

Brief summary of national SIMSAM meeting in Umeå 2013-11-04--05

The open conference “Using registers for research – SIMSAM five first years and beyond” was successfully organized by the Umeå node 4-5 November, 2013, at Umeå University. During the first day principal investigators of SIMSAM nodes and of SINGS (the graduate school) presented a wide spectrum of achievements, challenges, lessons learned and tips with respect to their efforts during the first SIMSAM period 2009-2013. Numerous PhD students are/have been trained via SINGS and at the nodes in using registers in research. Also many postdocs, visiting and senior scientists have (had) the opportunity to work with the goldmine of Swedish register data and to present their results as peer-reviewed publications and at national and international meetings. Meetings, courses and seminars have been arranged by nodes/SINGS with various foci such as methods development, data management, study design as well as more research specific topics.

In order to investigate and improve the quality of register data, validation studies have been performed. Nodes and SINGS have promoted using registers in research via debate articles and an information booklet developed together with the project SIMSAM-INFRA (see below). Competent administrative/data management staff together with skilled biostatisticians were identified as success factors. Also a specific “study protocol strategy” for streamlining and speeding up the research process was recommended. Fruitful collaboration with respect to registers has taken place between nodes and for instance Statistics Sweden (SCB), the National Board of Health and Welfare (SoS) and the Swedish National Data Service (SND). However, also lengthy processes for ethical vetting and retrieving data from central authorities were described.

The second day, Øystein Kravdal (Norway) and Elsebeth Lynge (Denmark), members of the international Scientific Advisory Board (SAB) of SIMSAM, provided Nordic perspectives on research using registers. In addition, emphasis was again put on the importance of documentation (for instance on coverage and variables) and on the benefit of facilitating Nordic collaborations.

The last session included information on national coordination of SIMSAM by Xavier de Luna (Umeå University) and an update on the project SIMSAM-INFRA by Magnus Stenbeck (Karolinska Institutet). Among other things Magnus promoted the recently established new web portal www.registerforskning.se. This web site contains general information about available registers and biobanks at Swedish government agencies and organizations, information on legislation, and when appropriate, links to information held by other data owners.

Bengt Westerberg provided an interesting and positive update on his ongoing investigation on the prerequisites for register based research in Sweden. Bengt will probably suggest new legislation making it possible to build wide purpose research registries (e.g. Life Gene), that relevant authorities should have "support to research" included in their basic instructions, and that the key for pseudonymised research data bases normally should be saved for, perhaps, 10 years.

The meeting was concluded by a panel discussion focused on the future of research using registers and biobanks. The discussion was moderated by Lars Weinehall (Umeå University, UmU) and panel members were: Anders Brändström (UmU), Johan Carlsson (Swedish Institute for Communicable Disease Control, SMI), John Hobcraft (SAB, UK), Beatrice Melin (UmU), Nancy Pedersen (Karolinska Institutet) and Bengt Westerberg. Panel members agreed that future legislation should allow maximal accessibility of register data via methods providing adequate safety. Simplicity, consistency and focus on research infrastructures were emphasized. The importance of communicating with the public was highlighted together with the need of educating/training both researchers and representatives of governmental agencies in relevant matters. The importance of proper documentation and metadata was further stressed.

For additional information on the presentations given during the conference, please access <http://simsam.nu/past-events-and-presentations/>.