

ENMC Workshops

Toolkit for Patients and Patient Representatives

A practical guide for individuals directly or indirectly affected by neuromuscular disorders

Table of Contents

1. Introduction
2. Why patient participation matters
3. What patients and patient representatives contribute
4. What to expect before and during the workshop
5. How to prepare for the workshop
6. Confidentiality and data protection
7. Travel, accommodation and reimbursement
8. Accessibility
9. Carer
10. After the workshop
11. Contact

1. Introduction

The European Neuromuscular Centre (ENMC) promotes international collaboration in neuromuscular research and care. Its mission is to improve diagnosis, treatment development, standards of care, and quality of life for people living with neuromuscular disorders and their families.

ENMC workshops are one of the organisation's core activities. Approximately 8–10 workshops are organised each year in the Netherlands. These workshops bring together clinicians, researchers, healthcare professionals, patients, carers, and patient representatives from around the world.

The workshops are designed to encourage collaboration and open discussion between participants from different disciplines and backgrounds. They provide an opportunity to:

- Share the latest scientific and clinical developments
- Discuss unmet needs in research and patient care
- Identify future research priorities
- Improve standards of care
- Strengthening collaboration between professionals and patient communities

Patient participation is an essential part of the ENMC workshop model. Individuals affected by neuromuscular disorders are considered experts through lived experience and contribute directly to workshop discussions and outcomes.

2. Why patient participation matters

Patient involvement is one of the core values of the ENMC.

People living with neuromuscular disorders bring practical knowledge and lived experience that complement scientific and clinical expertise. Their involvement helps ensure that research priorities and healthcare discussions remain focused on real-life needs and meaningful outcomes.

Patient participation helps to:

- Improve understanding of daily challenges faced by patients and families
- Ensure research remains relevant to patient priorities
- Encourage more practical and patient-centred outcomes

- Strengthening communication between researchers, clinicians, and the patient community
- Improve standards of care and support services

Patients, carers, and patient representatives play an important role in helping researchers understand better what matters most in everyday life with a neuromuscular condition.

3. What patients and patient representatives contribute

Patients and patient representatives contribute unique expertise that cannot be gained through textbooks, research papers, or clinical practice alone.

You may contribute by:

- Sharing personal experiences and perspectives
- Explaining the day-to-day impact of living with a neuromuscular disorder
- Identifying unmet healthcare and research needs
- Raising issues researchers may not have considered
- Helping to make scientific discussions more understandable and patient-focused
- Highlighting priorities related to quality of life, independence, mobility, fatigue, pain, or access to care

Your contribution helps ensure that workshop outcomes remain meaningful and relevant to people affected by neuromuscular disorders.

4. What to expect before and during the workshop

Before the workshop

Before attending the workshop, you will receive:

- Information about the workshop topic and programme
- Travel and accommodation information
- Information about your role during the workshop

An introductory online meeting may also be organised to explain the workshop aims, your contribution and answer any questions.

The ENMC office will assist with:

- Accessibility arrangements
- Accommodation requirements
- Dietary requests
- Transport between the airport and the venue

Participants are encouraged to communicate any requirements as early as possible.

During the workshop

ENMC workshops usually take place from Friday afternoon (12.30 PM) until Sunday (12.00 PM). The workshop takes place at the Courtyard Marriot Hotel, Bosweg 15 Hoofddorp, 2131LX The Netherlands.

Participants are encouraged to attend the full programme. Workshops are interactive and involve presentations, discussions, and group sessions.

All participants are expected to give a presentation and to take part in the discussions.

During the workshop:

- You will hear presentations from researchers and clinicians
- Participants will discuss research priorities and future directions
- Unpublished scientific information may be shared
- Everyone is encouraged to participate and ask questions

It is normal if some discussions feel technical or unfamiliar. You are not expected to understand every scientific detail. Your personal experiences and perspectives are highly valuable.

Participants may step out of sessions if they feel tired or overwhelmed.

5. How to prepare for the workshop

You can prepare for the workshop by:

- Reading the workshop materials in advance
- Writing down questions or topics you would like to discuss
- Speaking with your patient organization, if you represent a wider community
- Learning about the workshop topic and current challenges in the field

6. Confidentiality and data protection

Because workshops may include unpublished scientific or clinical information, all participants are asked to sign a confidentiality agreement before the workshop begins.

Participants are also asked to consent to the processing of personal data in accordance with GDPR regulations.

ENMC handles personal information responsibly and only for workshop-related purposes.

7. Travel, accommodation and reimbursement

ENMC will cover the following:

- Hotel accommodation (booked by ENMC)
- Meals during the workshop
- Travel expenses (see below)
- Shuttle bus transport between Schiphol Airport and the venue (in case of special requirements, transport will be booked by ENMC)

Travel reimbursement policy:

- Travel should be booked as early as possible (booked by patient/patient representative)
- Travel costs for all participants are covered by the ENMC. Participants from Europe will be eligible for reimbursement of travel expenses, with a maximum limit of **€ 300**. Participants from outside Europe will be eligible for reimbursement of travel expenses, with a maximum limit of **€ 1000**.
- Travel costs in the country of origin (taxi, car, train, parking) are not refunded. Should you travel to Hoofddorp by car, € 0.29 per kilometre can be refunded (also up to a max. of € 300). If you are traveling by train, ensure you arrive at Schiphol Airport train station.

8. Accessibility

ENMC workshops take place in an accessible venue suitable for individuals with mobility or other support needs.

The ENMC office can assist with:

- Accessible hotel rooms
- Special transport arrangements
- Dietary requirements
- Medical or mobility support needs

9. Carer

In case a carer is needed to accompany you during the workshop, ENMC will cover the following:

- Hotel accommodation (double occupancy)
- Meals during the workshop
- Travel expenses (see chapter 7)
- Shuttle bus transport between Schiphol Airport and the venue (in case of special requirements, transport will be booked by ENMC)

Maximum one person can accompany the patient. The carer has in principle no seat in the workshop.

10. After the workshop

At the end of the workshop, participants may collaborate on a short summary describing the workshop outcomes in lay language.

After the workshop:

- Travel expenses should be submitted within two months after the workshop for reimbursement.
- The lay summary is reviewed and published on the ENMC website
- Participants may be invited to review reports and translations
- Scientific reports are prepared for publication in (peer-reviewed) journals

11. Contact

For questions regarding the workshop, please contact the ENMC office (enmc@enmc.org).