

NorPEN Executive Committee Meeting

November 24, 2023, 13.00-15.00 CET

Present: Lotte Rasmussen (chair of the meeting), Carolyn Cesta, Maurizio Sessa, Jacqueline Cohen (note taker), Angela Lupattelli, Heidi Taipale, Mika Gissler, Arto Puranen, Chaitra Srinivas, Maarit Leinonen

1. Approval of the minutes from last meeting

Minutes from the meeting on October 24, 2023 were approved

2. Election of the new EC members

PhD students

- Chaitra Srinivas, Norwegian Institute of Public Health, volunteered for the regular position but plans to serve for <1 year; therefore, we elected two substitutes
- Saad Hanif Abbasi from University of Southern Denmark elected as substitute member
- Alexis Christine Carson from University of Oslo elected as next substitute

Register holders

- Maarit Leinonen, Finnish Institute for Health and Welfare (THL)
- Heini Kari, Social Insurance Institution of Finland (KELA)

Iceland

- Larus S Gudmundsson, University of Iceland

Society representatives

- Lina Steinrud Mørch has stepped down from the board of the Danish Pharmacoepidemiological Society, and we therefore need to find a replacement for her. Lina is in the process of finding a replacement potentially from the Danish Society (no need to vote).

3. Presentation of feedback from NorPEN members and discussion of the bylaws

The updated NorPEN bylaws were approved with only one minor change based on feedback from one member group.

4. Preliminary status on Oslo 2023

There were 113 participants in total: 95 registered as attendees, 10 committee members, and 8 invited speakers. It was appreciated that we were all in the same session (i.e. no parallel sessions) and that we included poster presentations. We could anticipate having posters again, which were added based on the volume of abstracts received. Jackie asked for input on the feedback survey and will include questions about the pre-conference course, presentation formats, and suggestions for next year's meeting (Copenhagen 18-20 Nov, 2024 - Role of AI in advancing pharmacoepidemiology).

The committee discussed the format and content of the course. More advanced topic is preferred to basic one since the focus is on PhD students and researchers. Preparation material could help a diverse audience prepare. It was encouraged to have clear description of courses so that people can see what level is required beforehand. Previously there were two parallel sessions with one for register holders. A more basic course could be offered with a flipped classroom design, but we have limited time/resources.

PhD event was late so they did not have time to play mini-golf, but there was good networking.

If there are left-over funds, we aim to use them to support NorPEN, ideally transferring the funds from NIPH/UiO to The Norwegian Pharmacoepidemiology Society which provided scholarships this year for two students to attend NorPEN.

5. NorPEN 2024 in Copenhagen

Maurizio gave a detailed plan for NorPEN 2024 at the end of the conference and said that this was a proposal and that plans could change with further input. It was raised that there were few women on the scientific committee and more effort could be made to achieve better gender balance.

6. Update from education group

PhD survey was launched just before the annual meeting, with a deadline Dec 11. Angela will prepare the output. Ingvild Odsbu and Laura Pazzagli are planning the schedule for the next seminars

7. Initial discussion of roles and responsibilities of the representatives for societies and register holders

What purpose do we want these positions to serve? What resources/contacts do they need to achieve their purpose?

Register holders

How do the current representatives go about representing the register holders? Who is in their contact list? Are the register holders in contact?

There is no official communication, and most contact/networking was around the NorPEN meeting and a few workshops. Room for improvement. A suggestion was made the representatives could collect contact information, and then ask for annual updates from the different registers about changes or new legislation that could affect use of register data. This could be shared at the NorPEN annual meeting. The EC role is usually held by Norway and/or Finland, which may be due to policies by some registers in Denmark and Sweden that limit employee's involvement in research. All of the EC members could help identify the right contacts – health data authority, statistical agencies – ideally someone who understands the research use and the content of the registers. Another possible task of the register holders representatives could be to plan a parallel workshop for registry holders during NorPEN meeting.

Society representatives

Society representatives was not present at the meeting but their role could be to maintain a list of contacts and request annual updates from the societies. We will discuss more in 2024 when we have the new representatives.

8. Goals for 2024

New tasks for next year? New aims for NorPEN? New subgroups?

Sharing basic exercises for learning R (Lotte will check the PE group at SDU), basics of GitHub, computer sciences/data management

NorPEN common data model subgroup tailored to drug utilization and safety studies – first task could be to identify what models exist within NorPEN, e.g. CARING project, NorPreSS. Something regarding this could be put in our newsletter (see below).

9. Content for the first annual newsletter

Aims to showcase the activity of the network. First newsletter will introduce the executive committee and new members, provide a summary and highlights from this year's meeting, provide some NorPEN news, e.g. updated bylaws, major projects/publications, seminars, upcoming NorPEN. Carolyn and Lotte will draft and send to the EC for input with aims to finalize in January.

10. AOB

Status on GDPR overview: each country representative will be responsible to remind current member group leaders to fill the GDPR form

We plan to have a shared folder with previous applications for funding NorPEN

Discussed the possibility that NorPEN 2026 could be in Norway instead of Finland so that we can plan in conjunction with the Nordic Conference on Epidemiology and Register-Based Research in Tromsø. The chair of the Norwegian Epidemiological Association (NOFE) has invited us via Angela to collaborate. Present representatives from Finland open to swapping to 2027 instead of 2026. We will keep discussing this during 2024.

11. New date in January for the first meeting with new EC members

Lotte will chair, Carolyn will be notetaker. Date will be discussed later.