

**Results Report of Workshops for “Paraforum: an interactive platform for sci”;
ESCIF, Nottwil, June 6th 2013, 10.00 am – 14:30 pm, Aula Swiss Paraplegic Center**

1. Introduction

On June 6th 2013, ESCIF conference in Nottwil hosted a presentation and a workshop led by Sara Rubinelli and Mirjam Brach on the concept and current development stage of PARAFORUM, an internet-enabled platform dedicated to Spinal Cord Injury. PARAFORUM will be launched in November 2013 on behalf of the Swiss Paraplegic Foundation.

During the presentation of PARAFORUM, Sara Rubinelli presented the challenges that – from a health communication perspective – were taken into consideration in the design of the platform. In particular, PARAFORUM is developed to enhance interactivity among four main stakeholders in the field of spinal cord injury (SCI): SCI consumers and their families, health professionals and researchers. It is, thus, expected to complement important online information sources (e.g. ISCOS eLearning).

Also, Sara Rubinelli gave a general overview of the different sections that the platform will implement and how interactivity is expected to work in an expert-to-expert dimension, where the different stakeholders share and comment information, ideas and experiences in the world of SCI.

2. The workshop

The workshop was introduced as an essential step to promote the growth of PARAFORUM as a platform that follows a participatory design approach: in order to build a platform that meets the needs and expectations of potential users, it is important to involve the community of expected users and capture their insights on the benefits, strengths and perceived limitations of the product presented.

The ESCIF community was split in two working-groups and each group was invited to present their views on some of the services that PARAFORUM will offer. Below is a summary of the results from the two working-groups.

2.1 Summary of working-group 1 session

Session moderated by Sara Rubinelli

Protocol: Fabian Diesner

Technology-expert: Michele Giacobazzi

Overall 19 people attended the working-group 1 session led by Sara Rubinelli and focused on four sections of PARAFORUM: *My Ideas*, *Life&Culture*, *Research Corner* and *Get connected*. The group was very active and also discussions not directly linked to the questions of the moderator were very useful and provided the PARAFORUM team with important information. All topics planned could be addressed and the overall feedback on the development, purpose and design of the online platform was very positive. Sara Rubinelli gave a more detailed presentation of sections of PARAFORUM at stake and the following results were achieved.

MyIdeas

What is My Ideas about

The section *MyIdeas* is an important part of the online-based innovation and communication platform PARAFORUM. The main objective of *MyIdeas* is to exploit and trigger the innovative potential of the spinal cord injury community and interested users of the platform. In order to achieve that, *MyIdeas* is created as part of an overall innovation process to develop innovations in terms of products, services, and processes as well as support the formation of social capital. Users can take part in ideas competitions (Ideas Contests), state problems and give solutions (Problems and Solutions Forum) or they can develop and test new ideas in a collaborative effort.

Outcome of Workshop

The overall feedback of this section of the platform was very positive. It is perceived as an ambitious and expensive endeavor to maintain the interactivity of the application but the creative input of peers and other contributors would be of high value for the community, especially when it comes to assistive devices and health-related products.

Some interesting websites that deal with innovation already exist especially in Great Britain and in the Netherlands. However, most of the communication and interaction

happens in secured areas of Fora where only registered users have access to. The participants pointed out that it is absolutely crucial that answers are given in a short time span to keep the section (inter-)active. Furthermore, the input has to be trustworthy and serious which demands a professional content management system to avoid fraud and to ensure high quality of user input. A very positive feature of *My Ideas* would be that idea contests trigger competition and therefore create traffic on the website. Another important aspect would be that users are free to write on any subject they see as valuable. The audience raised the open question of how to proceed with commercial input by users from the community. Clear guidelines have to be developed for this scenario. Overall, advertising should not be allowed (or it can be allowed but only in special dedicated section where the marketing purpose is clear and well-communicated).

Life&Culture

What is Life&Culture about:

The Section *Life&Culture* will be designed as a complementary section that is not a priori problem oriented (compared to the *Library* or *MyIdeas*) but gives users the possibility to give input of their choice on cultural issues in relation to the new and constantly evolving field of medical humanities.

In a blog roll format that allows every signed-in user to contribute texts in combination to hypertext elements (embedded videos, pictures, audio files), the following topics can be addressed: literature, art (paintings, sculptures) but also exhibitions, performances, dance, architecture etc., creative writing, drama, film, music, philosophy, anthropology, travelling, sports (if it is about a specific feature, competition, experience etc. that goes beyond the general description and information content of the library), self-management etc.

The texts can be about a very personal opinion, experience, interpretation, reflection or critical argument about the topics listed above with regard to disability and health in general. A direct link to spinal cord injury does not have to be implicit. The quality of the texts has to be high as they could be seen as short online publications.

Outcome of Workshop

This section needs a more detailed explanation since the added value for the website was not obvious to the participants. More specifically, it is not clear why – if one has a story in mind- he or she should write on PARAFORUM instead of writing on other dedicated internet platform. *Life&Culture* needs to have a clear profile to ensure not only an active readership but also to encourage users to write blog posts. For instance, it should be clear that it is in relation to ‘disability’. Furthermore, no trivial topics should be addressed but critical articles should be composed in a higher standard than posts about daily life topics in the Forum.

Research Corner

What is Research Corner about

The *Research Corner* is a section of PARAFORUM dedicated to SCI research. The main focus will be on news and updates from Switzerland and its neighboring countries but also embedding significant international studies. The user will find lay articles and abstracts of the latest research in the field of spinal cord injury and updates and news for events. In addition, the community can take an active part in research by getting involved in current projects.

Outcome of Workshop

The workshop participants were in favor of the *Research Corner* as a communication channel for news and updates in the field of spinal cord injury. However, it was pointed out that presumably only a limited number of users might be interested in this section. Also, it is not clear why having a special section for Switzerland alone. Also, it is important to understand how to present or take into consideration research which is more driven by the psycho-social model of health versus the more biomedical approach. Overall, it was seen as essential that consumers should be involved in new research questions to set the agenda, especially on an international basis. For new research publications a good lay summary and abstract would be sufficient.

Get Connected

What is Get Connected about

Get Connected is a Facebook-like service of PARAFORUM where users can create a profile and have a wall where they can post and share personal information or information perceived as relevant by individuals.

Outcome of Workshop

A social network for people with spinal cord injury is a good way of ensuring interaction between the users and to strengthen relationships between them. Apart from the basic information that will be visible in each of the members' profile also the lesion level could be made visible in form of a sketch or graph if the user chooses to do so. This might enhance the interaction among users with regard to topics of self-management and daily living.

2.1 Summary of working-group 2 session

Session moderated by Mirjam Brach

Protocol: Andrea Glässer

Technology-expert: Diego Pansica

Overall 21 people attended this section of the workshop that was led by Miriam Brach. Miriam Brach opened the workshop with a short summary of the background of the development process of PARAFORUM within the Swiss Paraplegic group (SPG) as an innovation and communication platform for services, as an innovation tool of the SPG and last but not least as a research tool by using participatory design. This means that in the near future experts in the field of SCI will be invited to take part in online surveys accessible on PARAFORUM for getting insights about the needs of the community. Each section was introduced very briefly in terms of the main aspects of the usage, goals and navigation area before the discussion started. The following sections of PARAFORUM were discussed in the workshop: *Library, My Dairy, Forum*.

Library

What is the Library about

The Library of PARAFORUM offers information about living with SCI and will contain several articles organized into five main categories in relation to SCI: The Body, Activities of Daily Living, the Environment, Spinal Cord Injury and Yourself. Users are invited to propose a topic for the library, what they miss so far and they can suggest texts related to a specific topic to be added to the *Library*.

Outcome of Workshop

The overall feedback of this section was positive. Regarding the introductory question: *“Do you search for health information online and what is your experience?”*, the participants answered this question from different points of view including taking into account the accessibility of information in regions with a less developed infrastructure whereas countries like Denmark support and promote the usage of online communication. Online usage includes a generation aspect, in the sense that older people are less familiar in using the computer and the internet, although they could be supported by their family members. The younger generation is familiar in using social media tools or the internet in general, nevertheless the overall usage is still increasing. The group discussed the language issue from a global perspective in contrast to country-specific advantages.

In the context of searching information online, two webpages were named: one from the United Kingdom, www.apparelyzed.com, and one website from Sweden www.spinalis.se.

To add information to the library the group suggested the following main topics: pain, aging related to the demographic development, working conditions, sexuality, incomplete SCI community, and also favored the option of expanding the list of topics by other neurological conditions (e.g. spina bifida, cauda equina).

In principal, the group agreed on the possibility of proposing a topic, but highlighted the challenge of using the same terminology in four different languages. A content management would be an important support to close gaps of information.

My Diary

What is My Diary about:

The section called *MyDiary* works as a dairy to track important aspects of one's health. It provides the opportunity to monitor how the user feels, the management of taking medication, or to plan exercises. Furthermore, the tool includes the option to generate and print a report for the next consultation with the health professionals and to recall important health aspects from one visit to the next. The individual health status can be visualized by a graph and a calendar function is integrated to monitor the individual frequency of usage (daily, 3 times a week, weekly...)

Outcome of Workshop

The overall feedback on this section was that people might benefit from the use of an online diary in relation to specific problems, especially people in the early stages of SCI. The application could probably be most useful with regard to pain management, bowel and bladder management, physical activity or sports, but also in relation to the prevention of complications and comorbidities. Some of the participants already have experiences in using a diary, mostly however paper-based versions. In general, the group agreed upon that younger users will probably use it more often but this has to be evaluated over time. The reminder function to recall health related aspects more easily was considered a useful feature. Also the option for a longitudinal follow-up and to print an extraction of the diary or to send the print-extract as a pdf.-file to the health professional before the consultation was seen as a positive aspect. In the future, health professionals should be informed about this application of *MyDiary* to ensure the usage of the information based on print-reports or email for the consultation.

Forum

What is the Forum about

The *Forum* of PARAFOPUM has the aim to enable interactions between users which are interested in an exchange with people about and beyond SCI. The functionalities will be similar to other fora with the additional added value that discussions in the forum of PARAFORUM can be led in four languages: English, Italian, French and German. In addition, a doctor online will be available for questions and comments in

relation to SCI. Furthermore, the *Forum* will be content managed to keep the exchange interesting and focused.

Outcome of Workshop

The participants consider the content management of the forum as a very important quality aspect and appreciate that the long-term funding for that is guaranteed. A smartphone application would be very welcome to increase the traffic of the forum. A dynamic interaction and feedback regarding posts will be expected within 2 to 3 days. Critical aspects pointed out by the participants were the generalization of the discussed posts and their lack of value for users in different countries, e.g. the financing of assistive devices which differs internationally. As solution to this problem, they suggested country-specific forum as subgroups in PARAFORUM.

One additional aspect in relation to the forum (that was, however, pointed out by workgroup 1) is that it is important and essential to have a content-manager. However, the content-management should not prevent the community from expressing what they think (also in relation to more medical-aspects), otherwise we risk missing the value of the community, where in certain cases they might know better how to do or manage something.

3. Concluding remarks

Participants at ESCIF came from the Netherlands, Spain, Italy, Scotland, Germany, Denmark, Switzerland and other countries. This international perspective was a very good stimulator for a productive and engaged discussion of questions, comments, suggestions, and also critical remarks. All topics could be addressed, some of them in more detail, others on a more summarizing level.

The workshop was driven by very active and informative discussions of the groups which underline the high interest of the people in a tool such as PARAFORUM. Nevertheless, also some important critical aspects were discussed. In a nutshell, the PARAFORUM team was inspired by the team-work and exchange with this group of participants. The team of PARAFORUM would like to thank all the participants of the workshop for the lively discussion, their questions and suggestions. Thanks to the insight derived from ESCIF, there are good reasons to be optimistic that PARAFORUM will be a platform of value and use for the SCI community, and that will

be a very important support to promote important fruitful sharing and collaboration at an international level.