

Brief summary

The open conference “Registry-based research in Sweden – past, present and future” was organized by the UGIR node 25 April, 2013, at Eugeniahemmet (Karolinska University Hospital). In the first session, “Opportunities and limitations”, SIMSAM and its activities during 2013 were described. Also the pros and cons of register-based research were presented including comparing benefits and drawbacks of randomized controlled trials with those of observational studies. The importance of socioeconomic factors was highlighted, not only as common confounding factors, but also as mediators. Perspective on the requirement for and establishment of a nationwide register, the Prescribed Drug Register, was provided. Finally ethical issues related to register-based research and the importance of scientists to maintain public trust was emphasized. “Long-term goals might not always be reached by short term actions”.

In session number two, “Fund giver perspectives”, the background to and developments of SIMSAM and SIMSAM-INFRA were presented by Vetenskapsrådet. Also the Swedish Council for Working Life and Social Research (FAS), soon to be known as the Swedish Council for Health, Working Life and Welfare, is supporting register-based research by different grants. However, FAS is unable to provide funding for infrastructure aspects. When the Ministry of Education and Research provided their perspective discussions/questions focused on judicial and structural aspects. It was emphasized that since 2008 universities are in charge of infrastructures related to register-based research. Perhaps lessons could be learned from the recent UK report from the Administrative Data Taskforce: “[Improving Access for Research and Policy](#)”.

In the last session, “For improved health”, a number of studies using cancer registers were described and the importance of hypothesis driven research was highlighted. Also the term “register-based research” was questioned. Studies with genetically informative designs were praised since these provide possibilities to understand mechanisms and familial factors, to test for causality and to identify preventive measures.

For additional information on the presentations given during the conference, please access PDF versions at: <http://simsam.nu/events/historic-events/>.