

## Invitation Letter

**Thank you** for your interest in participating in the eHealth cataloguing efforts of the Global Patient Reported Outcomes for Multiple Sclerosis (PROMS) Initiative (<https://www.aism.it/proms>). The PROMS Initiative is a multi-stakeholder collaboration working to enable science with and of patient input to the process of research and advances in the care of people with MS. On 12 September 2019, the global Patient Reported Outcome for Multiple Sclerosis (PROMS) Initiative was launched at the 35th Congress of the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS), held in Stockholm, Sweden. The multi-stakeholder PROMS Initiative is jointly led and coordinated by the European Charcot Foundation (ECF) and the Multiple Sclerosis International Federation (MSIF) with the Italian MS Society (AISM) as lead agency on behalf of and for the MSIF Movement. PROMS has the ambition to (i) maximise impact of “science with and of patient input” on the health, healthcare and quality of life of people affected by MS, and (ii) represents a unified view on Patient-Reported Outcomes (PROs) for MS to people affected by MS, healthcare providers, regulatory agencies and Health Technology Assessment (HTA) organisations/bodies. Areas of interest were defined and assigned to 4 working groups with members representing different stakeholder categories.

More information on the PROMS Initiative can be found in “The agenda of the global patient reported outcomes for multiple sclerosis (PROMS) initiative: Progresses and open questions” - Multiple Sclerosis and Related Disorders<sup>1</sup>.

A dedicated working group within the PROMS initiatives focuses on “eHealth”. This working group concluded rapidly that there are many existing and emerging (i.e., “in development”) eHealth Tools available that collect relevant PROMS for people with MS. Improved awareness of these tools is needed. Therefore, we aim to execute a landscaping exercise with the following aims:

1. Identify the gaps in the landscape in order to steer and inspire the clinical validation and/or the development of additional eHealth innovative tools in the future.
2. Support stakeholders (e.g., people with MS, clinicians, industry, researchers, etc.) to identify and select the most relevant eHealth tools based on their own specific requirements.

The landscape exercise focuses on following eHealth tools:

- The design, research or use for people with MS of the tool is ongoing.
- The focus of the tool is on collecting PROMS, with PROMS broadly defined (active/electronically supervised, passive/unsupervised).

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<sup>1</sup> Paola Zarin, Patrick Vermersch, Maria Pia Amato et al., On behalf of the PROMS Initiative Working Groups The agenda of the global patient reported outcomes for multiple sclerosis (PROMS) initiative: Progresses and open questions, Multiple Sclerosis and Related Disorders, Volume 61, 2022, 103757. <https://doi.org/10.1016/j.msard.2022.103757>.

- The tools collect data that is mostly patient-initiated.

To participate in this survey, we kindly ask you to write to [proms\\_ehealth@aism.it](mailto:proms_ehealth@aism.it) to be invited to the Survey and receive further instructions.

One of the members of the eHealth working group is Liesbet Peeters, chair of the MS Data Alliance (MSDA) that will host the meta-data on the MSDA Catalogue. Please feel free to already create an account on <https://msda.emif-catalogue.eu/login>.

The results of the survey below will be used as follows:

1. **Internal use:** A working group within the PROMS initiative will use the results of the survey to identify the gaps and steer the PROMS global agenda moving forward.
2. **Scientific publication:** We aim to publish the summary and interpretation in a Scientific Journal. We will acknowledge all contributors according to academic customs.
3. **Dynamic digital Catalogue:** Because we believe the ecosystem of eHealth tools is continuously evolving, we aim to develop a web-based catalogue that will provide an overview of the available digital self-monitoring or assessment tools and allows end-users to browse metadata based on the information collated on the measures and tools available and in development. The Catalogue will be hosted on the MS Data Alliance (MSDA) Catalogue.

**IMPORTANT NOTE:** the MSDA Catalogue only consists of meta-data. However, in order to be able to create an account and to get access to the MSDA Catalogue, you will have to agree with the general Terms of Use of the MSDA Catalogue and give your specific and informed consent to the processing of your personal data as stated in this Privacy Notice.

**The survey has been developed by PROMS and all rights are reserved (©COPYRIGHT Global PROMS Initiative).**

If you have questions, do not hesitate to contact [proms\\_ehealth@aism.it](mailto:proms_ehealth@aism.it).

**PROMS Scientific Committee Co-chairs**

Paola Zarin (Italy) and Patrick Vermersch (France)

**PROMS WG3 eHealth Working Group**

Co-Leaders: Letizia Leocani (Italy), Robert Hyde (Switzerland)

Members: Shibeshih Belachew (USA), Valerie Block (USA), Richard Dobson (UK), Joanna Dronka-Skrzypczak (Poland), Marcus DSouza (Switzerland), Ludwig Kappos (Switzerland), Daphne Kos (Belgium), Marni Hall (USA), Anne Helme (UK), Johannes Lohrscheider (Switzerland), Paul Matthews (UK), Liesbet Peeters (Belgium), Johan Van Beek (Switzerland), Ana Zabalza (Spain).