

# Patient-Reported Outcomes in Multiple Sclerosis Care in the Nordic countries



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## Table of contents

<b>Introduction and aim</b> .....	3
<b>Methods</b> .....	3
<b>Results</b> .....	4
<b>Phase 1 - Mapping of PRO initiatives 2020</b> .....	4
<b>Phase 2 - The role of PROs in clinical care, rehabilitation, research, and regulatory decision-making in the field of MS</b> .....	8
<b>Phase 3 - Nordic healthcare professionals' experiences with PRO</b> .....	10
<b>Summary</b> .....	15
<b>References</b> .....	17
<b>Appendix 1 – Questionnaire to identify PRO activities in the Nordic countries (phase 1)</b> .....	18
<b>Appendix 2 – Workshop program (phase 2)</b> .....	22
<b>Appendix 3 – Interview guide (phase 3)</b> .....	23
<b>Appendix 4 -Abbreviations</b> .....	24

## **Introduction and aim**

Multiple Sclerosis (MS) is an autoimmune, non-curable progressive disease, where symptoms such as fatigue, numbness, cognitive impairments, pain, or spasticity in limbs constitute some of the symptoms. Both cognitive and physical disabilities affect everyday life, and the symptom burden is complex and is experienced in several different ways from individual to individual (1) (2). Therefore a one-size-fits-all approach in MS care is not sufficient, and to improve health outcomes and quality of life, people with MS should be involved in their MS care and treatment (3).

Patient-Reported Outcomes (PRO) can be used to improve patient involvement in MS care, by getting insight into the patient's experiences of symptoms, challenges with MS in everyday life and needs and preferences related to care and treatment (4) (5) (6).

The development and use of PRO increases, and new medical areas continue to include PRO in their work. Since 2016 PRO has been used for people with anxiety and depression, diabetes, heart diseases, apoplexy, damages in hip/knee, and prostate cancer in Denmark (7). In 2020 an integration of PRO in Danish MS care began and the use and integration of PROs in the field of MS are increasing in other Nordic countries.

The overall purpose of this report was to investigate the use of PRO in MS care in the Nordic Countries (Denmark, Norway, Sweden, Finland, and Iceland). This is to identify differences and similarities in the use of PRO in the Nordic countries and to identify areas for possible cross-border cooperation.

## **Methods**

The data collection consisted of three phases. In the first phase, representatives from the Nordic MS Federations were asked to fill out a questionnaire developed by the Danish MS Society to identify PRO activities and initiatives in their country (appendix 1). The purpose of this phase was to map Nordic PRO initiatives.

In the second phase, a workshop was held. The purpose of the workshop was to discuss the role of PROs in clinical care, rehabilitation, research, and regulatory decision-making in the field of MS. 19 people participated and reflected a diverse group of clinicians, patients, and academia, who have a stake in implementing safe and valuable PROs in MS care. The workshop consisted of a two-part

program (appendix 2) with presentations relevant to the current work on PRO, followed by a discussion on the current and future use of PRO in clinical MS care. In the first part of the program, the mapping of Nordic PRO initiatives from the first phase was presented by the Danish MS society. The participants from the first phase also participated in this phase and had the opportunity to elaborate or revise the identified PRO activities. Subsequently, they were asked to elaborate on a few aspects of the mapping to ensure coherence in information from each country. Then the global initiative *PROMS* and a Finnish sub-register dedicated for PROMS named *Myms*: an electronic health system to collect PROs were presented. The second part of the workshop constituted group discussions on three topics concerning the current work on PROs. The workshop participants were divided into three groups: 1) neurologists and academia, 2) physiotherapists, nurses, and other types of healthcare professionals, and 3) people diagnosed with MS. After the group discussion, all participants took part in a plenary debate to share views on the already discussed topics. The discussion questions were as followed:

- a. What role should PRO play in MS treatment and care in the future?
- b. What are the possible benefits of integrating PRO in the encounter between MS patients and healthcare professionals?
- c. What are the barriers to implementing PRO in MS treatment and care?
- d. How do you believe that Nordic collaboration can help us strengthen the use of PRO in MS treatment and care?

In the third phase individual interviews with two MS Nurses and one neuropsychologist from Sweden, Norway, and Finland respectively were conducted. The healthcare professionals were interviewed because of their experiences with PRO in their daily work and to follow up on clarifying questions from phase 1 and 2. Questions regarding specific PRO questionnaires used in each country, the frequency in use of PROs, the purpose of PRO, and advantages and disadvantages of using PRO were discussed (appendix 3). Due to Covid-19, the interviews were performed virtually.

## **Results**

### **Phase 1 - Mapping of PRO initiatives 2020**

The results of the mapping of Nordic PRO activities are presented in Table 1 and 2. Table 1 shows to what extent PROs are used in each Nordic country. In Sweden and Finland several PROs are

implemented and they have developed programs to systematically collect PROs as the first Nordic countries. In Norway, PROs have more recently been implemented in the Norwegian MS registry and currently include two PRO measures. Implementing PROs in the Danish MS registry is under development and is planned to be implemented during 2022. Currently, Iceland has not initiated any PRO activities in MS care, nor does an MS registry exist. Across PROs used in Sweden, Norway, and Finland, the impact scale MSIS-29 and health-related quality of life measures are used. This suggests that these measures are assessed as central PROs in the field of MS. Currently, Sweden has implemented the most PROs compared to the other Nordic countries. However, people with MS in Sweden are by default presented a basic package of questionnaires including MSIS-29, EQ-5D, and MS-kollen (abbreviations are explained in appendix 4). The remaining questionnaires are used by the individual clinician when seeing fit. Moreover, other PROs that assess disability and fatigue are also used in Sweden and Finland.

**Table 1. Map of PRO activities**

<b>Country</b>	<b>Denmark</b>	<b>Norway</b>	<b>Sweden</b>	<b>Finland</b>	<b>Iceland</b>
<b>PRO in MS registry</b>	Under development	Yes	Yes	Yes	No MS registry
<b>Measures</b>		RAND-12 MSIS-29	MSIS-29 FSMC TSQ HAD EQ-5D WAQ-MS MADRS-S MS-kollen NeuroQoL- Fatigue Smoking Physical activity	MSIS-29 FSS EQ-5D 15D  <b>From 2020:</b> PREDSS MSNQ FSMC NARCOMS performance scale	
<b>Data collection platform</b>	COMPOS	MRS HEMIT	COMPOS	Myms	

<b>Implementation of PRO</b>	2020-2021	2019	2015	2010 2017: Clinical MS register 2014	
<b>Frequency of registration</b>		Annually (in October/November)	Annually	At the time of diagnosis/baseline, PRO questionnaires on neurological symptoms and quality of life are filled out, and thereafter whenever possible	
<b>Registered MS-patients (December 2020)</b>		5.790 PwMS (constituting 73% of registered MS patients)	18.746 PwMS	1600 PwMS use Myms out of 12.000 PwMS in MS registry	

Table 2 shows the current role of PROs in MS rehabilitation within each Nordic country. Currently, only Denmark, Sweden and Finland use PROs in MS rehabilitation, suggesting that it is not as widespread as in MS clinical care. In Finland, PROs used in rehabilitation focus on the patient's well-being (depression and quality of life measures), whereas PROs in Danish rehabilitation focus on the patient's functioning and satisfaction.

**Table 2. PRO in MS rehabilitation**

<b>Country</b>	<b>Denmark</b>	<b>Norway</b>	<b>Sweden</b>	<b>Finland</b>	<b>Iceland</b>
<b>PRO in MS rehabilitation</b>	Yes	No	Yes	Yes	No

<p><b>Purpose of PRO in MS rehabilitation</b></p>	<p>Screening tool for placement on waiting lists and assess patient satisfaction</p>	<p>Under development</p>	<p>Screening tool, defining the patient perspectives on their function and symptom, aid in evaluating and prioritizing patients' need/symptoms as well as care and rehabilitation.</p> <p>-</p>	<p>Used to define the patient perspectives when evaluating patients' needs and planning the contents of the rehabilitation.</p>	
<p><b>Measures in MS rehabilitation</b></p>	<p>FAMS Patient satisfaction questionnaires</p>		<p>MSFC (PASAT, 9HPT, T25W), SDMT, 6 minute walk test, 10 min walk, EDSS walking ability, WAQ/WAQ-Extended</p>	<p>BDI II WHOQOL-BREF  GAS - Goal Attainment Scaling  Questions related to work whenever applicable</p>	

## **Phase 2 - The role of PROs in clinical care, rehabilitation, research, and regulatory decision-making in the field of MS**

In the workshop, the participants discussed four topics related to the use of PRO: 1) What role should PRO play in MS treatment and care in the future? 2) What are the potentials of integrating PRO in the encounter between MS patients and healthcare professionals? 3) What are the barriers to implementing PRO in MS treatment and care? 4) How do you believe a Nordic collaboration can help us strengthen the use of PRO in MS treatment and care? Results from this discussion are presented in the following.

### Potentials and barriers of implementing PROs in clinical care

PROs were considered to have great potential in MS care, e.g. the potential to improve the relationship between the healthcare professional and the patient. Moreover, some of the participating healthcare professionals emphasized that PROs could direct clinicians' focus on invisible symptoms such as cognitive challenges and fatigue that often are characteristic for people with MS. Also, some of the healthcare professionals described how PROs may promote self-care among people with MS. Other participants stated that PROs can provide a more detailed and nuanced picture of everyday life with MS which may help improve the rehabilitation. Finally, it was mentioned that PROs might be helpful in decision-making to receive other types of treatment such as physical therapy or be referred to a psychologist.

People with MS who participated in the workshop highlighted that many people with MS are motivated to engage in their treatment, and that use of PROs could be highly relevant in this regard. Moreover, they explained how PROs could potentially empower people with MS and provide a sense of control of their health. Both healthcare professionals and people with MS emphasized that PROs may facilitate a common language between clinician and patient and may further support healthcare professionals to better understand the everyday life with MS.

One main challenge that was emphasized, if/when implementing PROs, was to ensure that all stakeholders, including clinicians, academia, and patients, know and agree upon the purpose of using PROs, how PROs can become meaningful and how PRO data can be used. Within the discussion, it became clear that clinicians and researchers had different interests in the purpose of using PROs. Clinicians were mainly interested in the patients' state of health before the consultations, whereas



researchers were more interested in disease progression over time. The participants suggested that this challenge could be met by formulating a consensus on why and how PROs should be used prior to the implementation. Researchers also underlined that validated questionnaires used as PROs would benefit clinicians in their daily work. Other challenges related to PROs, mentioned by neurologists imply a lack of validated questionnaires and licenses to use already existing validated questionnaires. The healthcare professionals and researchers also described how e-health programs, allowing for PRO data to be collected systematically, are lacking. Also, they argued that programs developed to systematically collect PROs need to be easy to access and use for both clinicians and patients. Furthermore, a representative from Iceland described that one of Iceland's most critical challenges is the lack of clinicians in the country, limiting the opportunity to implement PROs in clinical care.

People with MS emphasized that cognitive challenges often experienced by people with MS are necessary to accede to when implementing PROs in clinical care. Moreover, the patient burden of reporting PROs needs to be considered, as some people with MS may find it challenging and fatiguing to report PROs systematically. Finally, several participants highlighted that both people with MS and clinicians must find it meaningful to complete PROs if implementation should be successful.

#### Future role of PROs in the Nordic countries

There was a consensus among the participants that PROs should not only play a central role in future clinical care but also in the field of MS research. A future Nordic collaboration across disciplines was viewed positively among the workshop participants and as something to strive for in future clinical care. Through a Nordic collaboration, healthcare professionals and researchers can share knowledge and experiences with methods for data collection and allow for greater comparative research by developing and using similar PROs across the Nordic countries. This could encourage researchers to establish larger datasets to gain a greater understanding of MS, e.g. which factors influence disease progression, and which non-medical treatments are the most efficient. Such type of research may potentially affect the clinical care and treatment for MS in all Nordic countries. However, some participants highlighted the importance of validated and standardized questionnaires to ensure the quality of the measures across countries.

### **Phase 3 - Nordic healthcare professionals' experiences with PRO**

After processing data from the first and the second phase of this project, further questions related to the use of PROs in MS care in Norway, Sweden, and Finland emerged. Therefore, individual interviews were conducted to clarify these questions.

In all three countries, PRO questionnaires are being filled out by the patients annually. In Norway, PRO questionnaires are primarily used for research. Almost 70% of the Norwegian surveyed patients are willing to fill out the PROs, however, some are dissatisfied that the questionnaires are not used in clinical care. However, a PRO questionnaire used for clinical care, exploring the patient's perspective of MS care and supporting the patient in preparing for the consultation, is under development. In the interview it was underlined that to explore the full potential of PROs, they should be used for both research and clinical care. Despite this, there is no specific plan for the enrollment of PRO questionnaires in clinical care in Norway.

In the Swedish MS registry, there are 63 units, whereof 50-55 use PRO both for research and in clinical care. A unit is the health care facility that the patients belong to. In clinical care, the PROs are used as a screening tool and as a dialogue tool. However, there is no systematic use of PRO questionnaires; it depends on the specific nurse or physician. From a Swedish healthcare professionals' perspective, PROs are beneficial for both patients and clinicians; it helps the clinician specify the dialogue and supports the patient in setting the frame for the consultation. Furthermore, PROs can optimize the use of time during the consultations. However, it was emphasized in the interview that PROs are not suitable for all patients, and especially newly diagnosed patients can find the questions overwhelming.

In Finland, PROs are frequently used in some hospitals but have not been systematically implemented within or across the hospitals. Therefore, National Clinical Guidelines on how to use PROs are currently under development. The patients' responses to PROs are not necessarily used actively in the dialogue between healthcare professionals and the patient but are more often used as a screening tool. However, there is a perception of PROs as a tool to explore the patient's perspective and obtain a better understanding of the patients' needs and preferences related to MS care. Furthermore, it was emphasized in the interview that PROs can make it possible to detect invisible symptoms and establish early support to the patient. This makes MS care more individualized and may support patient self-care. Furthermore, it was emphasized in this interview that it is important to notice that

some patients might report more MS-related problems to receive more help, and further that it is important to be aware of confounding related to self-reported data. In Finland, 1.000 out of 12.000 registered patients in the MS registry have recorded their information in Myms. At the end of 2021 total 1600 users of MyMS. The patients can get information on the disease and the symptoms as well as support to come along with cognitive problems and fatigue. An initiative to add tools for remote rehabilitation to the MyMS register are under development in 2022. Myms is a personal profile, where the patients, besides the PRO questionnaires, can log their health status and follow their health and disease development making it motivating for the patient to fill out the PROs.

Across all three countries, PROs are perceived as beneficial for both patients and clinicians. However, a systematic way of using PROs is lacking in all three countries. Results from these interviews are presented in table 3.

**Table 3.** Nordic Healthcare professionals’ experiences with PRO

<b>Question</b>	<b>Norway</b>	<b>Sweden</b>	<b>Finland</b>
<b>Frequency in use of PRO questionnaires?</b>	Once a year (in October/November).	Once a year pre-collected questionnaires/an annual package of PROs (MSIS-29, MS-Kollen, TSQ and EQ-5D) are filled out by the patients. However, these can vary depending on the patients' situations.	At the time of diagnosis/baseline, PRO questionnaires on neurological symptoms and quality of life are filled out, and thereafter annually.  1.600 out of 12.000 registered patients in the MS registry have recorded their information in Myms. At the end of 2021, 3.000 patients with MS will be using the Myms.

<b>Most frequently used questionnaires?</b>	RAND-12 and MSIS-29	MS-Kollen	MSIS-29, EQ-5D, 15D and FSS PRO questionnaires are used frequently, but there is no systematic use.
<b>How many healthcare professionals use PRO?</b>	The questionnaires are used in the MS Registry, but it is unknown how many healthcare professionals use them.	There are 63 units in the MS registry, and 50-55 units use the PRO questionnaire. Currently, there is no systematic use of the PRO questionnaires. It depends on the specific nurse or physician.	Currently, the questionnaires are only being used at some hospitals/clinics, and it is unknown how many healthcare professionals use them.
<b>Purpose of PRO questionnaires?</b>	PROs are primarily used for research purposes. However, a PRO questionnaire for clinical use is currently under development in Bergen. MSIS-29 would be useful in clinical care. RAND-21 is only useful in connection with MSIS-29.	PROs are both used as a screening tool and as a dialogue tool.	In hospitals, PROs have not been systematically used and is most often used as a screening tool and to get an idea of the patient's perspective.
<b>Are PRO questionnaires suitable for research? Clinical use?</b>	Most PROs are suitable for clinical use to explore the patient's perspective of their MS. Furthermore, the questionnaires can be	All questionnaires are suitable for research, but some are more helpful in a clinical setting, e.g., FSMC.	PROs are suitable for clinical use, both as a screening tool and to get the patients perspective and a

	<p>a supportive tool for the patients to be prepared for their consultation and what specific areas of their MS they would like to discuss with the physician.</p> <p>PRO is also found to be suitable for research.</p>		<p>better understanding of the patients' needs and preferences related to their MS.</p> <p>The questionnaires are also suitable for research purposes when the limitations are carefully considered.</p>
<p><b>Advantages of using PRO questionnaires?</b></p>	<p>Information on patients with MS can be systematically collected, which is valuable for research and to compare people with MS in Norway with other people with MS in other countries.</p>	<p>From the healthcare provider's perspective, the major advantage of a PRO is that it can be used as a tool to specify the dialogue.</p> <p>From the patient's perspective, the major advantage may be that it can help to set the frame for the consultation and help bring up sensitive and private topics such as bladder, bowel and sexual dysfunction.</p> <p>In general, it can optimize the time in the consultations, which</p>	<p>Using PROs makes it possible to improve the involvement of the patients.</p> <p>PROs make it possible to get a more holistic view of the disease and detect invisible symptoms and to establish earlier support to the patient.</p> <p>PRO data makes it possible to make the MS care more individualized and to support patient self-care.</p>

		also is a major advantage.	Mymys is motivational for the patient because it is a personal profile, where the patients besides the PROs can log their health status, follow their disease progression and health development and get information and support.
<b>Disadvantages of PRO questionnaires in your country?</b>	<p>Most patients (70% of the asked patients) are willing to answer the questionnaires, but they are dissatisfied that the questionnaires are not used in clinical care.</p> <p>Another disadvantage is that there is no specific plan for the enrollment of PROs in clinical care.</p>	Some PROs can be overwhelming for some patients (mostly newly diagnosed), because they risk an ‘overload’ of information on the and symptoms of MS.	<p>Using PROs some patients may report a greater amount of MS-related symptoms to receive more help and support.</p> <p>In general, it is important to be aware of the confounding related to self-reported PRO questionnaires.</p> <p>Some patients with MS are not able to fill out the questionnaires due to cognitive</p>

			impairments or the fact of not having access to the register.
<b>Something specific to highlight as helpful or important when using/implementing PROs?</b>	<p>It is essential for the use of PRO questionnaires that the patients are digitally active.</p> <p>To explore the full potential of PROs it should be used for both research and in clinical care.</p>	<p>For PRO data to succeed both patients and clinicians must see the potential in the tools.</p> <p>PROs should seek a holistic approach/perspective on everyday life with MS.</p> <p>PROs must be translated into the specific country's language.</p>	<p>It is useful and motivating for the patients to have access to their data and to follow their development.</p> <p>Further, to have a platform for remote rehabilitation.</p>

## Summary

Use of PRO data can 1) potentially improve the relationship between healthcare professionals and patients, 2) give a more nuanced picture of everyday life with MS and 3) make invisible symptoms, e.g., cognitive impairments, more visible, 4) promote self-care and empower patients and 5) be a helpful tool in decision making. However, it was suggested that the patient burden related to filling out PROs could be a potential barrier. Furthermore, different understandings among healthcare professionals and researchers on the purpose for the use of the tool were suggested as a potential barrier. Also, both healthcare professionals and patients must find it meaningful to use PROs, otherwise this might also be a potential barrier.

There is currently a great diversity in the use of PRO across the Nordic countries. The data collection platforms used across the countries are not the same, and there is no systematic in the frequency of registration/use. Whether PROs are used for research or in clinical care also differs across the Nordic countries. In countries where PROs are used in clinical care, it is further diverse whether PROs are used as a screening tool or as a dialogue tool. There is limited use of the same PRO-questionnaire, however, the impact scale MSIS-29 and health-related quality of life measures are used across Sweden, Norway, and Finland.

However, there is a common wish for a future Nordic collaboration across all the Nordic countries. The collaboration should improve the possibilities of 1) sharing knowledge and experiences with methods for data collection and 2) allowing greater comparative research by developing and using similar PROs in the Nordic countries for healthcare professionals and researchers. In long term, this could encourage larger datasets to gain a greater understanding of MS.



## References

1. Dobson R, Giovannoni G. Multiple sclerosis – a review. *Eur J Neurol.* januar 2019;26(1):27–40.
2. Barin L, Salmen A, Disanto G, Babačić H, Calabrese P, Chan A, m.fl. The disease burden of Multiple Sclerosis from the individual and population perspective: Which symptoms matter most? *Mult Scler Relat Disord.* oktober 2018;25:112–21.
3. Rieckmann P, Centonze D, Elovaara I, Giovannoni G, Havrdová E, Kesselring J, m.fl. Unmet needs, burden of treatment, and patient engagement in multiple sclerosis: A combined perspective from the MS in the 21st Century Steering Group. *Mult Scler Relat Disord.* januar 2018;19:153–60.
4. Nowinski CJ, Miller DM, Cella D. Evolution of Patient-Reported Outcomes and Their Role in Multiple Sclerosis Clinical Trials. *Neurotherapeutics.* oktober 2017;14(4):934–44.
5. Black N. Patient reported outcome measures could help transform healthcare. *BMJ.* 28. januar 2013;346(jan28 1):f167–f167.
6. Snyder CF, Aaronson NK, Choucair AK, Elliott TE, Greenhalgh J, Haylard MY, m.fl. Implementing patient-reported outcomes assessment in clinical practice: a review of the options and considerations. *Qual Life Res.* 2012;21(8):1305–14.
7. Madsen CH. Det tværregionale projekt om værdibaseret sundhed. McKinsey & Company; 2019 s. 67.

## Appendix 1 – Questionnaire to identify PRO activities in the Nordic countries (phase 1)

1. Is PRO-data being registered in the national MS registry?	Yes	No
<i>If yes, please answer the following questions. If no, go to 2.</i>		
What information/set of domains is registered as PRO-data in the MS registry (e.g. fatigue, spasms, quality of life etc.)?  Write here:		
How/why was these measures/set of domains chosen?  Write here:		
Do you use validated questionnaires/scales/tools to collect the information – which?  Write here:		
Who register the PRO-data (e.g. the patients have access to the MS registry and can fill in the data, patient report on a paper form, PRO-data are registered by the neurologist, PRO-data are registered by a nurse, etc.)?  Write here:		
What purpose serves the PRO-data registered in the MS registry/what are the PRO-data used for?  Write here:		
Which experiences have come from registering PRO-data in the registry? (e.g. challenges, is it working as intended, what have gone well/less well)  Write here:		
Have the data been used for research or documentation work?  If yes, please list the purposes and refer to potential publications and reports.		
2. Is PRO-data used actively in the treatment and/or rehabilitation of MS-patients?	Yes	No
<i>If yes, please answer the following questions. If no, continue to 3.</i>		
Which health care professionals use PRO-data in their treatment/rehabilitation of MS-patients?  Write here:		
What information/set of domains are being used?		

Write here:		
For what purpose are the PRO-data used?		
Write here:		
How are the PRO-data collected (e.g. online, an app, paper, wearables or other)?		
Write here:		
Which experiences have come from using PRO-data in treatment/rehabilitation? (e.g. challenges, is it working as intended, what have gone well/less well)		
Write here:		
Do any publications or reports exist on how PRO-data is used in treatment or rehabilitation?		
Please list below:		
Is this initiative part of any guidelines or policies for regulatory agencies, HTA decision making processes, organizational services or policies, etc.?		
Write here:		
<b>3. Within the past five years have any already existing PRO-tools been translated and/or validated within the field of MS in your country?</b>	<b>Yes</b>	<b>No</b>
<i>If yes, please answer the following questions. If no, continue to 4.</i>		
Which existing questionnaires/tools/scales has been validated/translated to apply in your country?		
Write here:		
When was the questionnaire(s)/tool(s)/scale(s) validated/translated?		
Write here:		
Who has overseen the validation/translation?		
Write here:		
Which experiences have come from translating/validating PRO measures? (e.g. challenges, is it working as intended, what has gone well/less well)		
Write here:		
Do any publications or reports exist regarding this process?		
Please list below:		

<p>Have the results of the initiative or study been included into any guidelines or policies for regulatory agencies, HTA decision making processes, organizational services or policies etc?</p> <p>Write here:</p>		
<p><b>4. Within the past five years have current or past projects developed ways/tools to collect PRO-data (e.g. apps, questionnaires, other) in the field of MS?</b></p>	<p><b>Yes</b></p>	<p><b>No</b></p>
<p><i>If yes, please answer the following questions. If no, continue to 5.</i></p>		
<p>Please describe the tool and how it works</p> <p>Write here:</p>		
<p>What information/set of domains does the tool(s) collect?</p> <p>Write here:</p>		
<p>How/why was this information/set of domains selected to be included?</p> <p>Write here:</p>		
<p>Who/which stakeholder have overseen the project(s)?</p> <p>Write here:</p>		
<p>Which experiences have come from the development of PRO-tools/scales?</p> <p>Write here:</p>		
<p>If any publications have been made based on this work, please list below:</p>		
<p>Have data from the new PRO-tool(s) been used for research or documentation work?</p> <p>If yes, please list the purposes and refer to any publications and reports.</p>		
<p>Have the results of the initiative or study been included into any guidelines or policies for regulatory agencies, HTA decision making processes, organizational services or policies, etc.?</p> <p>Write here:</p>		
<p><b>5. Have any new approaches to the collection of PRO been tested on people with MS (e.g. passive data collection)?</b></p>	<p><b>Yes</b></p>	<p><b>No</b></p>
<p><i>If yes, please answer the following questions. If no, go to the end.</i></p>		
<p>Which institution has tested the new PRO tool?</p> <p>Write here:</p>		

<p>What kind of PRO-tools/scales have been tested and how do the patients register their data (e.g. new questionnaire/scale/tool, wearables)?</p> <p>Write here:</p>
<p>What information/set of domains are reported/collected in the tool?</p> <p>Write here:</p>
<p>Which experiences have come from testing this? (e.g. challenges, is it working as intended, what has gone well/less well)</p> <p>Write here:</p>
<p>Do any publications or reports exist regarding the experience of using PRO-data in the treatment of people with MS?</p> <p>Please list below:</p>
<p>Have the data been used for research or documentation work?</p> <p>If yes, please list the purposes and refer to potential publications and reports.</p>
<p>Have the results of the initiative or study been included into any guidelines or policies for regulatory agencies, HTA decision making processes, organizational services or policies etc.?</p> <p>Write here:</p>

## Appendix 2 – Workshop program (phase 2)

Dear participants,

I am happy to announce the following program for the Nordic Conference on Patient Reported Outcome Measures in Multiple Sclerosis.

### Program:

15:00 - 15:05	Welcome
15:05 – 15:20	Presentation of Nordic PRO mapping by Katrine Westergaard from the Danish MS Society
15:20 – 15:35	Presentation of international PRO experiences by Anne Helmer from MSIF
15:35 – 15:50	Presentation of a Finnish Initiative by Päivi Hämäläinen, neuropsychologist, director of the Masku Neurological Rehabilitation
15:50 – 16:00	Break
16:00 – 16:25	Group Discussion of future use of PROs in MS treatment and care
16:25 – 16:50	Plenary discussion
16:50 – 17:00	Thank you

### Appendix 3 – Interview guide (phase 3)

<b>Question</b>
Introduction
How often do you use PRO questionnaires? The frequency in the use of PRO?
Are there some of the questionnaires that are being used more frequently than others?
How many health professionals use it? Patients?
How do you define PRO/what is the purpose of PRO? Do you use it as a screening tool? A dialogue tool? For research purposes?
Do you think it is more suitable for research? Or clinical use?
What are the main advantages of PRO questionnaires?
What are the main disadvantages of PRO questionnaires?
Is there something specific you will highlight as helpful, or that works well? Questionnaires? Specific questions? Ways of using it in consultations?
Is there something specific you will highlight that does not work well? Questionnaires? Specific questions? Ways of using it in consultations?
When did you implement PRO?
End of interview

## **Appendix 4 -Abbreviations**

**MSIS-29:** Multiple Sclerosis Impact Scale

**FSS:** Fatigue Severity Scale

**EQ-5D:** Quality of Life

**FSMC:** Fatigue Scale for Motor and Cognitive Functions

**WAQ-MS:** Work and study ability (and extended)

**MADRS-S:** Montgomery & Asberg Depression Rating Scale

**PREDSS:** Patient reported Expanded Disability Status Score

**NARCOMS performance scale:** Multi-dimensional disability scale in MS

**Rand-12:** Health Status Inventory, quality of life

**MSNQ:** Multiple Sclerosis Neuropsychological Questionnaire

**BDI II:** Beck Depression Inventory 2

**WHOQOL-BREF:** Quality of Life

**FAMS:** Functional Assessment in Multiple Sclerosis

**HAD:** Hospital Anxiety and Depression Scale

**MS-kollen:** Assessment of symptoms on visual analogue scale

**NeuroQoL:** Quality of Life in Neurological Disorders

**TSQ:** Treatment Satisfaction Questionnaire