

SIMSAM



[www.simsam.nu](http://www.simsam.nu)

## SIMSAM and additional initiatives promoting Swedish register-based research facilitated by the Swedish Research Council

[www.registerforskning.se](http://www.registerforskning.se)

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Registerdata för forskning



# Overview

- The national SIMSAM network
- The SIMSAM-INFRA project
- [www.registerforskning.se](http://www.registerforskning.se)
- The VR assignment

SIMSAM



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

# The national SIMSAM network

- Aims
- Organization
- Focus of nodes + graduate school

SIMSAM



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

# Aim of SIMSAM

**Create internationally leading research community for register-based research, by:**

- conducting, supporting, initiating interdisciplinary research
- improving the quality of data
- enlarging pool of scientific knowledge produced
- supporting, sharing methodological developments to maximize the possibilities for the use of Swedish register data for research purposes
- encouraging, taking part in international research collaborations

SIMSAM



# SIMSAM organization(I)

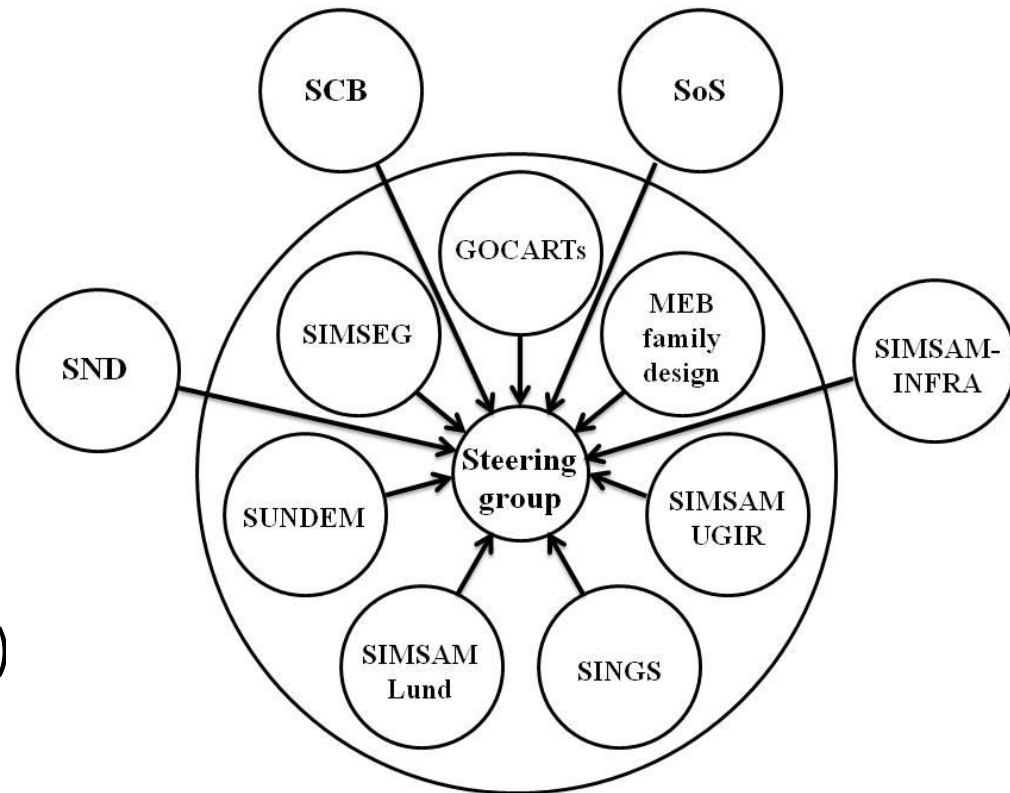
- The Swedish Research Council (VR): 27 million SEK/y in two 5y periods
- Framework grants + grant for a graduate school
- 6 research nodes + graduate school (SINGS):

## Period 2: Jan 2014 – Dec 2018

- |                                     |                                    |
|-------------------------------------|------------------------------------|
| ▪ Karolinska Institutet (KI)        | UGIR<br>MEB family design<br>SINGS |
| ▪ Stockholm University (SU)         | SUNDEM                             |
| ▪ Lund University (LU)              | SIMSAM Lund                        |
| ▪ University of Gothenburg (GU)     | GOCARTs                            |
| ▪ Institute for Future Studies (IF) | SIMSEG                             |

# SIMSAM organization (II)

- Steering group
- National coordinator 50%
- [www.simsam.nu](http://www.simsam.nu)
- Scientific Advisory board (SAB)



# SIMSAM Lund (LU)



- Interdisciplinary research on early life exposures in a life course perspective  
Division of Occupational and Environmental Medicine, Centre for Economic Demography,  
Centre for Health Equity Studies
- Study determinants of health during early life + contribution to educational success, active working life and healthy aging using Swedish microdata.
- Contribute to the development of new methods to analyze register data in a life course perspective.
- Promote infrastructures for research based on biobanks, surveys and registries via:
  - courses, seminars
  - webpage - advice on data access
  - a study advisory board directed towards young researchers and their supervisors
- Selected publications
  - Increased risk for gestational diabetes and preeclampsia among women who have been exposed to air pollution. (*EHP 2013*)
  - Cognitive reserve measured as score is an important early predictor of dementia. (*In review*)
  - Maternal smoking during pregnancy and daughters' risk of gestational diabetes and obesity. (*Diabetologia 2013*)

# SIMSAM MEB Family Design



- Unique registers and advanced family designs to address causes and consequences of common childhood disorders  
Dept. of Medical Epidemiology and Biostatistics (MEB), Karolinska Institutet
- Advanced family designs: within twin/sibling/cousin and within-individual designs
- Develop efficient statistical methods to address causal effects using genetically informed population based register data
- Studies:
  - large, longitudinal
  - appropriate measures of health and environments
  - designs account for familial confounding
- Selected publications
  - Critical need for family-based, quasi-experimental designs in integrating genetic and social science research. (Am J Public Health. 2013)
  - Observed association between maternal anxiety and adolescent asthma: children of twin design. (Plos One 2013)
  - Patterns of recurrence of postpartum hemorrhage in a large population-based cohort. (Am J Obstet Gyn 2014)



# SIMSAM UGIR (Upper Gastrointestinal Research)



- Registry-based research of three associated public health concerns: upper gastrointestinal cancer, reflux and obesity Dept. of Molecular Medicine and Surgery (KI)
- Aim: Fewer deaths, reduced morbidity and better health-related quality of life
- Strong clinical profile, 40 members, two co-located research groups
- Selected publications:
  - Centralisation of esophageal cancer surgery saves lives. (J Clin Oncol [IF 18] 2013)
  - Obesity surgery does not decrease obesity-related cancer, but increases colorectal cancer. (Ann Surg [IF 7] 2010 + 2013)
  - Surgery for heartburn does not prevent oesophageal cancer due to relapse in heartburn. (Gastroenterology [IF 13] 2010 + Ann Surg [IF 7] 2013)
  - Medication with tetracycline and cortison increase the risk of acute pancreatic inflammation. (Gut 2012 [IF 11] + JAMA Intern Med [IF 11] 2013)
  - Quality of life after esophageal cancer: Has prognostic value, decrease strongly in 15% of long-term survivors, is particularly reduced by acute complications. (J Clin Oncol x 4 [IF 18] 2010-2012)
  - Debate articles aiming at stimulating clinical scientists to use register data in their research. (Läkartidningen x 4 2010-2013 + Svensk Kirurgi 2012)

# SIMSEG (IF)



- Large-scale SIMulation models => understand how schools become SEGregated along socio-demographic dimensions, via statistical analyses of Swedish register data (1990 to 2012)
- The role of social interactions - how individuals' decisions to leave/enter a specific school are influenced by other individuals' past decisions.
- The effects of segregated school environments on the school performance of the students.
- Swedish register data - uniquely suited for studying these kinds of processes:
  - Longitudinal
  - Data on the entire population
- Highly interdisciplinary research team: social scientists, computer scientists, visualization experts, and applied mathematicians.

# SUNDEM (SU)



- Stockholm University SIMSAM Node for Demographic Research  
Demography Unit (SUDA) of Department of Sociology, Dept. of Human Geography
- SU expertise on migration and family dynamics + Nordic/European register researchers
- Expertise on space and time: spatial and longitudinal methods in register research
- Goal: produce research that exploits the unique qualities of register data
- Five main themes:
  1. Spatial careers
  2. Intergenerational demographic careers
  3. Immigrant demographic integration
  4. Interrelated demographic processes
  5. Research based on new household and dwelling data
- Selected publications
  - Families where the father uses long parental leave more likely to have another child. (J. Eur. Soc. Policy 2010)
  - Positive effects of “daddy months” on fathers’ parental leave use, but no effect of “gender equality bonus”.  
(J. of Eur. Social Policy 2012)
  - No difference in final number of children between women of different educational groups. (Dem. Research 2009)
  - Free school choice increases the variation in grades between schools. (Urban Studies 2013)
  - No negative effect of residential segregation on immigrants’ labor market integration. (Urban Studies 2009)

# GOCARTs (GU)



- GÖthenburgh Cardiovascular RegisTry Studies Dept. of Molecular and Clinical Medicine, Sahlgrenska Academy.
- Clinical research + cardiovascular epidemiology => unique platform for register-based research in cardiovascular diseases (CVD) and diabetes.
- New insights into clinical presentation, social distribution, management, complication rate and prognosis in various manifestations of CVD:
  - coronary heart disease, stroke, heart failure, grown-up congenital heart disease, diabetes
- Create strong research environment, researchers within medicine, statistics, social sciences + health economics, 40 members
- Selected publications
  - Dudas K, Lappas G, Stewart S, Rosengren A. Trends in out-of-hospital deaths from coronary heart disease in Sweden (1991 to 2006). (Circulation 2011;123:46-52. [IF 15.2])
  - Lind M, Bounias I, Olsson M, Gudbjörnsdottir S, Svensson AM, Rosengren A. Glycaemic control and incidence of heart failure in 20,985 patients with type 1 diabetes: an observational study. (Lancet 2011;378:140-6. [IF 39.1])
  - Rosengren A. Better treatment and improved prognosis in elderly patients with AMI: but do registers tell the whole truth? Eur Heart J 2012;33:562-3. (editorial)
  - Rosengren A, Giang KW, Lappas G, Jern C, Torén K, Björck L. Twenty-four-year trends in the incidence of ischemic stroke in Sweden from 1987 to 2010. (Stroke 2013;44:2388-93. [IF 6.2])
  - Barasa A, Schaufelberger M, Lappas G, Swedberg K, Dellborg M, Rosengren A. Heart failure in young adults: 20-year trends in hospitalization, aetiology, and case fatality in Sweden. (Eur Heart J 2014;35:25-32. [IF 14.1])

# SINGS Graduate School (KI) I



## Swedish INterdisciplinary Graduate School in register-based research

- Institute of Environmental Medicine (IMM)
- Steering group: SIMSAM nodes + other research groups
- Interdisciplinary profile
  - quantitative research disciplines; epidemiology, public health, sociology, demography, psychology, statistics, health economics, other medical and social sciences
- Objectives
  - thorough knowledge of existing registers
  - ability to identify + formulate problems, use appropriate methods to perform register-based research
  - capacity to perform and assess register-based research, following laws and research ethical principles
  - methodological + practical skills when undertaking register-based research
  - insight into the possibilities and limitations of register-based research
- Cross-fertilization between disciplines
- Communication within and outside the SIMSAM initiative

# SINGS Graduate School (KI) II



- 25-30 students/cohort – 12 HECs, 2 years
- Workshops and courses: core courses + elective courses (given by SINGS/others)
- Advanced courses in collaboration with Epi-program KI and others
- On-line seminars
- Extra "seats" at courses/workshops: non-SINGS students + post docs, advertised via [www.simsam.nu](http://www.simsam.nu) + nodes
- SINGS vacancies announced before summer
- First new cohort starts fall 2014
- Contact: [anita.berglund@ki.se](mailto:anita.berglund@ki.se) / 08-524 874 66 / 070-7986534

# The SIMSAM-INFRA project

- VR planning grant 8 million SEK (2012-2015)
- Magnus Stenbeck (KI) project manager
- SIMSAM infrastructure efforts => national resource
- Map actors contributing to identifiable data handling
  - [Registerforskning.se](http://Registerforskning.se)

[www.registerforskning.se](http://www.registerforskning.se)

- Information portal about Swedish register data for researchers
- Describes national resources + guidelines
- VR: develop + English version

The footer features a decorative design with a light green background. It includes a bar chart with several bars of varying heights in shades of green. Overlaid on this are scattered binary digits (0s and 1s) in a light green color. The text "Registerdata för forskning" is written in a white, sans-serif font across the middle of the footer.

Registerdata för forskning



# VR infrastructure for register-based research

- Assignment from the government: improve prerequisites for scientists to use Swedish register data.



- VR shall:

- Allocate 175 million SEK (2013-2016) for establishment of infrastructures for register-based research
- Whithin the agency establish an area of operation aiming at increasing the availability of and facilitating the use of register data for research purposes
- Support scientist with information on registers and on relevant legislation

# The VR assignment – 3 projects

1. Establishment of a Register Data Board
2. Provide functions for information, support and education related to register-based research
3. Improve the availability to registers for research purposes via coordination of data



# 1. The Register Data Board

- Established in 2014
- High level representatives of big data owners and national research community
- Provide advice to VR on issues related to register-based research
- Establish important decision with relevant authorities etc.
- Support VR's project: "Infrastructures for register-based research"
- Contribute to establishing a longterm, strategic area of operation => strengthen Swedish register-based research
- Support ongoing work focusing on harmonization of microdata at Nordic, European and international level

## 2. Provide functions for information, support and education related to register-based research

- Research community needs increased knowledge on
  - Existing registers
  - How to access registers
  - Relevant legislation
  - Integrity issues
  
- Establish a national function accessible via VR
  
- Dialogue with researchers, legal expertise and expertise at data owners => where/how to build the function
  
- Registerforskning.se starting point– VR take over, further develop

### 3. Improve the availability to registers for research purposes via coordination of data

- Different data sources:
  - Data at public authorities
  - Data from regional and local authorities (esp. health care quality registers)
  - Biological data
  - Data generated in research projects
  
- => different requirements (organization, legal, technical) =>
  - a) Data from authorities responsible for statistics (initially SCB + SoS)
    - VR dialogue with SCB + SoS => MONA-like remote access system at SoS
  
  - b) Data from authorities and data from research projects
    - Develop safe systems for connecting the data
    - Develop methods for deidentification and systems for safe storage of keys

# Additional issues

- Researchers want quicker access to data from SCB
  - Maybe a VR-funded SCB pilot project similar to Registerservice at SoS
- A need for updating and harmonization of web-based information at authorities (initially SoS + SCB)
- Contact person at VR: Maria Nilsson ([maria.nilsson@vr.se](mailto:maria.nilsson@vr.se))

# Future vision

