

NorPEN executive committee

**Face-to-face-meeting**

9-11 CET, 14 November 2019

NorPEN 2019, Aarhus, Denmark

Present: Leena Saastamoinen (chair, registry holders), Kasper Kristensen (PhD students), Øystein Karlstad (NO), Larus Steinþór Guðmundsson (IS), Sirpa Hartikainen (FI), Miia Artama (pharmacoepi societies), Carolyn Cesta (organizing committee), Lotte Rasmussen (DK).

Chair: Leena

Secretary: Lotte

**1. Welcome**

Leena welcomed everyone.

**2. What is NorPEN? E.g. giving opinions, example: open call from EMA on big data.**

**Goal: Discussing the purpose of NorPEN and possibilities to enlarge the purpose. Bylaws: “The purpose of NorPEN is to facilitate research within the field of pharmacoepidemiology in the Nordic countries, through scientific meetings and research collaboration.” §2**

NorPENs role in given opinions (on e.g. open call from EMA on big data) was discussed. It was suggested that NorPEN could give general opinions e.g. about importance of pharmacoepidemiology. This would be facilitating research, as stated in the bylaws. Specific opinions will not be given by NorPEN. Preliminary discussion on the needs of writing a general statement about the importance of pharmacoepidemiology was postponed to the next TC.

The challenges with the GDPR was briefly discussed. A general opinion on the challenges with GDPR may be addressed in the article which is under construction.

The possibility to include non-Nordic countries (e.g. Scotland, the Baltic countries) as members of NorPEN was discussed. Pros and cons were discussed. There is an increasing interest in participating in NorPEN meetings. Too many members will make it more difficult to organize NorPEN meetings. The bylaws do not state that the research groups in NorPEN have to be Nordic. However, according to the bylaws, the purpose of NorPEN is to facilitate research in the Nordic countries and the Executive Committee shall include representatives from one research group in each of the five Nordic countries. This means that a research group outside of Nordic countries would not have a possibility to have a representative without a change in bylaws. Based on the discussion it was decided that non-Nordic countries can not be members of the NorPEN, and no new member status will be created for this purpose. However, we will invite non-Nordic countries to participate in the yearly meetings and make sure to include them in the Nordic research.

**3. Discussion on funding possibilities, both research and networking activities – NO and EU: Hedwig, DK: Lotte, FI: Sirpa, SE: Helle, IS: Larus**

**Goal: To enhance Nordic studies, to show NorPEN members the possibilities, to learn from succeeded applications.**

Lotte (DK), Sirpa (FI) and Larus (IS) presented funding possibilities from their country.

From Denmark: Novo Nordisk Fonden and the Lundbeck Foundation (both for meetings and conferences). Another option was “Styrelsen for Forskning og Uddannelse” which supports researchers who want to establish an international network (<https://ufm.dk/en/research-and-innovation/funding-programmes-for-research-and-innovation/eu-and-international-funding-programmes/international-cooperation/international-network-programme-1/international-network-programme>).

From Finland: In Finland there are no foundations or other funding possibilities that give funding to promote Nordic collaboration. In most topic orientated foundations, it is good to have international collaboration in the application. However, in these applications Nordic collaboration is no better than any other international collaboration.

From Iceland: Grant possibilities from The Nordic Council of Ministers and the Nordic Council are the main forums for official Nordic co-operation, which involves Denmark, Finland, Iceland, Norway, Sweden, the Faroe Islands, Greenland and Åland.

Their “vision is to make the Nordic region the most sustainable and integrated region in the world.”

So, if we find ways to show how we improve sustainability and integration then we have a chance here, especially if we involve Faroe Islands, Greenland and Åland. [www.norden.org](http://www.norden.org)  
Common data models, sustainability in coding, organization, structure, and format of analysis datasets and related metadata may be considered sustainability related.

The Nordic Cancer Union Research Grant

“The Nordic Cancer Union (NCU) provides funding to support and stimulate collaborative cancer research within the Nordic countries. Researchers working in two Nordic countries or more must be involved in the project. The research project must be cancer relevant and uniquely suited to be carried out within the Nordic countries, and the effect of collaboration should be synergistic.”

See examples or grants from The Nordic Council of Ministers and the NCU in Addendum below.

It was concluded that except from NordForsk and the Nordic Cancer Union, specific grants supporting Nordic research are limited in all countries. Most grants are topic specific.

Representatives from Norway and Sweden will present funding possibilities at next TC.

#### 4. Discussion on financing from industry

**Goal: Making a decision on NorPEN financing possibilities to the future. Bylaws: “NorPEN shall work in a transparent and independent manner.” §2 “NorPEN shall alliance with the national pharmacoepidemiological societies, the national register holders and the public authorities to promote inter-Nordic pharmacoepidemiological research collaboration.” §3**

Direct sponsoring by the industry of the yearly NorPEN meetings was discussed. Several challenges were raised, e.g. that some members of NorPEN are not allowed to organize meetings if they are directly sponsored by the industry. In general, independent funding options should be explored before industry-sponsored possibilities. Options for funding of meetings by industry-financed foundations will be decided on a case-by-case basis, like the financing of Lundbeck Foundation at NorPEN 2019.

#### 5. Developing NorPEN

**Goal: To look at the list from 2019 and setting new goals for 2020.**

Status:

- There are currently two on-going papers. It was decided to keep on-going papers as part of the agenda for future TCs.
- The discussion of making a think tank in google docs will be continued at next TC (Hedvig).
- Sharing experiences with development of common data models (CDMs) was discussed, e.g. publishing CDMs from on-going projects. It was suggested to include a CDM-workshop for researchers at next year's meeting in Stockholm where researchers can share their experience from on-going projects using CDMs. The ex com talked about inviting Morten Andersen to a future TC to tell about his experience with CDM. The discussion of CDM is an important part of the aim of NorPEN and therefore this was put as a goal in 2020.
- Education and training: there was a brief discussion of the status of exchange possibilities. It was discussed whether it should be put on the webpage that exchange between Nordic research groups is possible. The discussion will continue on next TC.

New goals:

- Funding options and development of CDM will be prioritized.

## **6. Deciding the new members for the Executive Committee**

**Candidates for the Executive Committee (ordinary, substitute):**

**IS: Ólafur B. Einarsson, Larus S Gudmundsson**

**DK: Lotte Rasmussen, Vera Ehrenstein**

**Register holders: Leena Saastamoinen, Maarit Leinonen**

**PhD students: Mikkel Höjlund, Sarah Hjorth Andersen**

The candidates above were elected. Carolyn Cesta will be adjunct member on behalf of organizers.

## **7. Choosing process of the chair of NorPEN**

**Goal: To discuss how the chair of NorPEN should be chosen. Bylaws: *"The Executive Committee shall elect a chairperson and secretary among themselves." "Decisions are made by open vote unless unanimously decided otherwise. At tie the chairperson has the casting vote."* §11**

The bylaws on this topic was discussed. It was decided that the chair will be elected in January every year. The ex com should remind themselves of the election approximately six months before the election of a new chair.

The existing practice of chairing the executive committee meetings in turns was also discussed. This was still regarded as a good practice, because this will ease the burden of the actual chair and provide others to bring their opinions and ideas forward.

## **8. Next Skype meeting (Chair: Leena, Notes: to be decided)**

Next TC: 30/01/2020 at 13.00 (DK time)

Chair: Leena

Notes: Helle Kieler.

## 9. End of the meeting

### Addendum

#### **Here are examples of grant proposals and grants from The Nordic Council of Ministers**

Here are examples for calls for proposals:

- Initiatives for cooperation among Nordic diplomatic missions to promote Our Vision 2030
- Kontrakt om kartlegging av strategier, tiltak og metoder og formidling av disse på området forebygging av negativ sosial kontroll og æresrelatert vold

Here are examples of grants:

- Initiatives for joint branding of the Nordics by diplomatic missions
- The Nordic Council of Ministers Open Call Funding Opportunity for Nordic-Russian co-operation

#### **Here are examples of NCU grants awarded in relation to treatment and or chemotherapy**

Jakola, Asgeir S. -- Disulfiram response as add-on to chemotherapy in recurrent glioblastoma. Sahlgrenska University Hospital and St. Olavs Hospital. 40.000 EUR

Engholm, Gerda -- NORDCAN development. Differences in cancer survival in the Nordic countries: the role of stage at presentation, treatment, comorbidity and education  
Danish Cancer Society. 50.000 EUR

Rodriguez-Wallberg, Kenny Alexandra. -- An investigation of GnRH $\alpha$  exposure in connection with cancer treatment: Effects on fecundity, cancer recurrence and death  
Karolinska Institutet and Karolinska University Hospital. 40.000 EUR