

# User Needs of Young Czech Adults with Multiple Sclerosis in a Lifestyle App Design

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**Abstract.** This paper presents a study that examined desired functionality, content, and design of a mobile application for young Czech adults living with Multiple Sclerosis (MS). The study was structured around a high-fidelity prototype developed for the corresponding user group in Norway. Both groups were active on social media and willing to contribute to designing an application promoting a healthy lifestyle and well-being. Adopting the content analysis, the study first compared the social content shared within the Facebook communities in the Norwegian and Czech user groups that were active. Regardless of the similarities, the Czech group expected that solutions regarding main functionalities and content should stand out from other competitive applications offered on the market. Most of all, they would like to see healthcare staff being engaged in content creation by providing credible information, especially regarding new treatments and clinical trials. Enhanced interaction between all the stakeholders (patients, and healthcare providers) would add value and relevance to the content already provided by social media.

**Keywords.** Multiple Sclerosis (MS), Young adults, Lifestyle application, User-Centered Design (UCD)

## 1. Introduction

MS is a lifelong disease requiring adjustments in lifestyle and keeping properly informed to get quick access to modern treatment and help in creating the conditions for living a completely normal life, including working, cultivation of leisure activities, and thus secure at least partial return of the funds that are spent on an economically very expensive treatment [1]. Consequently, if treated on time and properly, the course of the disease can be significantly managed in the majority of patients.

According to the literature, mobile applications provide a multidimensional toolbox for MS patients by supporting chronic disease self-management and well-being, helping patients adhere to the therapeutic regimen of their conditions, and collecting information on the MS progress pattern on a personalized level [2, 3]. To keep patients interested, the purpose of using mHealth applications should be supported and further enhanced by all

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means – the technology, content, and design to correspond to the needs of the particular user groups. To this aim, Norwegian researchers and users have built a high-fidelity prototype that is used in this study to provide structure and inform research questions [6]. A Design Science research study of an application promoting a healthy lifestyle aimed at increasing the quality of life for MS patients among newly diagnosed young adults [6]. Drawing from the results of social media content analysis and a consequent MS expert's evaluation, a low-fidelity prototype was first designed. Results from working with the patient focus group has informed further development that finally produced a high-fidelity prototype YmsE with main functionalities: *health, training, patient notes for next medical appointment, disease-related life and work issues, and a reward point system*. The prototype was finally tested and approved by the Norwegian young adults with MS (case study) and the medical staff.

## 2. Materials and Methods

The data was collected from the social media group posts and members. Content analysis was conducted in March 2020 on the collected data in tow steps:

1. A relevant Facebook MS community was identified in the Czech Republic that has at least three different communities of MS patients with more than 3.500 members. As the communities (Facebook groups) are private, the researcher was required to apply for membership. Only one of the 3 groups allowed a non-MS patient to join and that was the group named *Roztroušená skleróza*“, meaning MS the Czech language. The group was established in 2010 and at the time of the study it had 1 580 members.

2. The data was collected during the period of January 2019 to March 2020. A total of five hundred twenty one (N=521) posts were reviewed by two researchers and categorized to answer the research question: RQ1: *What type of content do Multiple Sclerosis Facebook community members share?*

Focus Group was comprised of the Czech MS community volunteers whose discussions and analysis were done following the referenced Norwegian study and it's high-fidelity prototype [4] that was presented to the focus group. There were 5 young MS patients, ages 20-30, interested in managing and increasing their quality of life and contributing to further application development. The demographics of the volunteer group are in Table1.

The whole discussion aimed at answering the second research question as set in the Norwegian study [4]: RQ2: *What functionalities need to be included in an application for young users with MS, that you think would help improve lifestyle changes?*

**Table 1.** Czech focus group participants from MS Facebook community

Gender	Age	Job	Years diagnosed	Type of MS
Female	26	Media Specialist	4	relapse-remitting form
Female	28	Beautician	3	relapse-remitting form
Male	27	Medical Student	4	relapse-remitting form
Male	29	IT Specialist	4	relapse-remitting form
Male	30	Store manager	7	relapse-remitting form

### 3. Results

The content analysis resulted in the three main categories of interest to the Social media community, namely: *Symptoms and Side Effects* (N=356), *Everyday life* (N=122), *Other information* (N=43). The focus group results are shown in Table 2.

**Table 2.** Patient preferred functionality, content, structure and design features of an application

Main category	Subcategories	Description of the functionality	Additional notes
User Profile	Personal information	User data	
	Medicine	Medicine prescribed	
	Symptoms evidence	Evidence and ataxia statistics	
	Appointments	Scheduled appointments	
	Notes	Personal notes	
Community section	News	Articles, blog posts, studies, legislative changes	Added by credible sources, erudite authorities
	Community newsfeed	Posts and comments section	Social community function supplying Facebook group
	Common activities	Planned leisure activities for app users and MS patients	
	Sport challenges	Gamification aspect, motivation by real awards	Optimization based on physical conditions required
Information section	Knowledge base	Dictionary, important info, videos explaining symptoms, medicine and its side effects	Simple and structured information with ability to label important points
	FAQ		Optimized and up to date
	Chat with experts	Chatbot and contacts	Chatbot logic implemented to avoid overloading experts with common questions answered in FAQ
	Medical appointment booking	Booking an appointment directly from the app	
	Experimental studies	Overview of currently opened experimental studies (ES)	It is important to include patients into ES as it adds further space for improvement for both, patients and healthcare experts
Settings	Design	Colour scheme User experience	
	Notifications	High scalability	

## 4. Discussion

There are two research questions to address. First RQ1: *What type of content do Multiple Sclerosis Facebook community members share?* The type of content posted by the Czech MS social community members on Facebook is comparable to the Norwegian one: *Symptoms and Side Effects, Everyday life, and Other information.*

Second RQ2: *What functionalities need to be included in an application for young users with MS, that you think would help improve lifestyle changes?* The Czech MS focus group results suggest that the application should be interactive and innovative in terms of technology, content and also design, so that it is competitive to other applications established on the market. Norwegian focus group's findings resulted in the implementation of main functionalities as follows: health, training, patients' notes for next medical appointment, disease related life and work issues and a reward point system [4]. The Czech focus group members, on the other hand, do not consider training, reward point system, and in some cases not even the records of symptoms and ataxia to be essential. They can easily and effectively cover all these functionalities with other applications to which they are already accustomed. They thought that the prototype could be good for senior patients less willing to utilize different technical tools. User experience based on a highly intuitive and quickly responsive system would be preferred. Their main priority would be a possibility to involve and communicate with medical staff. The research confirms also the importance of evidence-based communication [5].

## 5. Conclusions

The study shows benefits of utilizing high fidelity prototypes to assess user needs and preferences regarding the functionalities and design features. Similar in the content, Norwegian and Czech user groups had different preferences. Functionalities promoting lifestyle changes were valued by the Norwegian focus groups while the Czech group singled out as the most important functionalities enabling active engagement of the healthcare staff and interaction between all the stake holders involved in MS treatment.

## References

- [1] Petrleničová D. Najčastejšie chyby v diagnostike roztrúsenej sklerózy ("The most common mistakes in diagnostics of multiple sclerosis."). *Via practica*. 2016;13(1):21-4.
- [2] Antezana G, Venning A, Blake V, Smith D, Winsall M, Orłowski S, Bidargaddi N. An evaluation of behaviour change techniques in health and lifestyle mobile applications. *Health Informatics J*. 2020 Mar;26(1):104-113. doi: 10.1177/1460458218813726.
- [3] Salimzadeh Z, Damanabi S, Kalankesh LR, Ferdousi R. Mobile Applications for Multiple Sclerosis: a Focus on Self-Management. *Acta Inform Med*. 2019 Mar;27(1):12-18. doi: 10.5455/aim.2019.27.12-18
- [4] Jakobsen MO, Babic A. Lifestyle Intervention for Young Adults with MS: A Design Study. *Stud Health Technol Inform*. 2019 Jul 4;262:360-363. doi: 10.3233/SHTI190093.
- [5] Heesen C, Rahn AC, Köpke S. Communicating with people with MS: A key role for evidence-based patient information. *Patient Educ Couns*. 2022 Dec;105(12):3339-3340. doi: 10.1016/j.pec.2022.10.006