade que sente de procurar novas investigações para tratamentos?
   - Nenhuma
   - Pouca
   - Alguma
   - Muita
   - Extrema

8. Qual é a relevância que dá a possibilidade de ter um seguimento frequente do paciente?
Annex III

□ Nenhuma □ Pouca □ Alguma □ Muita □ Extrema

9. Com que frequência gostaria de receber notificações da evolução do paciente?
□ Nenhuma □ Diária □ Semanal □ Mensal □ Trimestral ou mais

10. Que aspetos gostaria de monitorizar dos pacientes?

____________________________________________________________________

11. Que utilidade teria se os familiares tivessem acesso as evoluções dos pacientes?
□ Nenhuma □ Pouca □ Alguma □ Muita □ Extrema

12. Qual é a relevância que dá a possibilidade de ter comunicação direta com o paciente?
□ Nenhuma □ Pouca □ Alguma □ Muita □ Extrema

13. Qual é a relevância que dá a possibilidade de monitorizar os pacientes sem estar frente a frente com o mesmo?
□ Nenhuma □ Pouca □ Alguma □ Muita □ Extrema

14. Qual é a quantidade de pacientes que acha que podem beneficiar com este site?
□ Nenhum □ Poucos □ Alguns □ Muitas □ Imensas

15. Qual é a relevância que dá a possibilidade de receber informações sobre novas investigações?
□ Nenhuma □ Pouca □ Alguma □ Muita □ Extrema

16. Qual é a relevância que dá a possibilidade de ter participar em novas investigações?
□ Nenhuma □ Pouca □ Alguma □ Muita □ Extrema

17. Que conteúdo deveria ter no fórum? Pode selecionar mais que uma!
□ Nenhum □ Perguntas Frequentes □ Informações sobre tratamentos
□ Artigos □ Conselhos □ Outros: ______________________

18. Como acha que deveria funcionar o fórum? Pode selecionar mais que uma!
□ Não devia existir □ Investigador-Medico □ Investigador-Investigador
□ Medico-Medico □ Paciente-Medico □ Outros: ______________

19. Quais foram os 2 aspetos que mais gostou? Porquê?
____________________________________________________________________

20. Quais foram 2 aspetos gostou menos? Porquê?
____________________________________________________________________

21. Que aspetos são os mais confusos para si, se é que teve algum?
____________________________________________________________________
22. Que aspetos melhoraria ou acrescentaria que não tem?

______________________________________________________________

23. Qual seria o seu grau de interesse em usar a ferramenta apresentada, mesmo que não costume usar internet, nem redes sociais?

☐ Nenhum    ☐ Pouco    ☐ Algum    ☐ Muito    ☐ Extremo

24. Algum comentário adicional que gostaria de deixar?

______________________________________________________________
Annex III

III.2. Patients Questionnaire

1. Costuma utilizar um computador? Quantas vezes ao dia?
   - □ Nunca
   - □ 1-3 horas
   - □ 3-5 horas
   - □ 5-7 horas
   - □ 7 ou mais horas

2. Costuma utilizar a internet? Quantas vezes ao dia?
   - □ Nunca
   - □ 1-3 horas
   - □ 3-5 horas
   - □ 5-7 horas
   - □ 7 ou mais horas

3. Utiliza as redes sociais (facebook, twitter, etc)?
   - □ Nunca
   - □ 1-3 horas
   - □ 3-5 horas
   - □ 5-7 horas
   - □ 7 ou mais horas

4. Com que frequência necessita de obter uma consulta do médico/terapeuta?
   - □ Nenhuma
   - □ Semanal
   - □ Mensal
   - □ Trimestral
   - □ Semestral ou mais

5. Quanto tempo despende na consulta do médico/terapeuta, desde sair até voltar a casa?
   - □ 0-1 horas
   - □ 1-2 horas
   - □ 2-3 horas
   - □ 3-4 horas
   - □ 5 ou mais

6. Qual é a distância que percorre para se deslocar ao consultório?
   - □ 0-10 Km
   - □ 10-20 Km
   - □ 20-30 Km
   - □ 30-40 Km
   - □ 50 ou mais

7. Que meios usa habitualmente para a comunicação com os médicos/terapeutas?
   - □ Visitas/Consultas
   - □ Telefone
   - □ Internet
   - □ Fórum
   - □ Chat
   - □ Outro: ____________________________

8. Classifique cada um dos meios de comunicação quanto ao seu potencial:
   Visitas/Consultas?
   - □ Nenhum
   - □ Pouco
   - □ Algum
   - □ Muito
   - □ Extremo

   Telefone?
   - □ Nenhum
   - □ Pouco
   - □ Algum
   - □ Muito
   - □ Extremo

   Internet?
   - □ Nenhum
   - □ Pouco
   - □ Algum
   - □ Muito
   - □ Extremo

   Fórum?
   - □ Nenhum
   - □ Pouco
   - □ Algum
   - □ Muito
   - □ Extremo

   Chat?
   - □ Nenhum
   - □ Pouco
   - □ Algum
   - □ Muito
   - □ Extremo

Profissão? ____________________________ Idade? ______
Doença/Défices? ____________________________ Escolaridade? ______
Sexo? □ Masculino □ Feminino
9. Qual é a relevância que dá a possibilidade de ter um seguimento frequente do por parte do médico/ terapeuta?

☐ Nenhuma  ☐ Pouca  ☐ Alguma  ☐ Muita  ☐ Extrema

10. Com que frequência gostaria de receber avaliações por parte dos médicos/ terapeutas?

☐ Nenhuma  ☐ Semanal  ☐ Mensal  ☐ Trimestral  ☐ Semestral ou mais

11. Qual é a relevância que dá a possibilidade de receber avaliações por parte dos médicos/ terapeutas sem estar frente a frente com o mesmo?

☐ Nenhuma  ☐ Pouca  ☐ Alguma  ☐ Muita  ☐ Extrema

12. Que conteúdo deveria ter no fórum? Pode selecionar mais que uma!

☐ Nenhum  ☐ Perguntas Frequentes  ☐ Informações sobre tratamentos

☐ Artigos  ☐ Conselhos  ☐ Outros: ______________________

13. Como acha que deveria funcionar o fórum? Pode selecionar mais que uma!

☐ Paciente-Paciente  ☐ Investigador-Médico  ☐ Investigador-Investigador

☐ Médico-Médico  ☐ Paciente-Médico  ☐ Outros: ______________

14. Quais foram os 2 aspetos que mais gostou? Porquê?

____________________________________________________________________

____________________________________________________________________

15. Quais foram 2 aspetos gostou menos? Porquê?

____________________________________________________________________

____________________________________________________________________

16. Que aspetos são os mais confusos para si, se é que teve algum?

____________________________________________________________________

____________________________________________________________________

17. Que aspetos melhoraria ou acrescentaria que não tem?

____________________________________________________________________

____________________________________________________________________

18. Qual seria o seu grau de interesse em usar a ferramenta apresentada, mesmo que não costume usar internet, nem redes sociais?

☐ Nenhum  ☐ Pouco  ☐ Algum  ☐ Muito  ☐ Extremo

19. Algum comentário adicional que gostaria de deixar?

____________________________________________________________________

____________________________________________________________________
III.3. Mockups test

Personal Information
Name: ___________________________ Age: ________
Sex:  □ Male    □ Female Nationality: ________

Professional Information
Occupation: ________________________ Scholar Degree: _________________________

Computer information
Experience with computers? □ Yes □ No
Experience with internet? □ Yes □ No
Experience with social networks? □ Yes □ No
Uses Computer as a Work tool? □ Yes □ No

Average number of hours/day using a computer: ________
Experience (0-5): ________

Testing

Before starting this test is important to notice that due to software limitations is not possible to fill the data and for this reason the spaces for text input by the user are already filled.

<table>
<thead>
<tr>
<th>Task</th>
<th>Instructions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Task 1 - To use the social network it is necessary to do the registration. Please access the content of the prototype as a researcher</td>
<td></td>
</tr>
<tr>
<td>Task 2- Please find a way to send a message to another user.</td>
<td></td>
</tr>
<tr>
<td>Task 3- Please manage your messages</td>
<td></td>
</tr>
<tr>
<td>Task 4 – Please create a new research to investigate the effect of a new activity for left leg on elderly. After see the results</td>
<td></td>
</tr>
<tr>
<td>Task 5 – Search in the forum a topic of recover from a stroke at 40 years. If it is not created yet, make a new topic for it</td>
<td></td>
</tr>
<tr>
<td>Task 6 – Add a user as a friend</td>
<td></td>
</tr>
</tbody>
</table>
ANNEX IV. Installation Manual

The following is a guide to the installation of the RehabNet social network. The OS used for this installation was Windows 7, but the install steps should be the same for all Windows OS. The recommended browsers are Google Chrome and Mozilla Firefox (other browsers should work but they were not tested).

To make a new installation please do the following steps:

1. Install «xampp-win32-2.5-installer.exe» (or higher version) as Administrator
   a) The installation dir should be «c:\», and the files will be automatically placed inside «c:\xampp\» folder
2. Copy the folder rehab that are in the cd into C:\xampp\htdocs\ 
3. Open xampp application and start the Apache and MySQL module
4. Go to localhost/phpmyadmin/ and sign in
5. Select the import tab
6. Choose the file that goes inside the bd folder and execute
7. Go to C:\xampp\htdocs\rehab\elgg\engine\settings.php
8. Change $CONFIG->dbuser = 'root'; for what username you have if it is not root
9. Change $CONFIG->dbpass = '123456'; for your phpmyadmin if you have any
10. Open a browser tab and type localhost/rehab/
11. Enter one the following users and passwords:
    a) user: arturvieira7@hotmail.com     pass: 123456 (admin/doctor)
    b) user: doctor1@teste.com          pass:123456 (doctor)
    c) user: researcher1@teste.com      pass:123456 (researcher)
    d) user: patient1@teste.com         pass:123456 (patient)
    c) user: patient2@teste.com         pass:123456 (patient)
    d) user: patient3@teste.com         pass:123456 (patient)
    c) user: patient4@teste.com         pass:123456 (patient)
    d) user: patient5@teste.com         pass:123456 (patient)
12. Test the prototype.