



## THE ENMC GRANT APPLICATION TEMPLATE NEEDS TO BE FILLED IN ACCORDING TO THESE GUIDELINES

#### INTRODUCTION

The European Neuromuscular Centre (ENMC) aims to encourage and facilitate collaborative research within the field of neuromuscular diseases (NMD). In order to foster this, the ENMC financially covers the costs of workshops on NMD topics and organises and hosts the workshops.

Workshop proposals should be based on well-focused topics relevant within the neuromuscular field. The organisers of a workshop are responsible for the scientific aspects of the programme and the composition of the inviting participants' list. This list should be according to ENMC's requirement to balance the specialisms, countries and different perspectives in the meeting. All workshops are held in The Netherlands and take place during the weekend to allow full participation by invitees.

Within five years after the workshop, organisers will be asked about the impact of their workshop for the neuromuscular research and patient community.

## 1. Workshop formats

## Regular, 3 days' workshop

Friday 13.30 - 18.30 hrs Saturday 08.30 - 18.30 hrs Sunday 08.30 - 12.00 hrs

Number of participants is 20-26 (including Early Career Researchers and Patient representatives)

Location: Courtyard Marriott Hotel in Hoofddorp, The Netherlands, nearby Schiphol Airport.

Alternative timetables are allowed (see below). This should be discussed with the ENMC office **before** submission.

## 1 1/2-day workshop:

Friday 13.00 - 19.00 hrs Saturday 08.00 - 13.30 hrs

Number of participants is 15-20 (including Early Career Researchers and Patient representatives)

Location: Courtyard Marriott in Hoofddorp, The Netherlands.

## 2. Participants

#### General

Participants are expected to join the workshop for its full duration. Organisers may propose a reserve list.

Organisers should not come from the same institution and avoid from the same country, unless there is a rationale for doing so.

An organiser can't be an Early Career Researcher at the same time.

It's recommended to avoid having more than one participant from the same institution, unless there is a rationale for doing so.

## Agreements

To enable sharing of unpublished data and create a safe discussion environment, the ENMC confidentiality agreement will be sent before the start of the meeting and needs to be signed by all participants. If someone cannot sign the confidentiality agreement, they will not be allowed to attend the meeting.

In compliance with European data privacy laws, all participants are informed—and must give their consent—that their personal data will be stored in the ENMC registry "Tribe" and that they will become members of the ENMC network.

Participants who do not agree to have their personal data stored and used for these purposes should contact the ENMC office at **enmc@enmc.org** to explore alternative communication methods.

For more information about your rights under European data protection laws, please refer to the ENMC website.

# Participation of Early-Career Researchers, Patient representative(s) and Industry representatives

The participation of 1 to 3 Early-Career Researchers, clinicians, or paramedics is **mandatory**. Support for their involvement is available through the ENMC Early-Career Programme.

Early-career participants are expected to actively contribute by presenting their research, helping to prepare the lay summary and co-authoring the full workshop report. If their contributions are substantial, they may be listed as co-authors alongside the workshop organisers. Please refer to the application forms available on the ENMC website.

The participation of at least one, and preferably more (up to a maximum of four), patient representative(s) is **mandatory**. Ideally, this should be an individual directly affected by the neuromuscular condition that is the focus of the workshop.

The role and expected contribution of the patient representative(s) must be clearly described in the workshop application.

If no patient representative is included in the participant list, a well-reasoned justification must be provided.

If you need assistance in identifying a suitable patient representative, please contact the ENMC office.

Industry representatives may be invited to participate in the workshop in an active role (e.g., as a speaker or session chair), provided there is a clear rationale for their involvement. They may also be invited as observers (with no active role) in cases where they are co-funding the workshop. Industry representatives are not counted toward the maximum number of participants.

The ENMC requires that, if industry representatives are invited—either as participants or observers—at least two different companies must be represented to avoid potential bias. All travel and accommodation expenses for industry representatives must be fully covered by their respective companies.

## 3. Funding policy

The ENMC covers accommodation expenses (including hotel, meals, and venue costs) for all participants, **excluding industry representatives**.

Travel expenses (flight/train tickets) for all participants—including early-career researchers, patient representatives, and their caregivers—are reimbursed by the ENMC up to a maximum of €300 for participants from Europe and €1,000 for those traveling from outside Europe.

To receive reimbursement, participants must submit a completed claim form along with the original travel documents to the ENMC office **within two months** of the workshop. Claims submitted after this deadline will not be processed, and it will be assumed that reimbursement is not required.

Although ENMC provides travel reimbursement (up to €300/€1,000), additional co-funding is often necessary, especially when a large number of participants are traveling from outside Europe due to limited ENMC resources.

Workshop organisers are therefore expected to propose co-funding opportunities (e.g., from patient organisations and/or industry) in their application. They should also keep the ENMC office informed and collaborate closely on securing such co-funding.

#### 4. Submission and deadlines

#### **Submission**

Workshop applications should be submitted to the ENMC office via email at **enmc@enmc.org**. The ENMC office will confirm receipt of your application. If you do not receive a confirmation, please follow up with the office to ensure your application has been received.

#### **Preview**

If you would like the ENMC office to perform an eligibility check, please submit your application at least two weeks before the official submission deadlines of 1 March or 1 September.

#### **Review Process**

Applications are reviewed twice a year by the ENMC Research Committee, typically in April and November.

<u>Please note</u>: Incomplete applications will not be reviewed. Applications are considered incomplete if they include:

- An incomplete programme (e.g., missing titles of presentations, names of speakers or session chairs, or the timeline), and/or
- An incomplete participant list (e.g., missing names or exceeding the maximum of 26 participants).

Applications submitted after the deadline will not be included in the review round.

### **Decision and Follow-up**

Organisers will be informed of the final decision **within three months** after the submission deadline.

The ENMC office, Research Director, and members of the Research Committee (RC) are available to discuss the content of the application and provide feedback based on the RC's suggestions.

The outcome of the review will be one of the following:

- Definite approval
- Conditional approval (subject to minor revisions)
- Re-application required (major revisions needed)
- Rejection

If the application is approved—either directly or after minor revisions—a workshop date will be assigned.

A dedicated ENMC Workshop Coordinator will be appointed to work closely with the organisers, participants, early-career researchers, and patient representatives to prepare and facilitate the workshop.

If the application is not selected, the organisers will be invited to revise and resubmit it for the next review round, taking into account the RC's feedback.

Please note: Applications may only be resubmitted once.

## 5. Workshop logistics

The ENMC office sends an official invitation and the workshop programme to each participant of the selected workshop, along with detailed information regarding organisational matters (e.g., hotel arrangements, local transfers, travel reimbursement policy, etc.).

Participants are responsible for booking their own travel to the workshop location.

If any adjustments to the workshop programme are required, the final version must be submitted no later than two weeks before the start of the workshop.

### 6. Mandatory reports

Lay summary for dissemination on the website of the ENMC and to its partner patient organisations and Company Forum, co-written with or at least reviewed by the patient (and/or patient representative/advocate) to guarantee their input in the document. This lay summary should be provided to the ENMC office within <a href="two-weeks">two-weeks</a> following the workshop. Participants are asked to help with translations of the lay report in several languages for a broad dissemination to patients and their families.

**Full report**, should be submitted to Neuromuscular Disorders within <u>6 months</u> following the workshop.

In agreement with Neuromuscular Disorders, the traditional four authors of the ENMC workshop report can now be extended with maximally three extra names of those Early-Careers who are proactive and efficient contributors to both the workshop and the writing of the full report.

(see the lay report template and full report guidelines on the ENMC website).