

**Erasmus+**  
**Methods for Hjernerystelsesguiden**  
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### **Methods and identification**

We have conducted several different studies to provide the best possible mapping of the needs and health literacy of the population with concussion symptoms, and to identify the wishes and regrets of this population while under treatment. We have also conducted several searches for scientific articles covering our aims.

### **Group discussions**

We built a basic understanding of the needs of persons with long term symptoms after concussion on the results of a Nordplus funded project called Nordic Brain Train. In said project, volunteers and peers met in Copenhagen and Svartskog outside Oslo for two three-day gatherings. Here we conducted several group discussions on practicalities of the different peer-to-peer call services offer by our associations, but also on the wishes for better and more relevant research and guides.

### **Searches**

We conducted several searches to gather research. Search terms were chosen to identify studies concerned with patient experiences with concussion in Pubmed. Both generic and specific terms were used to ensure the most common patient experiences and recommendations were picked up in the search. However, very few articles were found. Most of the results were experiences of injured athletes, and there were a few recommendations for clinicians, but we found very few concussion experiences from patients with long-term symptoms after concussion. This lack of patient reported experiences highlights the need for more research on concussion symptoms and treatment among patients with long-term effects after concussion. It also makes our research and guidelines all the more important.

### **Surveys**

We have conducted two surveys during the latter half of 2024, one in Denmark (N=74) and one in Norway (N=238). These provided important data both for this report and for an upcoming research paper. These studies provide valuable insight into the symptoms, needs, regrets and wishes of the population with long-term effects after concussion.

The surveys were mostly identical, but there were some differences:

1. Recruitment in Denmark ... (fyll ut). Recruitment in Norway was conducted through the association's home page (hjernerystelsesforeningen.no), but mostly through the facebook page which has more followers.
2. The survey in Denmark was presented using Google Forms. In Norway it was presented using SurveyMonkey.
3. The Danish survey allowed only one answer to the question on symptoms. The Norwegian survey allowed multiple answers, allowing for more thorough analyses.
4. The Norwegian survey was completely anonymous. The Danish survey had room for e-mail or phone information, allowing for follow-up interviews.

The methods and results of the studies have been thoroughly discussed with panels of peers, clinicians and researchers. We have conducted two online meetings and one small workshop at a conference with clinicians and researchers from both Norway and Denmark. These meetings helped us develop methods for conducting research and organising the surveys in ways that would be useful both for us and for further research. We formulated the questions to be able to provide answers to some of the unanswered research questions that were uncovered.

User involvement has of course been essential for our project, and a user panel with peers and guides from Denmark and Norway has followed every step of the process, from helping formulating outcome measures to interpreting results. We have conducted four online panel discussions, providing valuable insight into how we should proceed with analyses and present them in accessible and positive ways in the guides. We also discussed the content of the data, and what they would mean for our target groups. We are looking forward to collaborate further with the peers on issues such as communicating the results to the general public and to our organisations' members.

Surprisingly, over 60% of the respondents had symptoms for three years or more. This is probably quite representative of our members. It is also very interesting for researchers, since the group with long-term symptoms are heavily underrepresented in concussion research. The respondents also had a nice distribution of function levels, allowing for generalisability of our results. But about 80% of the respondents were women, and this limits the generalisability, but it is unfortunately common in PROMs (patient reported outcome measures).

Perhaps the clearest findings in the surveys were the wide range of symptoms that persons with long term effects of concussions suffer from. The surveys showed that fatigue was the most common symptom, followed by headaches and problems with concentration. Next followed neck pains, dizziness and visual challenges. Then followed social symptoms (isolation, low self-esteem and stress), sleeplessness, psychological symptoms (depression and worries) and hearing challenges. We also got very many interesting results from the questions on the respondents' thoughts on the most useful information given and wanted, errors in given information, and how information should be given. All these data have been used in the creation of the guides in Danish and Norwegian.