

BMSD Network – TC 5 meeting

Date: 13 May 2026 8:00 – 9:00 CET

Venue: Microsoft Teams meeting

Attendees:	Jiří Drahota, David Ellenberger, Katharina Fink, Lars Forsberg, Anna Glaser, Orla Gray, Tommaso Guerra, Kerstin Hellwig, Jan Hillert, Dana Horáková, Pietro Iaffaldano, Pernilla Klyve, Giuseppe Lucisano, Melinda Magyari, Elena Flavia Mouresan, Luigi Pontieri, Marco Salivetto, Alexander Stahmann, Maria Trojano, Clemens Warnke
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Meeting Agenda

1. Collaborative Projects
2. Data Sharing Among Registries
3. Update from the Finnish MS registry
4. ACTRIMS/ECTRIMS: Printing Service
5. BMSD Annual Meeting in Genoa: Participants and Programme Draft

Main discussion points

1. Collaborative Projects

The following updates were shared for each project:

a) De-escalation Project (Danish Group):

Luigi reported that a reminder will soon be sent where each registry will be asked to run the R script, preferably on the most updated data extraction. He suggested testing the script on the current data to identify any potential errors. The Danish group would like to receive the results from the script by the beginning of September. While the Italian, French, and Swedish registries have already obtained approval for the project, the German and Czech registries are finalising the last administrative steps before proceeding. If possible, preliminary results will be shared during the annual meeting in Genoa.

b) Gender Inertia Project (French Group):

The Italian Registry confirmed that the project has been approved by its Scientific Committee and that its feasibility has been tested. The Danish group reported that they are already working on two projects related to this topic and remain open to contributing to a joint publication. The German group confirmed that work is ongoing, while the Czech group is finalising the internal approval process to analyse their data. The ultimate goal is to produce a series of publications from each registry and/or a joint publication.

c) Prevalence and Predictors of Postpartum Disease Activity in Women with RRMS after Preconception Cladribine Treatment (French Group)

The Italian MS Registry has discussed the project internally. The Danish group is currently working on the initiative; however, they need to link their dataset with the national pregnancy registry, and pointed out that the data cannot be shared outside Denmark. The Swedish group also reported that they need to perform data linkage. MS Base confirmed that they collect pregnancy data in a separate field and are willing to join the project. Regarding the German group, Alexander reported that German Registry led by Kerstin is a long-established data source focused specifically on pregnancies and could be involved in the study. Kerstin noted that while they are already working on the project, the current numbers are too small to identify any predictors for postpartum relapses. Finally, the Czech group is finalising the internal approval process to begin data analysis.

d) MS TEAM Project (Czech Group)

The Scientific Committee of the Italian Registry will discuss the project in June.

e) Project on Ponesimod from Juvisé

Maria will reach out the representative from Juvisé to ask the German Registry to be contacted.

2. Data Sharing Among Registries

As anticipated during the previous TC, a preliminary online meeting with legal experts from each registry will be scheduled before the summer holidays. The aim is to discuss a simplified legal framework that allows each registry to share data among network members. A survey will be shared shortly to identify suitable dates for this meeting.

Jan reported that Sweden is currently undergoing a transitional period regarding the management of national quality registries; consequently, they are encountering difficulties with the administrative approvals required to initiate scientific projects.

3. Update from the Finnish MS Registry

The Finnish MS Registry is currently working on the implementation of the script. Results of the CDM implementation are expected before the summer holidays. Once completed, this will finalise the process for the Finnish Registry to officially join the network.

4. ACTRIMS/ECTRIMS: Printing Service

Marco informed the group that posters for the exhibition booth can be printed on-site in Toronto. It was agreed that the following new posters will be prepared: the BMSD criteria for the inclusion of new MS registries, the results of the EMA QO application, and a description of the NMOSD/MOGAD populations collected by each registry. An email will be sent shortly to request the descriptive data required to prepare the NMOSD/MOGAD poster.

5. BMSD Annual Meeting in Genoa: Participants and Programme Draft

Participants who booked flights independently are requested to share their arrival and departure times to organise the event logistics. Proposal of topics to be discussed during the meeting were shared, as detailed below:

- EMA Qualification Opinion (QO)
- Updates on BMSD Common Data Model (CDM)
- Collaborative Research Projects
- Procedures of Data Sharing Among Registries
- NMOSD/MOGAD Data Sharing or Comparison Between Registries
- PROMS Data Collection
- ACTRIMS/ECTRIMS 2026 BMSD Booth Presentation

Luigi proposed allocating sufficient time to the CDM, suggesting that a dedicated session for data managers could be organised during the event. Melinda suggested that when discussing collaborative projects, time should be allocated to establishing clear timelines and commitments in order to better organise future work.