



ENMC collaborative workshops - toolkit for persons directly involved with a neuromuscular disorder

This toolkit provides an overview of the ENMC workshop, the processes relevant for the conduct of the workshop and reporting of the workshop outcomes. It describes what is being expected from you as a patient representative, how you can prepare at and make arrangements for the workshop.

ENMC PatientPlus toolkit – *persons directly involved with NM disorder*



Office of the ENMC in Baarn, NL

(shared with Dutch patient organisation Spierziekten Nederland)



ENMC strategic workshop June 2012 (Musholm, DK)

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1. Introduction

The mission of the ENMC is to encourage and facilitate communication and collaboration in the field of neuromuscular research with the aim of improving diagnosis and prognosis, finding effective treatments and optimizing standards of care to improve the quality of life for affected people and their families.

This mission of the ENMC is accomplished through the organization of workshops (approximately 8 per year) which represent the core activity. The workshops usually take place in a conference hotel in the Netherlands lasting from Friday afternoon to Sunday lunch time. Around 20 scientists, clinicians and patients representatives attend. The aim is to share new ideas and the latest research advances followed by a discussion on work in progress and the next steps. A summary of the workshop is subsequently published in the Journal of Neuromuscular Disorders.

The workshops are aimed to be interdisciplinary to encourage a lively debate between the different experts working in clinical and basic research and the people who are affected with a neuromuscular disorder, being pre-eminently the 'day to day experts'. All participants are being given an active role to achieve the set outcomes of the workshop. The aim is to establish a long-lasting collaboration between basic scientists, clinicians and patient representatives resulting in improvements in diagnosis, development of treatments and the definition of care pathways for all neuromuscular disorders.

2. Why a patient toolkit?

At the time the ENMC was founded in 1991, the main aim of the workshops was to define diagnostic criteria and accelerate the pace of research in understanding the underlying genetic and molecular mechanisms of muscle and nerve wasting. Five years ago this strategic focus slightly changed with the addition of practical care workshops - discussing practical aspects of everyday patient care, e.g. the role of exercise training and management of pain and fatigue. To stimulate patient participation in the workshops, the Patient Plus Program was initiated at a strategic meeting that took place in 2012. The current toolkit has been developed as part of this Program to provide you with information and guidance and to give you advice on what to expect and how to prepare when planning to take part.

3. Why is participation by you, your relatives and patient advocates in ENMC workshops so important?

- The ENMC was originally founded by individuals directly or indirectly affected by a neuromuscular condition.

- It is a core value of the ENMC that the voice of individuals directly or indirectly affected by a neuromuscular condition is heard at the patient workshop to ensure the research and the topics discussed have the utmost relevance for patients.
- By being present at workshops, individuals affected by a neuromuscular condition, their families and advocates raise awareness among scientists and researchers of matters that are important in daily life. It raises issues that otherwise might be overlooked.

4. What can you, your relatives and patient advocates contribute to workshops?

- As an individual directly affected by a neuromuscular condition or as a partner or parent from someone with a neuromuscular condition you will be able to bring expertise to the meeting that clinicians, researchers and care professionals will not have. For example, you will be able to ask questions that clinicians and/or researchers may not consider in their daily routine.
- From a survey conducted in 2012, we learnt that participants of ENMC workshops do value the participation and input from patients and others directly or indirectly affected by a neuromuscular condition.
- You will also be able to raise awareness of what it means to live with the disease from day to day.
- Your participation will ensure that the focus of the research will remain relevant for the needs of affected individuals.
- Your participation will enhance the dialogue between researchers, clinicians and care professionals and their patients and will build a vital bridge between research and daily living with the condition.

5. What can you expect if you have been invited to participate?

- You will receive information about the workshop and the program from the ENMC office.
- You will be asked to make your own travel arrangements for your journey to and from the meeting venue (which usually is in the vicinity of Amsterdam Airport, Netherlands). The staff at the ENMC office will assist you in planning your journey and for taking care of special requirements that you and/or your accompanying person may need.
- The ENMC workshops typically start around 2 pm on a Friday afternoon and will last until 1pm on Sunday (including lunch). Workshop participants are asked to take part in the entire workshop; the return flight should therefore preferably be scheduled not before 4 pm on Sunday.
However, if you feel that you will not be able to take part for the whole length of the

workshop please let the staff in the ENMC office know so that it can be considered in the programme, where appropriate.

- During the workshop a large amount of potentially new information will be shared among the participants. Not all the information will be equally relevant and/or understandable to all participants – please feel free to skip certain lectures or discussions if you feel that you cannot contribute or if you feel exhausted.
- You will be reimbursed for your travel. The costs for the hotel, meeting and meals are directly covered by the ENMC and if required, you can bring a carer.
- The hotel is located in the center of the Netherlands, it is easy accessible, has a large parking area and has fully adapted rooms. Please inform the ENMC office of any special requirements for transport to and from the meeting venue, and also let ENMC know if you have particular dietary requirements and/or other services you need during the meeting.
- You will spend a weekend of hard work together with leading researchers and clinicians in the area of your condition to discuss topics in an interdisciplinary and open way.
- You will hear the views of the scientists and clinicians on the workshop topic and you are encouraged to directly interact with them and share your experiences and views as somebody directly affected by the condition.
- The ENMC has made participation of individuals directly or indirectly affected by a neuromuscular condition mandatory. Your participation is very important as a source of information for the scientific community and it is crucial that your “voice” will be heard.
- By participating and communicating your views to the other participants you are able to influence the direction of the research.

6. How can you prepare?

- You will receive comprehensive information about the workshop by mail in a timely manner including background information on all participants.
- Consult one of the workshop organizers (directly or via the ENMC office) in case you have any questions that require clarification prior to the workshop.
- If you are representing a patient organization or patient advocacy group liaise with them about the items that should be discussed and/or clarified during the workshop.
- Visit the ENMC website about how the ENMC is organized so you have a general idea about the topics being discussed.

7. What happens at the start of the workshop?

- An ENMC representative will give you a short introduction into the ENMC and will provide practical guidance during the workshop. The participants of the workshop will then introduce themselves and one of the organizers of the workshop will formally start the meeting.
- Because unpublished scientific data may be shared amongst participants, all attendees will be asked to sign a confidentiality agreement before the start of the meeting.

8. What expenses will be covered?

- Please make your travel bookings as early as possible so that you benefit from the cheapest possible air or train fare.
- Airline or train tickets will be reimbursed up to € 300,-. There might be special circumstances that require an airfare of more than € 300,-. However, this will need to be approved by the ENMC office before booking otherwise the amount exceeding € 300,- might not be reimbursed.
- Please note that travel costs in the country of origin (taxi, car, train, parking) are **NOT** covered.
- The ENMC will arrange and cover transport from Schiphol airport to and from the meeting venue.
- Should you travel to the workshop venue by car you can claim € 0.29 per kilometer.

9. How accessible are ENMC workshops?

- The ENMC workshops always take place in a hotel that is adapted for individuals with a neuromuscular condition and will be able to consider any special requirements you might have. The ENMC management assistant will work with you beforehand to arrange as much is possible.

10. What happens after the workshop?

- At the end of the workshop the participants will discuss a draft outline of the lay summary report ('lay statement') of the workshop. This workshop summary (approximately 1 page) will be completed and posted on the ENMC website within one week after the workshop has taken place.
- The lay report will be prepared with input of you as the patient representative who followed the presentations and discussions of the workshop. You should ensure that you

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have appropriate time to review the lay summary and feedback any comments or amendments you might like to make.

- Subsequently, this lay report will also be distributed through the ENMC network and placed on the ENMC website.
- The scientific workshop report will then be written by the workshop organizers and this report should also be reviewed and approved by all participants of the workshop.
- After publication of the workshop report in the peer reviewed Journal of Neuromuscular Disorders (usually 6-12 months after the workshop date) the ENMC office will disseminate the report through its network and will make it accessible through the ENMC website.



The screenshot displays the ENMC PatientPlus toolkit website. At the top left is the logo for the European NeuroMuscular Centre. The main content area is titled 'WORKSHOP REPORTS' and features a report on 'Newborn screening for DMD'. The report includes the following details:

- Date:** 2012-03-12
- Number:** 102
- City:** Naarden, The Netherlands
- Organized by:** The Dutch Duchenne Repeat Project, The Dutch Duchenne Repeat Project, Parent Project Muscular Dystrophy (USA)

The report also lists the organizers: Dr. E. Munton (United Kingdom), Dr. E. Unger (The Netherlands) and Dr. J. A. Sla (United Kingdom). The workshop was held on 10th-11th December 2012 in Naarden, The Netherlands. The report discusses the aim of the workshop, which was to assess the value of newborn screening programs for Duchenne muscular dystrophy, and the results of the workshop, which were published in the Journal of Neuromuscular Disorders.

