

# **SIMSAM-INFRA: Facilitating Register Based Research in Sweden**

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*National SIMSAM meeting  
Umeå, 5 September, 2013*

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# Complex landscape



Statistics Sweden:  
40 national registers  
and surveys of interest  
to health related  
research



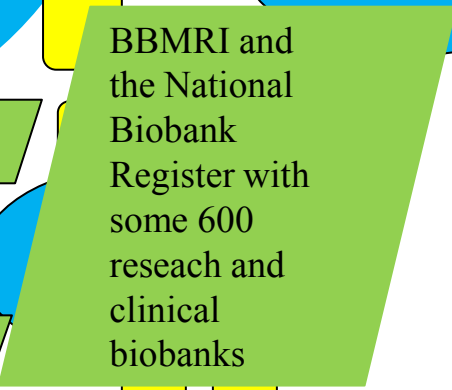
Health  
registers



12 central  
authorities  
with registers



100  
national  
health care  
quality  
registers



BBMRI and  
the National  
Biobank  
Register with  
some 600  
research and  
clinical  
biobanks

# Great new potential

- A rapid increase in the number of data sources
- Similar developments in the Nordic countries
  - Norway: Helsedataprojektet, national health registries, quality registries, Biobank Norway
  - Denmark: centralization of resources to SSI, Biobank Denmark
- Improved technical possibilities for data sharing
- Increased international collaborations

# Rapidly growing problems

- Outdated database handling systems
- Outdated systems for data sharing
- Outdated legislation
- Heterogeneous resources:
  - No coordinated or consistent information
  - Knowledge and technology among data providers
- Lack of legal competence in the researcher community

# Coordination needs =>

## The SIMSAM-INFRA application to VR:



”A coordinated infrastructure for population registers...” (2011)

<b>WP1 Project management</b>  <i>Magnus Stenbeck</i> <i>WP-responsible</i> <i>Competencies from relevant agencies (VR, SCB, SoS etc.)</i>	<b>WP2 Central registers</b> <i>Statistics Sweden (SCB), National Board for H&amp;W (SoS)</i>	<b>WP3 Healthcare quality registers</b> <i>Local authorities and regions</i>	<b>WP4 Researcher data</b> <i>SND, University of Gothenburg, UmU</i>	<b>WP5 Biobanks</b>  <i>LU + BBMRI</i>
<b>WP6 Databases/computing</b> <i>Swedish National Infrastructure for Computing</i>				
<b>WP7 Metadata/documentation</b> <i>Swedish National Data Service (SND)</i>				
<b>WP8 Legal and ethical aspects</b> <i>Uppsala University</i> <i>Stockholm University</i>				
<b>WP9 Researcher support</b> <i>SUNSTRAT/SU</i>				
<b>WP10 International collaboration</b> <i>Karolinska Institutet</i>				

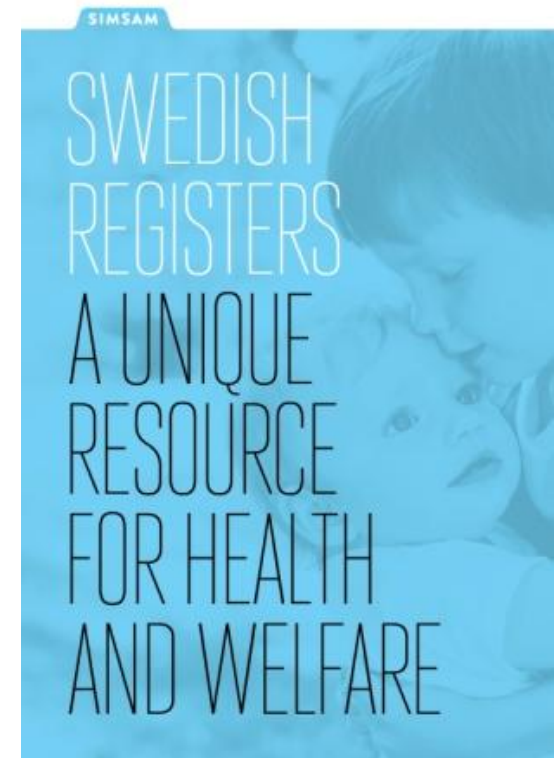
# SIMSAM-INFRA planning grant

- VR: 4 million SEK/year during 2012-2013 (2014)
- Map actors contributing to person identifiable data handling
- Infrastructure efforts of SIMSAM should develop into nationally available resource
- Continue technical developments for distributed data sharing
- Develop roadmap of national coordination of existing infrastructures (BBMRI, SNIC, SUNET, SCB, SoS etc.)
- Nordic coordination of infrastructure for person identified data

# Deliverables and output (I)

## ➤ A) Make the SIMSAM efforts visible

- Information booklet
- [www.simsam.nu](http://www.simsam.nu):
  - ✓ Data management information
  - ✓ SIMSAM competencies and contact persons



# Deliverables and output (II)

- B) [www.registerforskning.se](http://www.registerforskning.se) - a new web portal for researchers



## Välkommen till registerforskning.se

### News posts

VR continues to promote Swedish register based research via SIMSAM  
2013/11/04

The European Council summit pushes for a quick decision on

Registerforskning.se är tänkt att fungera som en informationsportal för forskare som är intresserade av befolkningsbaserade registerdata. Portalen innehåller övergripande uppgifter om tillgängliga register och biobanker vid myndigheter och organisationer, samt i förekommande fall länkar till de informationssystem som finns hos dataägarna. Webbplatsen tillhandahåller även övergripande information om lagstiftning och tekniska system för datahantering.

 Sitemap

### UPCOMING EVENTS

NOV 4 Mon	1:00 pm Open SIMSAM meeting on register-based research @ Umeå
NOV 11 Mon	all-day Conference on nonparticipation in public health and epidemiological



## Deliverables and output (III)

### ➤ C) Analysis of the ethical basis for the legislation on personal data protection

- Ethics behind current legislation
- Proposals for the future
- Report: "Etiken bakom juridiken"
- Letter in Science Magazine: "Beware Side Effects of Research Ethics Revision"



Registerforskning –  
Etiken bakom juridiken



## Deliverables and output (IV)

### ➤ D) Security solutions

- Review of security solutions etc. in the area of personal data for research  
=> propose legally acceptable security solutions for distributed (federated and other) data systems involving person identified data.
- Review of technical data protection systems (collaboration with BBMRI)  
=> report
- Collaboration initiated with Headlong Corp.  
=> develop the functionality of registerforskning.se and continue working on distributed solutions for data access.

# SIMSAM-INFRA project members

- Magnus Stenbeck
  - Project manager
  - Karolinska Institutet (Clinical Neuroscience/Insurance Medicine)
  
- Anna Holmström
  - [www.registerforskning.se](http://www.registerforskning.se) + make SIMSAM efforts visible
  - Karolinska Institutet (Clinical Neuroscience/Insurance Medicine)
  
- Joanna Stjernschantz-Forsberg (October 2012 – October 2013)
  - Ethics competence
  - Uppsala University (Centre for Research Ethics and Bioethics)
  
- Peter Somogyi (October 2012 – May 2013)
  - Technical data protection systems
  - Karolinska Institutet (Medical Epidemiology and Biostatistics)

# The future of SIMSAM-INFRA

- Funded by VR until 2014-12-31 (but new SIMSAM period 2014-2018?)
- [www.registerforskning.se](http://www.registerforskning.se) is to be included in VR's new function related to register based research (VR assignment based on SOU 2012:36)
- 2014:
  - Develop [www.registerresearch.se](http://www.registerresearch.se): for English language Swedish resident researchers and for international users. Requires much more development of "own content" than the Swedish version
  - Develop the functionality of the page to include user defined searches merging information in several data owner sites – the first step towards distributed data access?

# VR project for facilitating register based research

- 175 million SEK 2013-2016 targeted by the government
- VR Project manager 30% - Maria Nilsson (NordForsk)
- Reference group (Mats Ulfendahl, Kerstin Sahlin, Joakim Palme, Kjell Asplund)
- Research Data Council with Director Generals of SCB and SoS
- Plan "VR resident" functions for:
  - Information (*including [www.registerforskning.se](http://www.registerforskning.se)*)
  - Support
  - Training
- Increase accessibility to registers for research purposes - via coordination of data (*in collaboration with SIMSAM-INFRA*)
- "VR resident" functions may be performed by external contractors

Please visit [www.registerforskning.se](http://www.registerforskning.se),  
provide feed-back to [magnus.stenbeck@ki.se](mailto:magnus.stenbeck@ki.se)  
and [anna.holmstrom@umu.se](mailto:anna.holmstrom@umu.se)!



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