

BMSD Network – TC 3 meeting

Date: 08 April 2025 8:00 – 9:00 CET

Venue: Microsoft Teams meeting

Attendees: Massimiliano Copetti, Jenni Lilian Dalsgaard, Jiří Drahota, Frederik Elberling, Katharina Fink, Gregor Fistravec, Lars Forsberg, Anna Glaser, Tommaso Guerra, Jan Hillert, Pietro Iaffaldano, Hanna Paulina Joensen, Giuseppe Lucisano, Melinda Magyari, Luigi Pontieri, Marco Salivetto, Maria Trojano, Anneke Van Der Walt

Meeting Agenda

1. **Update CC:**
 - a) Next BMSD F2F 2025 meeting
 - b) Update on BMSD funding
 - c) Update on the BMSD website
2. **Update EMA qualification opinion:**
 - a) CDM
 - b) Feasibility study
3. **Research project proposal:**
 - a) Feedback on the project application submitted by the Danish team (Melinda)
4. **Statistical Meeting in Matera: preliminary program**
5. **ECTRIMS 2025: booth reservation**
6. **Other**

Main discussion points

1. Update CC:

- a) Next BMSD F2F 2025 meeting

Maria gave an update about the registered participants at the BMSD meeting in Matera. Most of the people invited completed the registration. Reminders will be sent to define the list of participants.

- b) Update on BMSD funding

Maria said that Juvisé Pharma is interested in the BMSD initiative and can support the network with funding, which needs to be defined. Anna clarified that the BMSD budget at the Karolinska Institute ended in 2024.

- c) Update on the BMSD website

Marco shared the latest updates on the website's public and restricted areas. Network members who want to access the restricted area need a personal account with credentials. To get them, they can send an email to bigmsdata@fismets.it. The governance page of the public area was also updated with the list of members of the Steering and DM Committees. On the home page, a counter showing some numbers of the network will be added.

2. Update EMA qualification opinion:

- a) CDM

Jiri shared the abstract for the ECTRIMS Congress on the CDM. All agreed to send the abstract for a poster presentation. To finalise the abstract, Jiri needs the number of patients included in the CDM. Participants agreed that the information on mean age at onset can be included without additional approvals/consents from each registry.

Jiri also suggested submitting another abstract about the identification of the eligible "PASS population" through the CMD, in terms of counts and data completeness. This abstract could be sent as a late breaking abstract at the end of June if it were not ready by the 10th of April.

Jiri updated the members that the manuscript on the CDM needs to be enriched with indicators and specific data to increase the likelihood of being accepted by Lancet Digital Health.

3. Research project proposal:

a) Feedback on the project application submitted by the Danish team (Melinda)

Melinda updated the network about the status of the Danish project. The Swedish, Italian, and French registries will participate. The OFSEP Scientific Committee will evaluate the project at the beginning of June.

Maria added that she would like to dedicate a session for new and ongoing projects at the BMSD meeting, and invited members to propose their contribution. Melinda suggested that the Danish study could be presented at that time.

4. Statistical meeting in Matera: preliminary program

Pietro presented the current draft of the agenda for the BMSD Statistical Meeting. Lars proposed to give a presentation on FedLite, a federated learning package for R which is currently capable of running logistic regression between registries. FedLite is part of the MoreEuropa project, and includes data from the Danish, Swedish, Czech and Italian registries.

Melinda suggested inviting Thomas Gerds, a professor in statistics she knows and who works at the University in Copenhagen, to give a talk on predictive models.

Pietro added that also discussants and facilitators need to be defined.

5. ECTRIMS 2025: booth reservation

Marco showed the current floorplan and the reserved booths.