PROMS
A Joint Global Initiative

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Engagement Co-ordination Team (ECT) member

Role description

Background

Patient-reported outcomes (PROs) are measures of how patients view their own health, for example through questionnaires or wearable technology like smartwatches. PROs are used in MS research alongside clinical and biological data to show how a patient is experiencing their MS. Currently there are many PROs used in the MS community, but their use needs to be streamlined and improved across countries and stakeholders to maximize their impact.

To address this, global Patient Reported Outcome for Multiple Sclerosis (PROMS) Initiative was established in 2019. This multi-stakeholder PROMS Initiative is jointly led by the European Charcot Foundation and the Multiple Sclerosis International Federation with the Italian MS Society acting as lead agency for and behalf of the Global MSIF Movement. This initiative aims to improve the quality of life of people affected by MS by maximizing the impact of PRO measures in MS research and clinical care. You can read more about this initiative and its activities here: https://proms-initiative.org/

It’s essential that the voices of people affected by Multiple Sclerosis (MS) are embedded into each stage of the PROMS initiative. Therefore, we created an Engagement Co-ordination Team (ECT) to lead on the engagement of people affected by MS. The ECT is composed of people affected by MS and experts in patient engagement from MS organisations. Members of the ECT are involved with the design and implementation of projects within the initiative, as well as the strategy for engaging people affected by MS across the world.

We’re now looking for around six people personally affected by MS to join the current members in the ECT.

Please note, that we’re using the term ‘engagement’ for the purposes of this programme. By using this term, we’re describing the process of working *with* people affected by MS to ensure that their experiences of living with the condition are embedded throughout the programme in collaboration with all the other PROMS stakeholders.

What is the purpose of this role?

The ECT ensures that the voice of people affected by MS is included in all stages of the initiative. This includes the design, decision-making, implementation, monitoring and evaluation stages of all projects, as well as in the translation of research results to the MS community.

What is the time commitment?

This role is initially for a 2-year term.

All members of the ECT are expected to:

- attend a 60-90 minute videoconference meeting once a month. These are currently held at 16.30 GMT on Tuesdays.
- read documents or meeting papers in advance of the meetings, as required.
- attend the face-to-face annual PROMS meeting in Italy if possible (travel and expense are covered by the PROMS Initiative).

We also encourage you to join a Working Group focused on a specific research activity. Working Groups meet for around 90 minutes every 2 months.

There may be occasions when you are unable to attend a meeting or teleconference due to ill health or other personal reasons; this is, of course, absolutely fine and meetings will be recorded.

What will be expected of me?

- Provide a perspective based on your personal experience of MS
- Work alongside other members of the ECT to engage a representative community of people affected by MS (through your networks in your region/country) throughout the PROMS initiative
- Preparation and follow-up from meetings
- Participate in discussion during meetings

How will I be supported?

We're committed to being as inclusive as possible and will consider reasonable adjustments to enable any individuals to fulfil this role.

All meetings will use 'Wordly', which provides AI-enabled captions and translations, allowing you to participate in your own language.

In relation to in-person meetings, this includes pre-paying or reimbursing reasonable and relevant travel and accommodation for you and a family member or carer if required. The meeting venue will have disabled access and parking, and accessible toilets. Videoconferencing will be available for those who aren't able to attend the meetings in person

You'll receive an induction on the aims and objectives of the PROMS initiative by videocall before the first meeting. In this briefing, you'll hear about the background to the initiative and have the chance to ask any questions.

Do I need any specific experience, training or skills?

The below skills and experiences are essential for effective patient engagement:

- Personal experience of MS as a patient, family member or non-professional caregiver
- Confidence sharing your views in a group, whilst also being able to listen to others respectfully
- Willingness to represent the MS community and to reach out to gather wider input from others affected by MS on a range of topics
- Willingness to think broadly about MS and consider the questions and priorities that are most important to the diverse range of people affected by MS globally
- Understanding of the impact of MS on people’s everyday lives

This role is open to all people with personal experience of MS, but we particularly welcome applications from those with a diagnosis of MS.

How do I apply?

Please answer the questions in the application form below, and return to Anne Helme, Head of Research and Access at the MS International Federation, and co-Chair of the PROMS Engagement Coordination Team. Email: **anne@msif.org**

The deadline for applications is 31 March 2025.

What happens next?

Shortlisted applicants will be contacted for a telephone or video-call interview, and six people will be appointed.

Applications will be administered by the MS International Federation, but will be assessed by members of the PROMS initiative (including current members of the ECT), who will make the final decisions.

If you have any questions about this role, please contact Anne Helme (anne@msif.org) who will be happy to talk to you before you apply.

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Engagement Co-ordination Team (ECT) member Application form

You are welcome to complete this form in your primary language.

1	**Your name**
2	**Your contact details**
	Email: Telephone (including country code):
3	**What is your local MS Organisation?** For example, the UK MS Society or the National MS Society (USA).
	Organisation name: Country:
4	**What is your connection to MS?** Please note that this role is only open to people with a personal experience of MS as a patient, family member or non-professional caregiver.
5	**What interests you about this position?**

6	**What skills and/or experience do you have that will help you in this role?** Please refer to the skills and qualities listed in the role description, and try to describe why you think you are a good fit for this role. We’re particularly interested in hearing about your experience of representing other people.
7	**What do you think the role of a member of the Engagement Co-ordination Team will be? What approach would you take to this role?**

By completing and returning this form, I declare that:

I consent to share the information on this form with those in MSIF responsible for the assessment process. I understand that information I have given on this form will be handled in line with the General Data Protection Regulations and MSIF’s privacy policy www.msif.org/privacy-policy, and will be used solely for the purposes of assessing my eligibility and competency for this role.

Thank you for your interest in the Engagement Co-ordination Team and the PROMS Initiative.