

SIMSAM



Information exchange - MEB

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MEB site visit 20 February, 2013

Overview

- Introduction – Anna Holmström
- SIMSAM background + developments
- MEB ↔ SIMSAM

SIMSAM



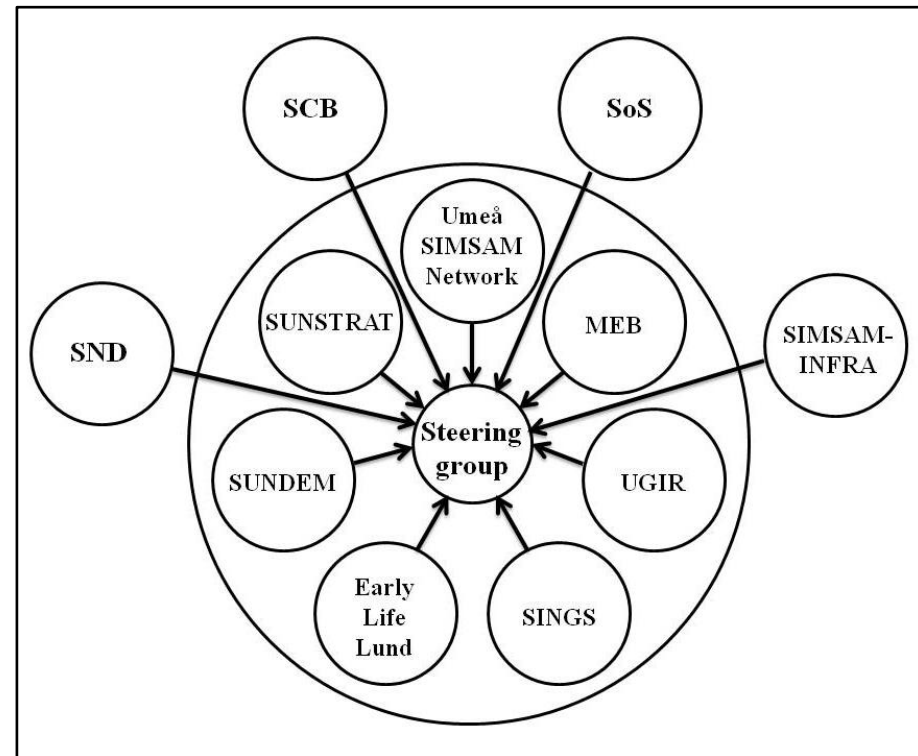
Swedish Initiative for Research on **M**icrodata in the **S**ocial **A**nd **M**edical Sciences

Introduction – Anna Holmström

- PhD molecular biology
- Post doc at European Molecular Biology Laboratory, Heidelberg
- Project manager at Swedish Defence Research Agency (FOI)
 - Virus research
 - Projects funded by Ministry for Foreign Affairs
- Spring 2011 - SIMSAM network coordinator
 - 50% national network
 - 50% Umeå node
 - Dept. of Public Health and Clinical Medicine
Unit of Epidemiology and Public Health, Umeå University

SIMSAM Organisation

- VR: 27 million SEK/year, Dec. 2008 - Nov. 2013
- 6 research nodes + graduate school (SINGS): National SIMSAM Network
 - Karolinska Institutet (KI) 2 nodes
SINGS
 - Stockholm University (SU) 2 nodes
 - Lund University (LU) 1 node
 - Umeå University (UmU) 1 node
- Steering group
- Umeå node - coordinating role
- National coordinator 50%
- Scientific advisory board
- Web page simsam.nu



SIMSAM Vision

To create a world leading research community for register-based research for health and welfare

SIMSAM



Swedish Initiative for Research on **M**icrodata in the **S**ocial **A**nd **M**edical Sciences

International scientific advisory board

Irma Elo

University of Pennsylvania

- * Socioeconomic and racial/ethnic differences in health and mortality
- * Migration and health
- * Early life conditions and adult health and mortality
- * Neighborhood context and health
- * Demographic methods

John Hobcraft

University of York

- * Life-course and longitudinal analysis
- * Interplays of genetic and epigenetic and social sciences
- * Pathways to child and adult wellbeing and disadvantage

Öystein Kravdal

University of Oslo

- * Socioeconomic resources
- * Health
- * Mortality
- * Fertility
- * Family Behaviour

Elsebeth Lyng

Copenhagen University

- * Register-based health research including mortality and cancer incidence/evaluation of cancer screening programs

Anders Skrondal

Norwegian Institute of Public Health

- * Statistics, biostatistics, social statistics
- * Psychometrics

The National SIMSAM Network

SIMSAM Early Life Lund (LU)

- Interdisciplinary research on early life exposure and health
- Division of Occupational and Environmental Medicine, Centre for Economic Demography, Swedish University of Agricultural Sciences (SLU)



The SIMSAM MEB node (KI)

- Transmitted and acquired determinants of health across the life-span
- Dept. of Medical Epidemiology and Biostatistics

The SUNDEM node (SU)

- Register-based research in Nordic Demography
- Demography Unit (SUDA) of Department of Sociology + Dept. of Human Geography

The National SIMSAM Network

The SUNSTRAT node (SU)

- Social stratification dynamics
- The Swedish Institute for Social Research (SOFI)

The Umeå SIMSAM Network (UmU)

- Microdata research on childhood for lifelong health and welfare
- Dept. of Public Health and Clinical Medicine
 - * Div. of Epidemiology and Global Health
 - * Div. of Occupational and Environmental Medicine
- Dept. of Statistics
- Dept. of Geography and Economic History
- Dept. of Sociology

The National SIMSAM Network

Upper Gastrointestinal Research (UGIR, KI)

- Register-based research of diseases and surgery of the upper gastrointestinal tract
- Dept. of Molecular Medicine and Surgery

SINGS (KI)

- Swedish INterdisciplinary Graduate School in register-based research.
- Cohort 1 (vt 2010 – vt 2012) n= 30
Cohort 2 (vt 2011 – vt 2013) n= 19
Cohort 3 (vt 2013 – ...) n= 28
- Retreat, courses, workshops + elective courses

The VR mid-term evaluation =>

- Terms of Reference document (steering group)
- Activity plan (steering group)
- Common scientific advisory board
- SIMSAM survey => SIMSAM data management group
- SIMSAM knowledge/information at <http://simsam.nu/>
 - News, events
 - Discussion forum
 - Competencies
 - Information on SIMSAM data + experiences

The SIMSAM-INFRA project

- Project manager - Magnus Stenbeck (KI)
- VR: 2 x 4 million SEK, report to SND board
- Priorities:
 - A. SIMSAM info + infrastructure => research community
 - B. New web site: info on available register data from central and regional/local authorities
 - C. Review + suggest legally acceptable security technology for distributed data systems involving person identified data
- A + B: Magnus Stenbeck + Anna Holmström (UmU)
- C: Magnus Stenbeck, Peter Somogyi (MEB, KI) + Joanna Forsberg (Uppsala University)

Developments related to register-based research in Sweden

- Investigation of SCB + system of the public statistics (121210)
- Suggest measures to facilitate register-based research (120502)
 - Coordinating authority
 - Research data board
 - Distributed data systems for person identified data
- Investigation of prerequisites for register-based research (140630)
 - Facilitate ability of authorities to provide information for research purposes taking into account the protection of the privacy of individuals
 - Facilitate co-processing of records for research purposes
 - Enable collection of personal data for registers kept for special and explicit research purposes and for longitudinal studies that are within the framework of such purposes, and at the same time safeguarding integrity
 - Examine if existing confidentiality of data handled in research is sufficient to protect the individual's integrity during the research process

Developments related to register-based research in Sweden and in the EU

- Research and innovation proposition of 2012:
 - VR: 25 mSEK 2013 + 50 mSEK/year until 2016
 - Facilitate register-based research
 - Provide information on available data sources and regulations
 - Direct support to researchers
 - Collaborate with the big data owners

- EU data protection regulation proposal
 - Reducing possibilities to continue and/or develop better systems for population register-based medical and social research
 - Additional demands on informed consent
 - Suggests deletion of the special standing of scientific research (possibility to use register data without consent or with a simplified procedure for consent)

SIMSAM calls from VR in 2013

- New call open
- Dead-line April 17
- 2014-2018
- Framework grants + graduate school
- 3-5 million SEK/year 2-3 million SEK/year (max 5 yrs)
- Info at VR + simsam.nu

SIMSAM activities 2013

- SIMSAM information booklet – Why register-based research?
- Data management group – share information (data + experiences)
- Dialogue with SoS och SCB – facilitate access to data for researchers
- Affect EU data protection proposal
- National meeting + meeting with SAB - Stockholm **25-26 April**
- National meeting + meeting with SAB - Umeå **16-17 October**
- SIMSAM knowledge/infrastructure => researchers via SIMSAM-INFRA

MEB views on info exchange?

➤ MEB => SIMSAM

- Hosted 2nd national SIMSAM meeting 110929-30
- Data management experience (DMG)

➤ SIMSAM => MEB : needs/requests?

SIMSAM



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