

Making Swiss cohort data better findable:

Call for letters of intent

Switzerland has a long tradition of high-quality cohort studies, collecting a large variety of health-related data. In order to exploit their full potential, the further use of these cost-intensive data collections - in accordance with regulatory requirements - must be enabled and promoted. Cohorts contain typically highly structured data, they are thus very interesting in the context of SPHN, and may allow to address other questions than clinical routine data with a view to personalized health research. Therefore, it must be of high interest of the SPHN research community to catalogue metadata of cohorts and make them findable and accessible.

As an important step in this direction, the Swiss Personalized Health Network (SPHN) started a collaboration with the Maelstrom research team¹ to bring information about Swiss cohort data to an internationally renowned catalogue², in order to increase the findability and usability of these data sets. The Maelstrom catalogue is already serving the metadata dissemination of more than 240 studies from across the world, grouped into several international networks, and provides a user-friendly solution for data discovery.

In a first pilot phase, meta-data of a first set of Swiss cohorts has been catalogued according to the Maelstrom schema, allowing researchers to search and identify cohorts that include data relevant for their research study. This important step will not only foster the reuse of data, but also promote new national and international research collaborations.

After completion of the pilot-phase, SPHN would now like to motivate further Swiss cohorts to bring their metadata to Maelstrom.

The Swiss Cohort Consortia Network (Maelstrom catalogue)

The Maelstrom Catalogue follows a standardized approach to document and disseminate epidemiological study metadata. The study description model and variable classification scheme developed are being used to create comprehensive study metadata catalogues in numerous collaborative projects from all over the world. The catalogue contains comprehensive information about epidemiological research networks and studies including the data that have been collected, thus providing a user-friendly solution for data discovery.

The Maelstrom Catalogue comprises search tools that allow users to:

- learn about existing research networks;
- identify studies with targeted designs that collected information useful in answering specific research questions;
- search for variables collected within and across studies;
- obtain information about harmonization potential across studies and harmonized variables generated.

¹ Maelstrom Research: <https://www.maelstrom-research.org/>

² Maelstrom Catalogue: <https://www.maelstrom-research.org/page/catalogue>

In 2020, SPHN founded the Swiss Cohort Consortia Network on Maelstrom. For its pilot-phase, the network will encompass the metadata of five Swiss cohorts with an overall of approximately 17'000 variables ([link](#)).

Participation requirements and conditions

Financial support:

For the selected cohorts, SPHN will cover the costs incurred on the Maelstrom side (2000-5000 CHF depending on the number of collected variables). This includes the preparation of the study description with general meta-data information and the mapping of all the variables collected until the time of the application. The matching funds principle applies, i.e., the cohort must match the funds provided by SPHN to cover the costs on the Maelstrom side with its own contributions (in cash and/or in kind). There will be no financial contribution to the individual cohorts with regards to the preparation of codebooks.

Eligibility criteria:

- The cohort must be managed by a not-for-profit organization based in Switzerland
- The main applicant must be employed by a Swiss higher education institution (ETH Domain, universities, universities of applied sciences) or university hospital;
- The cohort must be publicly funded with a clearly defined funding schema;
- The cohort covers a relevant medical and/or public health research field;
- The cohort must involve more than one institution (multi-centric) or be of special interest (e.g., population-based with extensive pheno/genotyping);
- The cohort needs to be able and willing to share their data with third party researchers;
- The cohort has proven scientific output (i.e., relevant peer-reviewed publications are available).

Formal requirements for the application:

Swiss cohorts joining the Swiss Personalized Health Network Cohort Consortium need to provide their codebooks including variable names, description and value set to Maelstrom. Participating cohorts must be able to ensure the compatibility of their data dictionary with Maelstrom requirements, and to carry on the coordination work together with Maelstrom cataloguing coordinators. This may include:

- Work on the data dictionaries (if needed):
 - Selection of the variables metadata to be displayed on Maelstrom (full data dictionary recommended);
 - Overhaul of variable description;
 - Data dictionary format conversion. Preferred formats include: SAS, SPSS, STATA and Excel;
 - Variable transformation.
- Project coordination:
 - Providing the necessary documentation and feedback for the establishment of the study description;
 - Feedback during the cataloguing work;
 - E-Mail exchanges with Maelstrom coordinators

How to apply?

The deadline for the submission of letters of intent is 30/06/2021. Letters of intent should be sent by email in English to info@sphn.ch. In the letter of intent, the applicants express their interest to join the Swiss Cohort consortia on the Maelstrom catalogue and are expected to provide the following information:

Applicant responsible for communication with SPHN

- Name
- Employer
- Position
- Phone number
- E-mail address
- Acknowledgement of the need for the provision of own contributions in the case the application is approved for funding

Acknowledgement of compliance with the Ethical Framework for Responsible Data Processing
General Information about the cohort

- Area/Main focus
- Scientific relevance of the cohort for other researchers
- Study design
- Start and end Year
- Total number of participants
- Total number of variables collected
- Total number of biological samples collected
- Type of biological samples collected
- Type of consent / re-usability of samples

Populations

- Description of the subpopulations of participants
- Selection criteria
- Number of participants per subpopulation
- Data collection events
- Number of follow ups
- Start and end year of each collection event or follow-up
- Data types (e.g., health data, socioeconomic data, lifestyle data, genomics)

References, important publications on the cohort design (cohort marker paper)

Review and selection process

Review and selection:

The letters of intent will undergo a formality check by the SPHN Management Office (MO) and will be evaluated by the SPHN Cohort and Registry Task Force³ according to the criteria mentioned above. The SPHN National Steering Board (NSB) selects the cohorts to be funded. In case of approval, the amount of matching funds that have to be provided by the cohort will be communicated to the applicant in a ruling. Upon acceptance of the grant, the host institution(s) has to provide a commitment letter specifying the amount of matching funds that will be provided.

Timeline:

Deadline for the submission of the letters of intent: 30/06/2021

End of the evaluation by the Task Force: 31/08/2021

Decision and communication: End of September 2021

Beginning of the project: 1/10/21

Legal basis

This call for letters of intent is published in accordance with the Funding Regulations of SPHN and with the mandate of SERI. Selected cohorts will be funded under the category of “Infrastructure Development” projects for a maximum of 12 months. This call document describes the specific requirements and details regarding the application and evaluation procedures. Unless defined in this document, the provisions of the Funding Regulations of SPHN apply.

On the full or partial approval of the application (award), the applicants become grantees of SPHN. Grantees are obliged to comply with the conditions set out in the ruling, in the SPHN Funding Regulations and all other rules applicable to the grant.

³ SPHN Task Forces: <https://sphn.ch/organization/task-forces/>

Funding

The funds provided by SPHN are 100% earmarked to cover the costs incurred on the Maelstrom side and will be directly transferred to the SPHN Data Coordination Center (DCC) for that purpose.

Matching funds must be reported in the final report, no later than 3 months after the cohort metadata has been deployed in the Maelstrom catalogue.

Costs incurred by Maelstrom and not matched by own contributions (up to the amount specified in the ruling and host institution's commitment letter) have to be paid by the main applicant.

If the prerequisites for the award are no longer met after approval of the award or if the circumstances on which approval is based change considerably (e.g., milestones are not reached), SPHN may amend or revoke the approved award and:

- a. If the grant has not yet been transferred, it may amend or withhold it.
- b. If the grant has already been transferred, it may demand partial or full repayment of the grant.

Prior to taking such measures, SPHN will hear the parties concerned and communicate the amendment or revocation in the form of a ruling.

Questions

For questions regarding the content of this call please contact the SPHN Data Coordination Center at dcc@sib.swiss. For administrative questions please contact the SPHN Management Office at: info@sphn.ch.