



The POPLINK database

Demographic Data Base
Centre for demographic and ageing research
Umeå University

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The Demographic Data Base at Umeå University

- Founded in 1973
- One of the first large-scale infrastructural initiatives within the humanities and social sciences in Sweden
- First managed by the Swedish National Archives, from 1978 as a permanent unit at Umeå University
- A national commission to build, store and give access to research databases based on Swedish population data (UHÄ-FS 1990:8)
- Data collection with an infrastructural purpose – not for particular research projects
- Data collected from parish records



Longitudinal population databases at DDB

POPUM

Population based, individual level data for the period **1700-1900**

- ✓ 4,8 million records
- ✓ c.700 000 unique individuals
- ✓ > 100 Swedish parishes

Socio-economic and demographic variables, causes of death, kinship links (spouses, parents-children) up to 11 generations.

POPLINK

Population based, individual level data for the period **1700-1950**

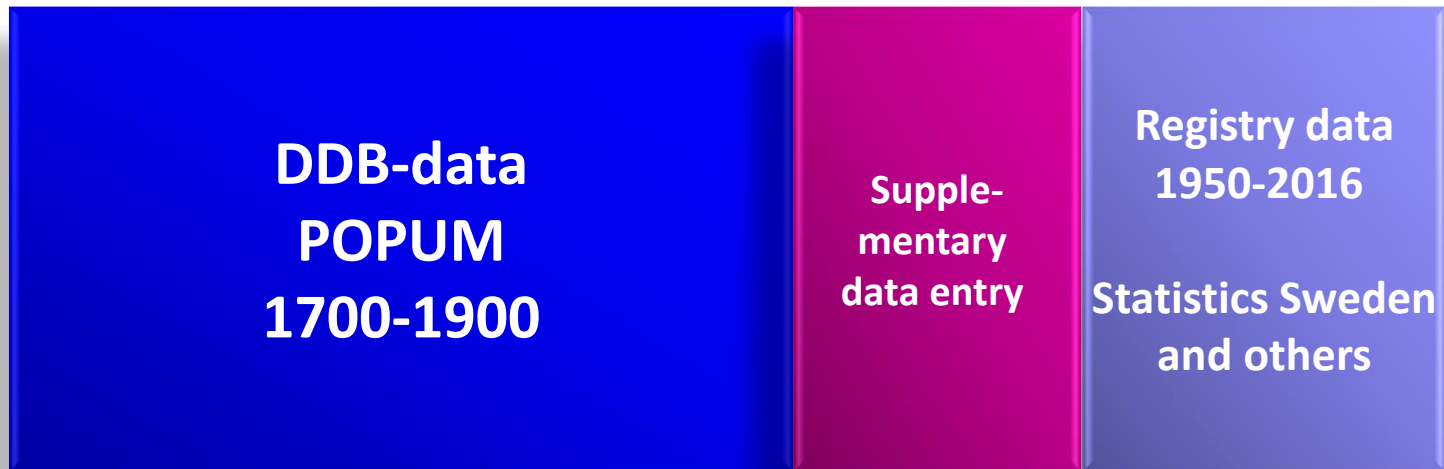
- ✓ Focus on the northern province of Västerbotten – synergies with biobanks and research registers
- ✓ 2,2 million records
- ✓ c.400 000 unique individuals, up to 15 generations

Can be linked to Swedish official registers, numerous research registers and biobanks.

Approval from ethical review board is required.

Covering the gap

← **POPLINK** →



1800

1900

2000

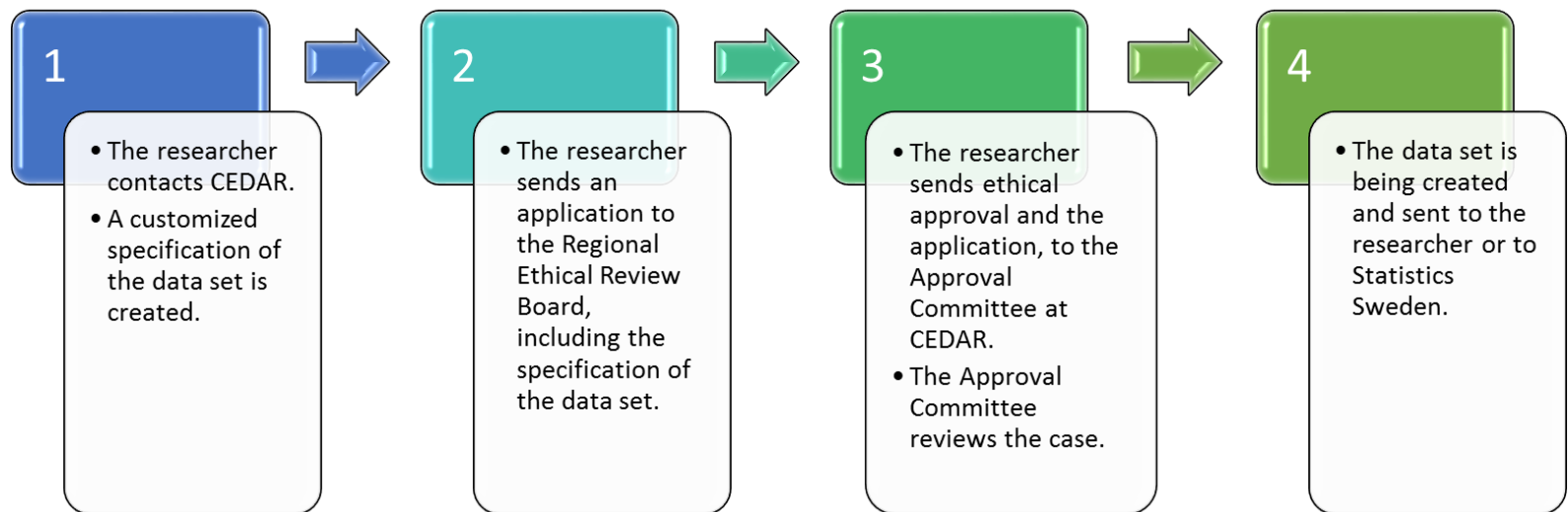
Covering the gap

- Supplementary data entry of parish records until c. 1950.
- Linkage between "old" and "new data" with automatic software. Quality of linkage tested and evaluated with good results. Improved data.
- Straightforward linkage with unique Swedish personal identity numbers introduced in 1947-1948.
- Persons without id-number are linked with conventional linkage variables and algorithms.
- Personal id-numbers also serve as a key to effective linkage between POPLINK and registers/databases/biobanks.
- Collaboration with Statistics Sweden, key-table for linkage to other databases

Legal impediments for registry based research in Sweden

- PUL Personal Data Act – governs the processing of personal data. The basic rule: data collection and processing is only allowed for specific and explicit purposes (eg. research projects) and with informed consent.
- Absence of legal support for permanent database-infrastructures outside government agencies, where data is collected for more general purposes.
- Certain data (race, ethnicity political opinions, religious beliefs, health etc.) are classified as sensitive and prohibited to process.
- Ethical Review Act and Ethical Review Boards. Approval of research concerning humans and human specimens. Personal data, sensitive data, issues relating to consent.
- Changes hopefully on their way – committees are preparing a new bill.

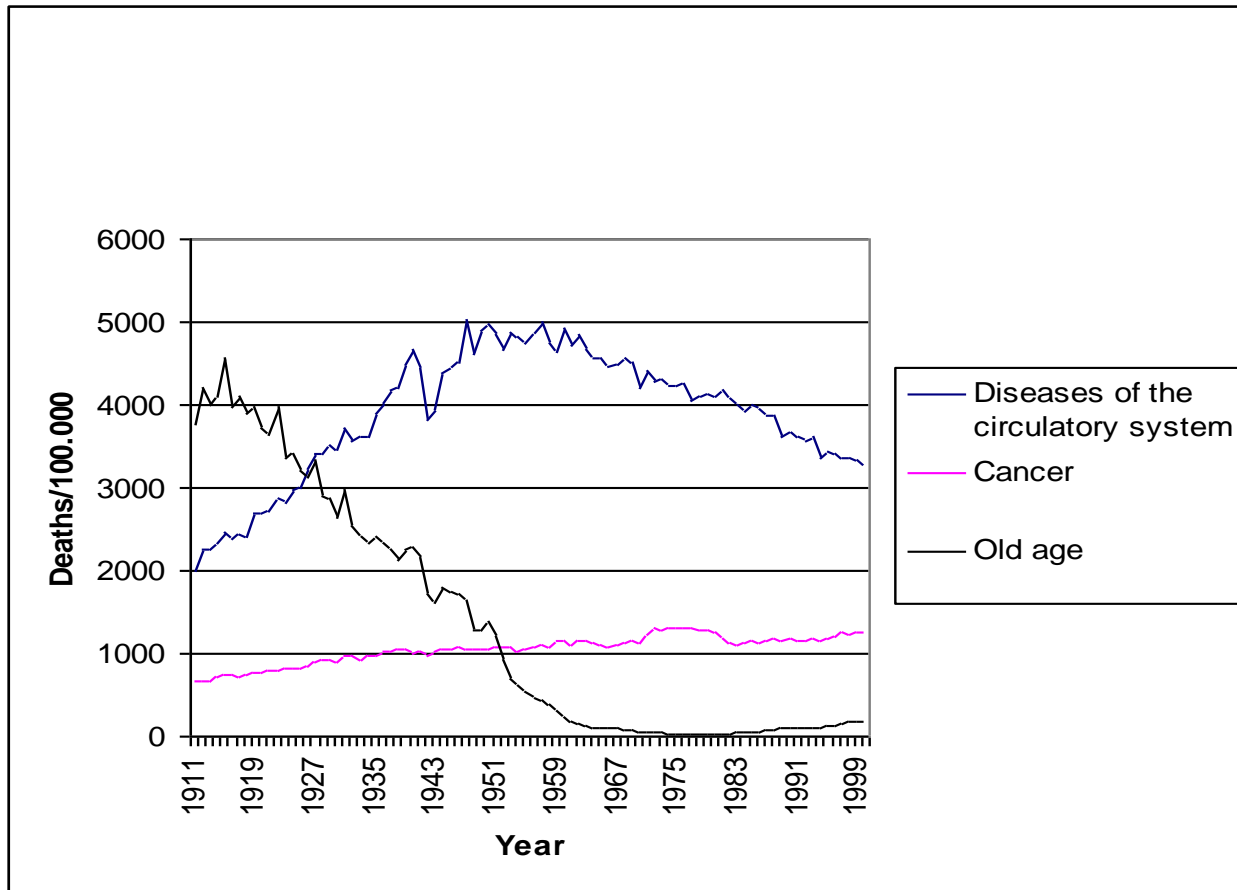
Linking data in POPLINK to other registers



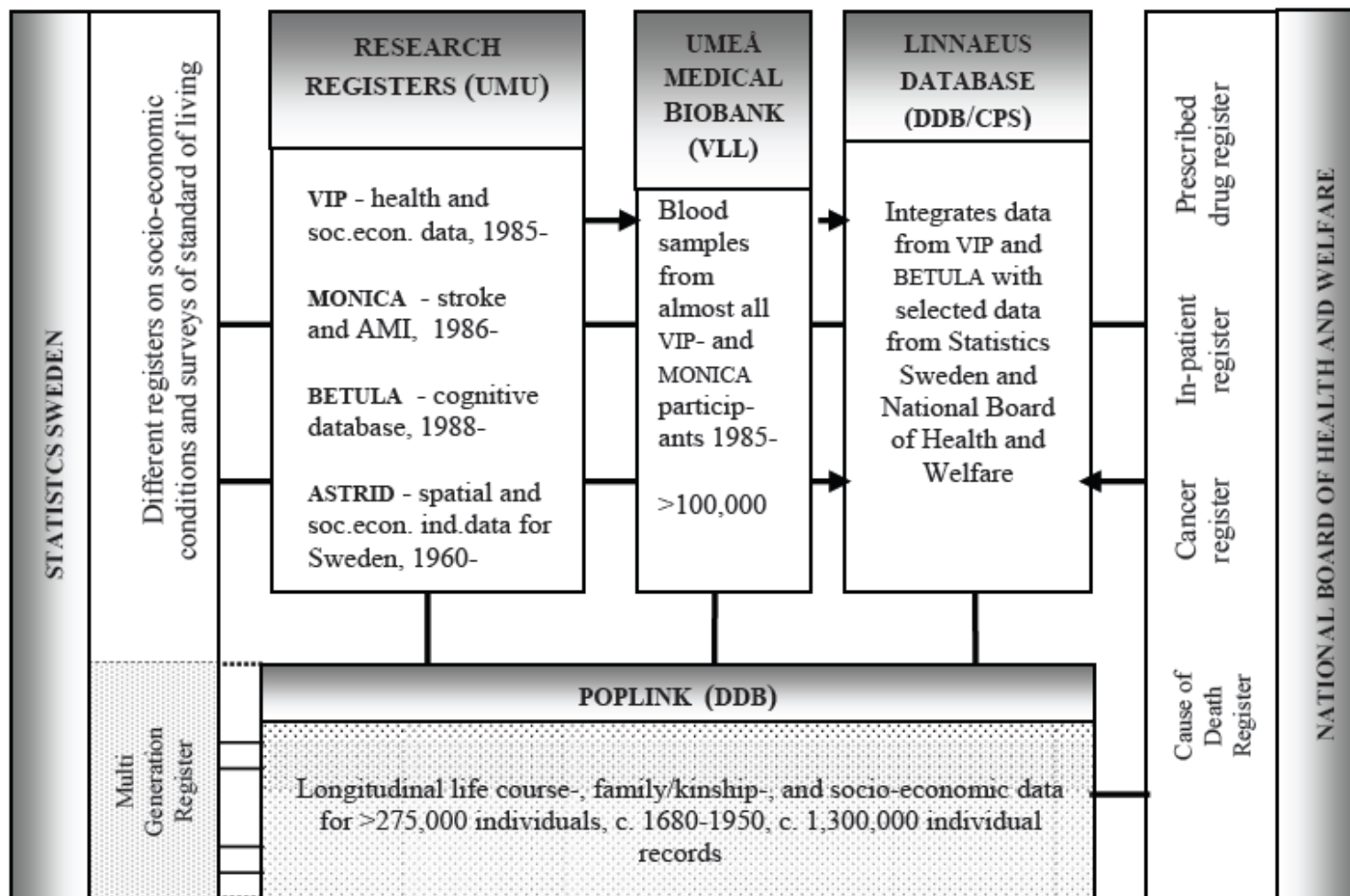
Health and mortality information in Poplink

- Death date/age at death
 - If death occurred within parishes of POPLINK
- Causes of death
 - Available from 18th century in Death and Burial registers as reported by parish ministers. Often vague diagnoses describing symptoms. From 1749, complete reporting expected
 - Less reporting in Death and Burial registers from the 1830s
 - Complete registration in towns and cities from 1860, based on death certificates from physicians
 - Complete registration for all Sweden from 1911, information controlled by physicians. Initially, substantial amount of unknown and diffuse diagnoses. Swedish nomenclature, joins ICD 1951.
 - POPLINK, cause of death classification using the ICD10 framework
- Disabilities
 - Notes in the parish registers.
 - POPLINK, information not organized in systematic form

Development of some causes of death, age group 70+, Sweden 1911-1999



Linkage to Swedish official registers, research registers and biobanks





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PUBLIC HEALTH AND TRANSLATIONAL MEDICINE (PW FRANKS, SECTION EDITOR)

Gene-Lifestyle Interactions in Complex Diseases: Design and Description of the GLACIER and VIKING Studies

Azra Kurbasic • Alaitz Poveda • Yan Chen • Åsa Ågren • Elisabeth Engberg • Frank B. Hu • Ingegerd Johansson • Ines Barroso • Anders Brändström • Göran Hallmans • Frida Renström • Paul W. Franks

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Abstract Most complex diseases have



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Research Article

On the association between weather variability and total and cause-specific mortality before and during industrialization in Sweden

Daniel Oudin Åström

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Daniel Hondula

Joacim Rocklöv

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BARBARA SCHUMANN