

Conducting Epidemiologic Research in Europe and the US

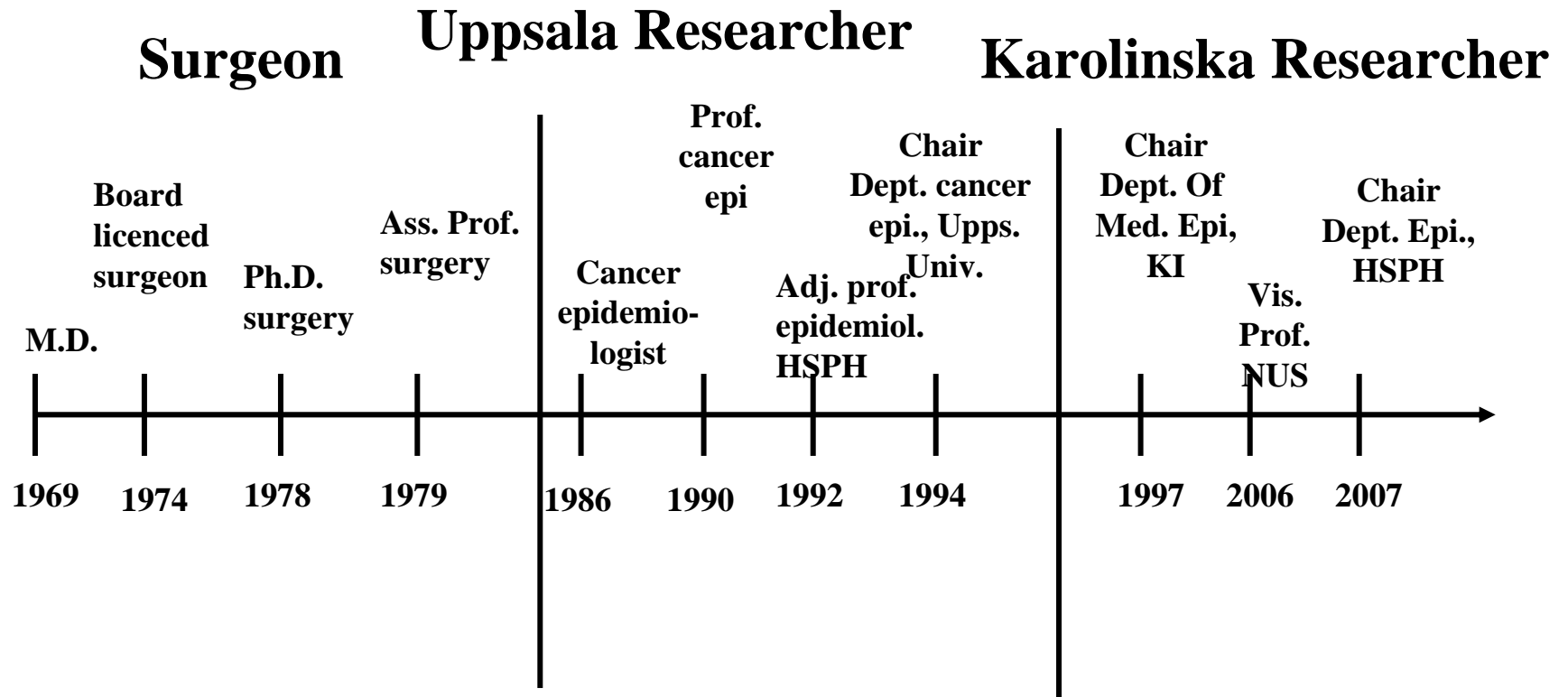
Hans-Olov Adami, MD, PhD

Chair, Department of Epidemiology
Harvard School of Public Health

Professor, Department of Medical Epidemiology
and Biostatistics

Karolinska Institutet, Stockholm

Who is Hans-Olov Adami?



A paradise for epidemiologists?

Adami HO. Lancet 1996;347:
588-589

Conclusion

- "Longstanding barriers need to be crossed – those between disciplines, between funding bodies, and between laboratory science and observational research
- We eagerly wait initiatives to take us beyond the tradition of small-scale thinking, provincial passivity, and self-sufficiency".

Outline (Abstract)

- Explain why, as a continent, Europe is even more heterogenous than North America
- Describe the specific attributes of (but also the heterogeneity among) Scandinavian countries
- Introduce you to the endless opportunities for record linkage studies in Scandinavia
- (Try to) demonstrate that population-based, case-control studies can still be conducted with high validity
- Emphatically convey that the sky is the limit if we combine methodologic skills, intellectual power, critical mass, and financial resources in the US (UW?) with opportunities and prerequisites in Scandinavia

Outline (Abstract)

- **Explain why, as a continent, Europe is even more heterogenous than North America**
- Describe the specific attributes of (but also the heterogeneity among) Scandinavian countries
- Introduce you to the endless opportunities for record linkage studies in Scandinavia
- (Try to) demonstrate that population-based, case-control studies can still be conducted with high validity
- Emphatically convey that the sky is the limit if we combine methodologic skills, intellectual power, critical mass, and financial resources in the US (UW?) with opportunities and prerequisites in Scandinavia

The European Network of Cancer Registries



**Karolinska
Institutet**

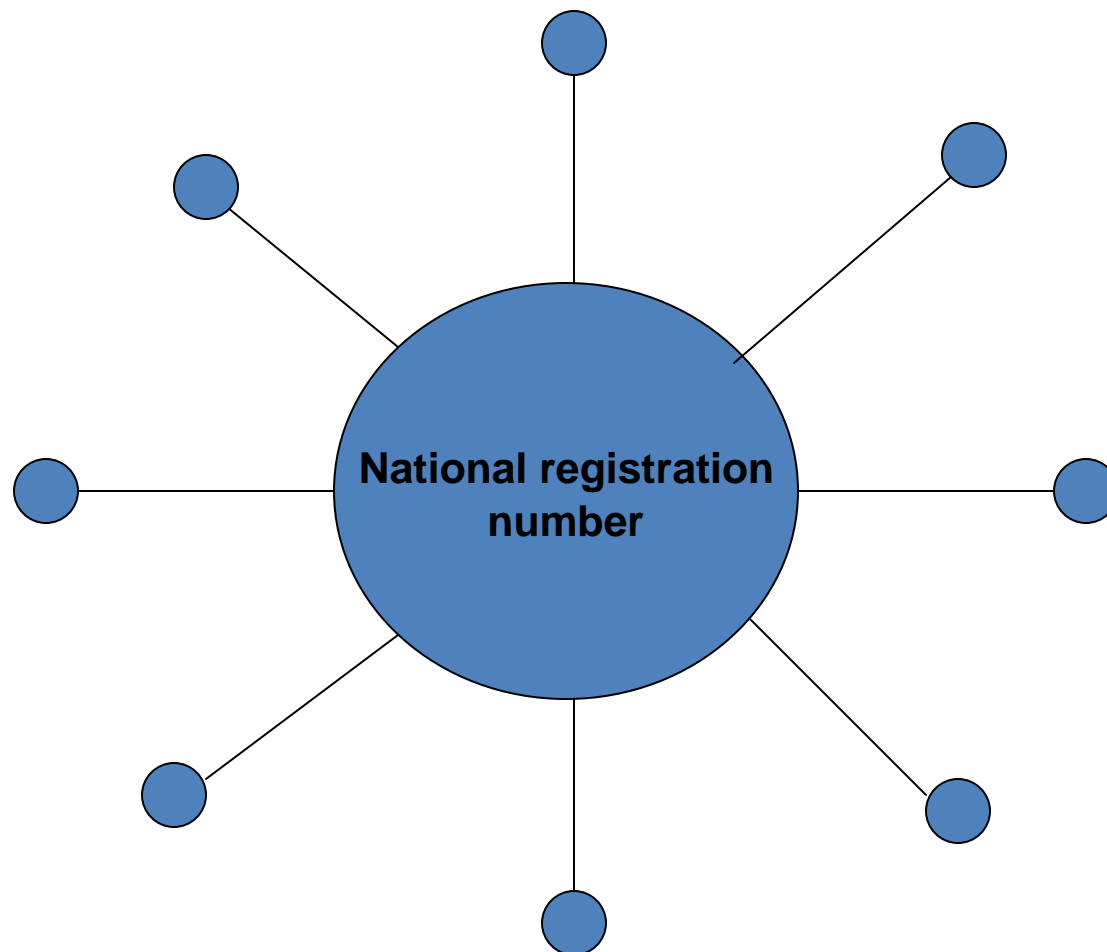
http://www.enrc.com.fr/images/europe_2006.jpg

Outline (Abstract)

- Explain why, as a continent, Europe is even more heterogenous than North America
- **Describe the specific attributes of (but also the heterogeneity among) Scandinavian countries**
- Introduce you to the endless opportunities for record linkage studies in Scandinavia
- (Try to) demonstrate that population-based, case-control studies can still be conducted with high validity
- Emphatically convey that the sky is the limit if we combine methodologic skills, intellectual power, critical mass, and financial resources in the US (UW?) with opportunities and prerequisites in Scandinavia

Attributes of Scandinavian countries

Numerous, nation-wide, high-quality registries



Outline (Abstract)

- Explain why, as a continent, Europe is even more heterogenous than North America
- Describe the specific attributes of (but also the heterogeneity among) Scandinavian countries
- **Introduce you to the endless opportunities for record linkage studies in Scandinavia**
- (Try to) demonstrate that population-based, case-control studies can still be conducted with high validity
- Emphatically convey that the sky is the limit if we combine methodologic skills, intellectual power, critical mass, and financial resources in the US (UW?) with opportunities and prerequisites in Scandinavia

The main types of national health data

- National health registries (EpC)
- National social registries (Statistics Sweden)
- National health survey (Statistics Sweden)
- National regionalized health survey (FHI)
- National health care quality registries
(Professional associations, County Councils, and the National Board of Health and Welfare)



What defines a national health register?

- Total population, not a sample
- Person identification number
- Includes everyone with some property
- General objective, not collected for a specific research purpose



The Health Data Registries

- The Cancer Registry
- The Patient Registry
- The Medical Birth Registry
- The Congenital Malformation Registry
- The Prescribed Drugs Registry
- (The Cause of Death Registry)



**Karolinska
Institutet**

Magnus Stenbeck



**CENTRE FOR EPIDEMIOLOGY
THE NATIONAL BOARD OF
HEALTH AND WELFARE**

www.socialstyrelsen.se/Statistik/statistikdatabas

Public Health in Figures



Interactiv communication



**Karolinska
Institutet**

Emil Löfroth



**CENTRE FOR EPIDEMIOLOGY
THE NATIONAL BOARD OF
HEALTH AND WELFARE**

The Cancer Registry

- Started in 1958
- Collects data on all malignant and some benign tumours
- Covers all Swedish residents
- Data on the tumour: diagnosis, pathological type
- Follow-up: date of discovery, date of death, cause of death
- 46 700 malignant cases diagnosed in 2002



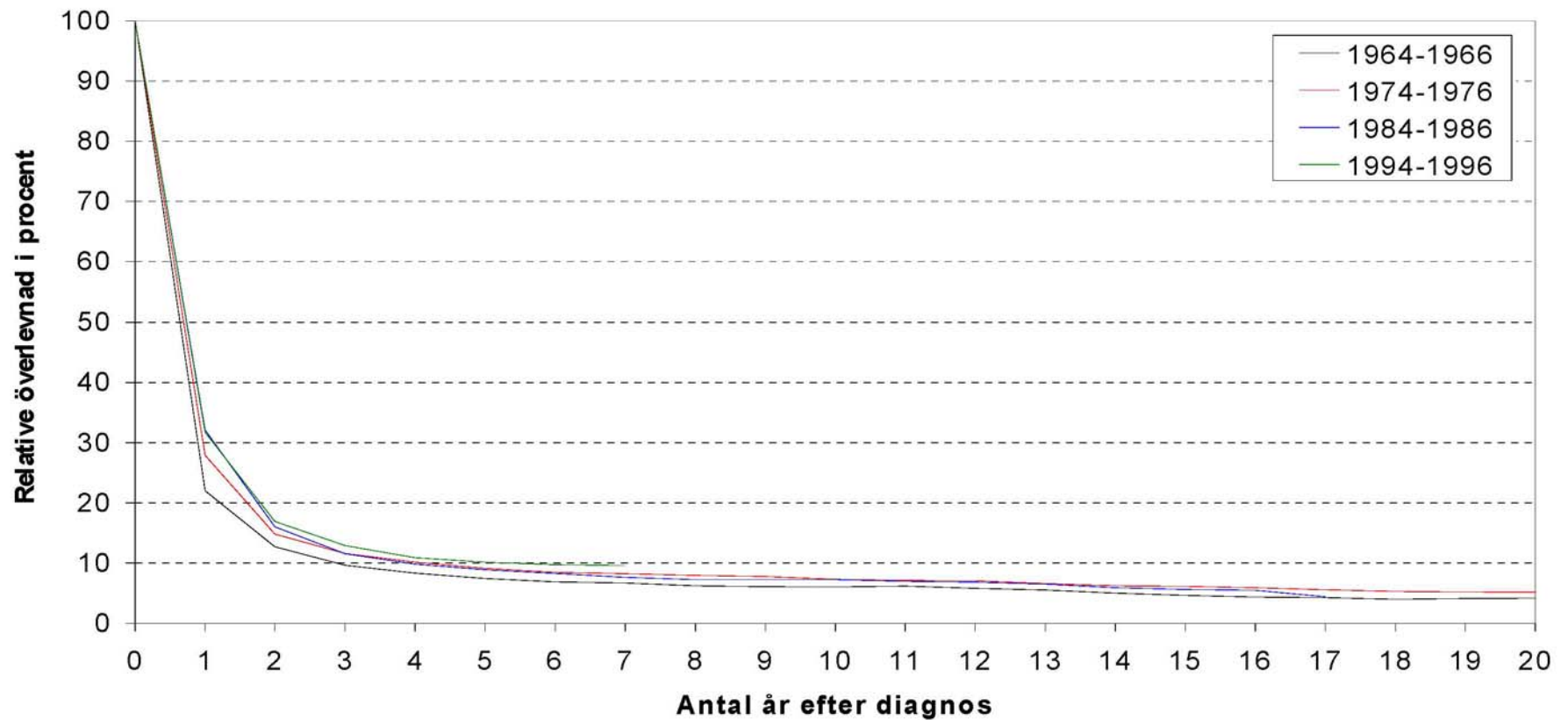
Lung cancer relative survival

- Males 0 - 89 of age at diagnosis



EPIDEMIOLOGICAL CENTRUM
SÖDERBYGATAN 18

Magnus Stenbeck



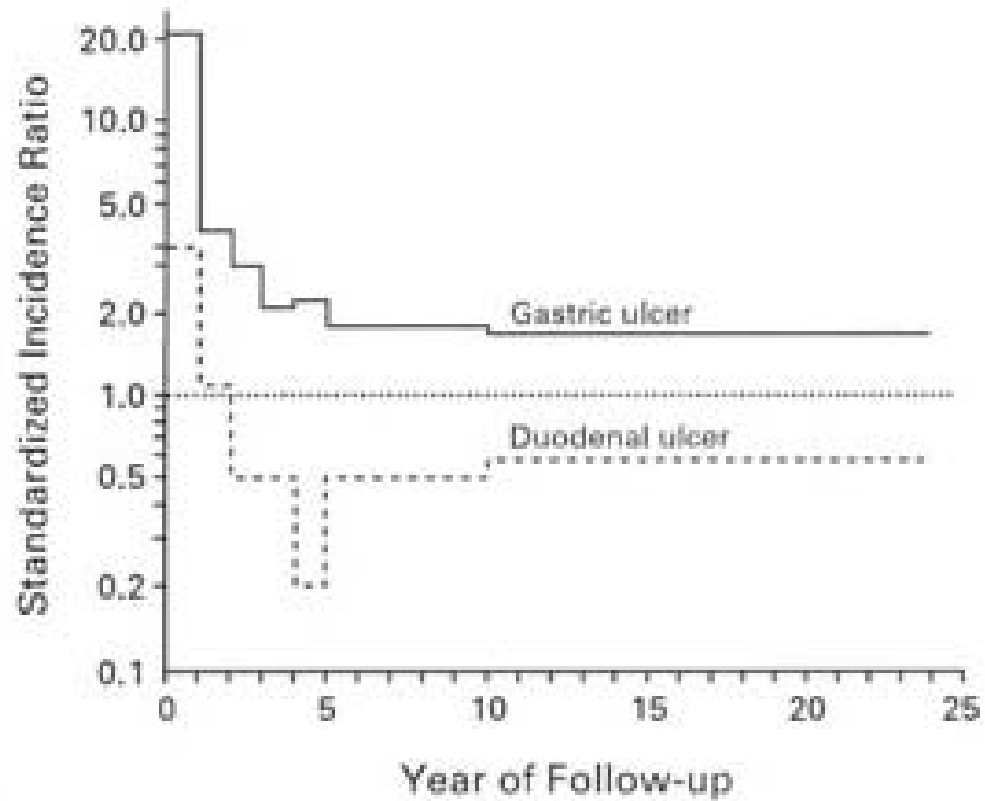


Figure 1. Standardized Incidence Ratio for Gastric Cancer in Patients with Gastric or Duodenal Ulcers, According to the Year of Follow-up.

The scale for the standardized incidence ratio is logarithmic.

Hansson LE et al. The risk of stomach cancer in patients with gastric or duodenal ulcer disease. N Engl J Med 1996;335:242-249

Hospital discharge register

- 50 million discharges
- Number of in-patients 1987 : 875 000
- Number of in-patients 2006: 791 000



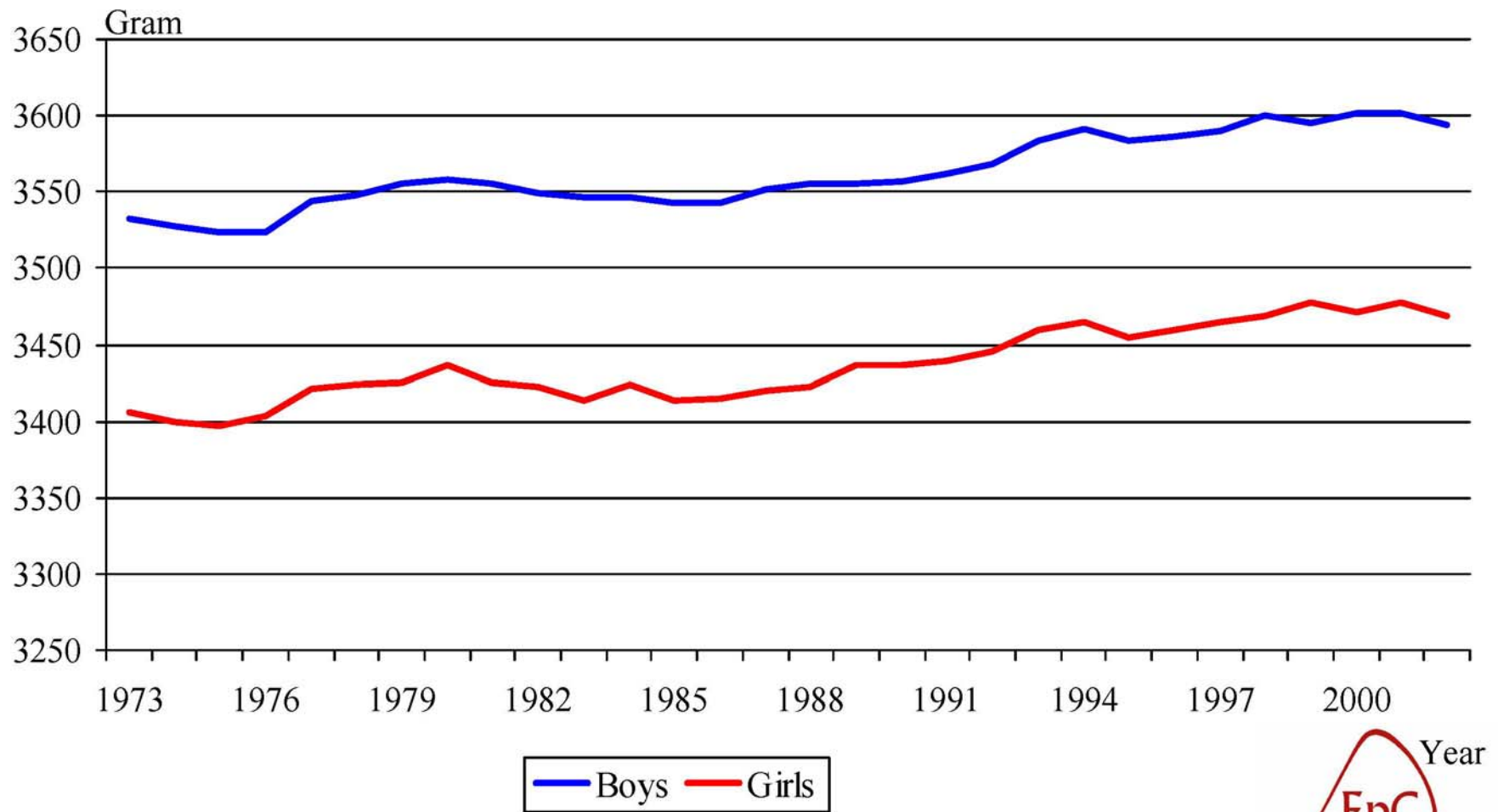
**Karolinska
Institutet**

Emil Löfroth



CENTRE FOR EPIDEMIOLOGY
THE NATIONAL BOARD OF
HEALTH AND WELFARE

Mean birth weight



Malformation Register

- Started in 1965 for surveillance
- Personal registration number since 1973
- Reports on malformations up till the age of 6 months
- 15/1000 reported malformations
- Induced abortions due to malformations: 5/1000 every year
- Approximately 2000 malformations a year -450 aborted after foetal diagnosis



**Karolinska
Institutet**

Emil Löfroth



**CENTRE FOR EPIDEMIOLOGY
THE NATIONAL BOARD OF
HEALTH AND WELFARE**

Cause of Death Register

- Statistics since 1749
- Computerised since 1952
- Only Swedish residents - wherever the death occurred
- No still-born
- No refugees



Cause of Death Register

- Number of deaths 2005: 91 775
- Diseases of Circulation organs
 - males 42 %, females 42 %
- Cancer
 - males 26 %, females 23 %



Prescribed drug register

- Started July 1, 2005
- All prescribed and dispensed drugs by Apoteket AB
- About 6 million individuals are recorded annually
- 95 million prescriptions the first year



**Karolinska
Institutet**

Emil Löfroth



**CENTRE FOR EPIDEMIOLOGY
THE NATIONAL BOARD OF
HEALTH AND WELFARE**

Other Health Statistics

- Injuries
- Myocardial infarctions
- Induced abortions
- Assisted reproduction
- Breast feeding

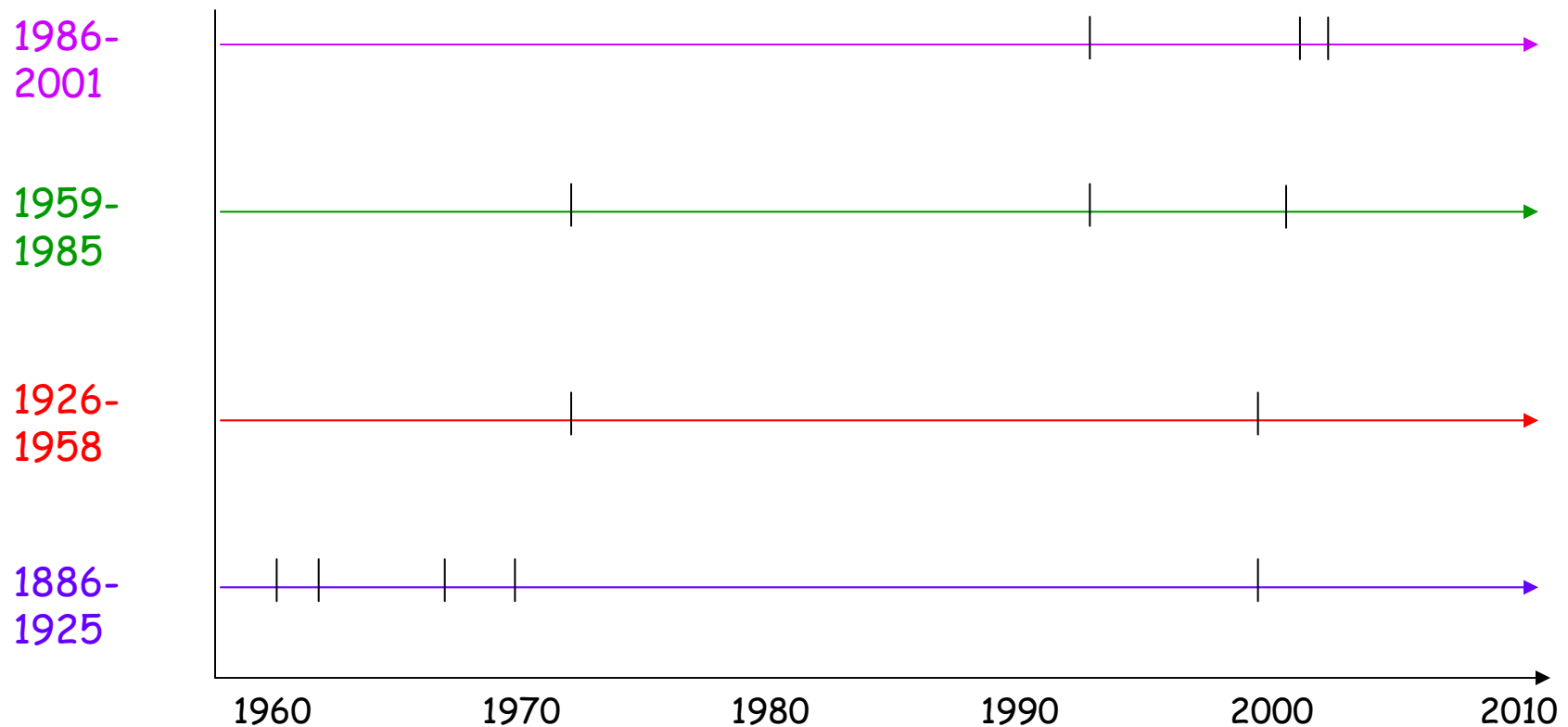


Swedish Twin Registry

- ~ 85,000 twin pairs
- 1/3 MZ
- 2/3 DZ

Nancy Pedersen 2008

The Swedish Twin Registry: The old data



**Karolinska
Institutet**

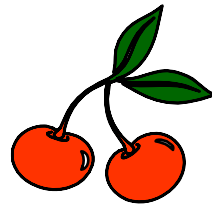
Paul Lichtenstein, September 2008,
tvillingregistret@ki.se

Approaches in twin research

- Quantitative genetic
 - Relative importance of genes and environments
 - Eg. *Science*, *NEJM*, *Lancet*, *Arch Gen Psychiatry*, *Arch Int Med*
- Epidemiological
 - Evaluate putative risk factors (controlling for genes)
 - Eg *NEJM*, *Lancet*, *JNCI*, *Arch Int Med*, *Arch Gen Psychiatry*
- Molecular genetic
 - Eg last week in *PNAS*, *PLoS Genetics*, *Neurobiol Aging*



Everything is twice as fun with twins



**Karolinska
Institutet**

Paul Lichtenstein, September 2008
tvillingregistret@ki.se

Characteristics of the registers

- Total population, not a sample
- National registration number
- Not collected for a specific research question



Overall rules

- No consent
- No right to be deleted



Every individuals right

- Patients and the public should be informed
- After written inquiry - to see information about themselves



The data are protected

- The data at EpC are strictly protected by the Official Secrets Act (9:4)
- There are only three exceptions to this



Official Secrets Act chapter 9, 4 §

The three exceptions

- Research
 - Statistics (official)
 - Data that in no way can be linked to a single person
-

- No harm



When you apply for data

THE RESEARCH GROUP

- Title
- Principal investigator
- The research group
- Contact person
- Invoice address
- Department where the data is analysed



**Karolinska
Institutet**

Emil Löfroth



**CENTRE FOR EPIDEMIOLOGY
THE NATIONAL BOARD OF
HEALTH AND WELFARE**

Outline (Abstract)

- Explain why, as a continent, Europe is even more heterogenous than North America
- Describe the specific attributes of (but also the heterogeneity among) Scandinavian countries
- Introduce you to the endless opportunities for record linkage studies in Scandinavia
- **(Try to) demonstrate that population-based, case-control studies can still be conducted with high validity**
- Emphatically convey that the sky is the limit if we combine methodologic skills, intellectual power, critical mass, and financial resources in the US (UW?) with opportunities and prerequisites in Scandinavia

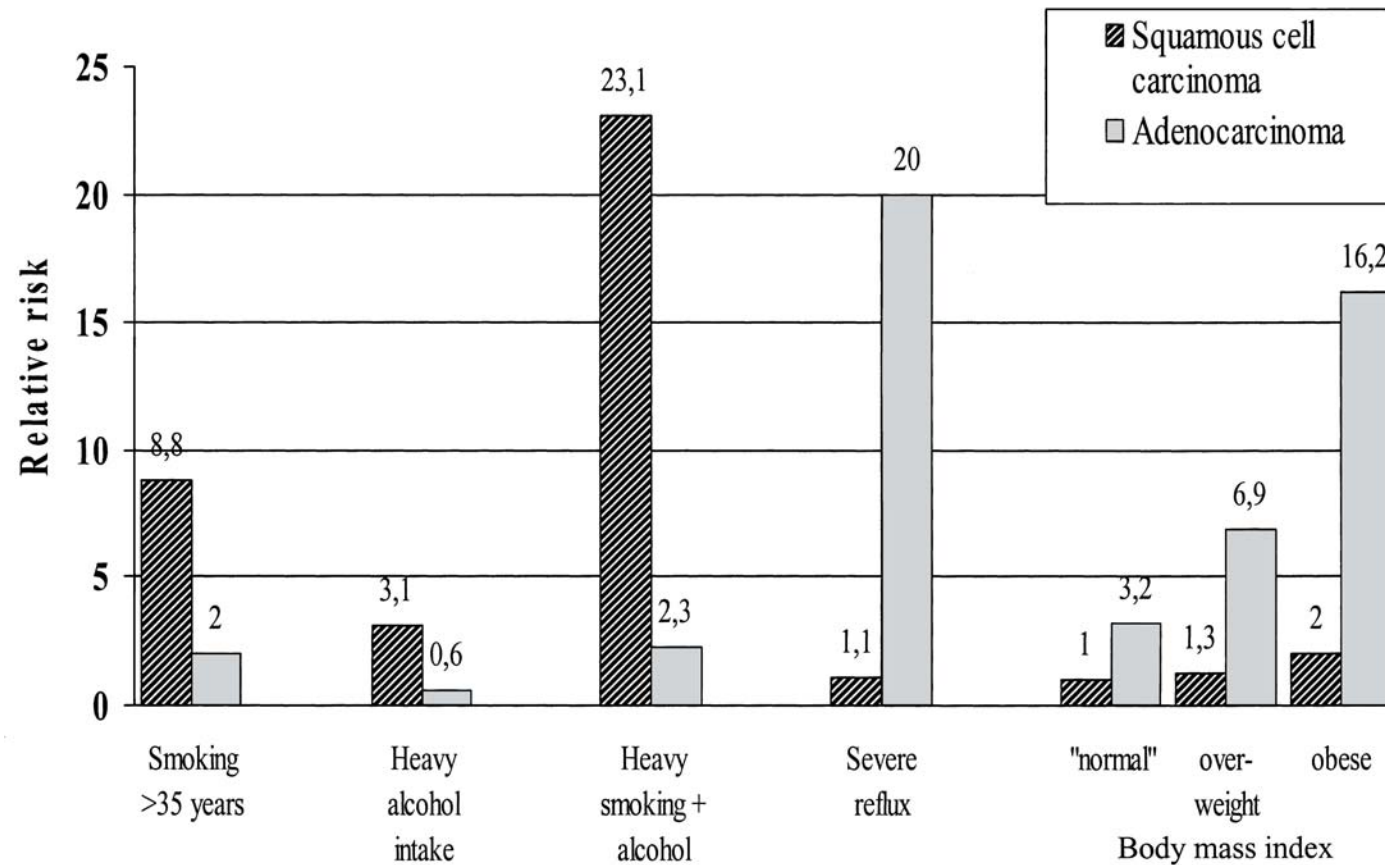


Figure 9-5. Major risk factors – and evidence for different etiologies – for squamous cell cancer and adenocarcinoma of the esophagus. (Source: Lagergren, 1999)

Lagergren J et al. Symptomatic gastroesophageal reflux as a risk factor for esophageal adenocarcinoma. N Engl J Med 1999;340:825-31

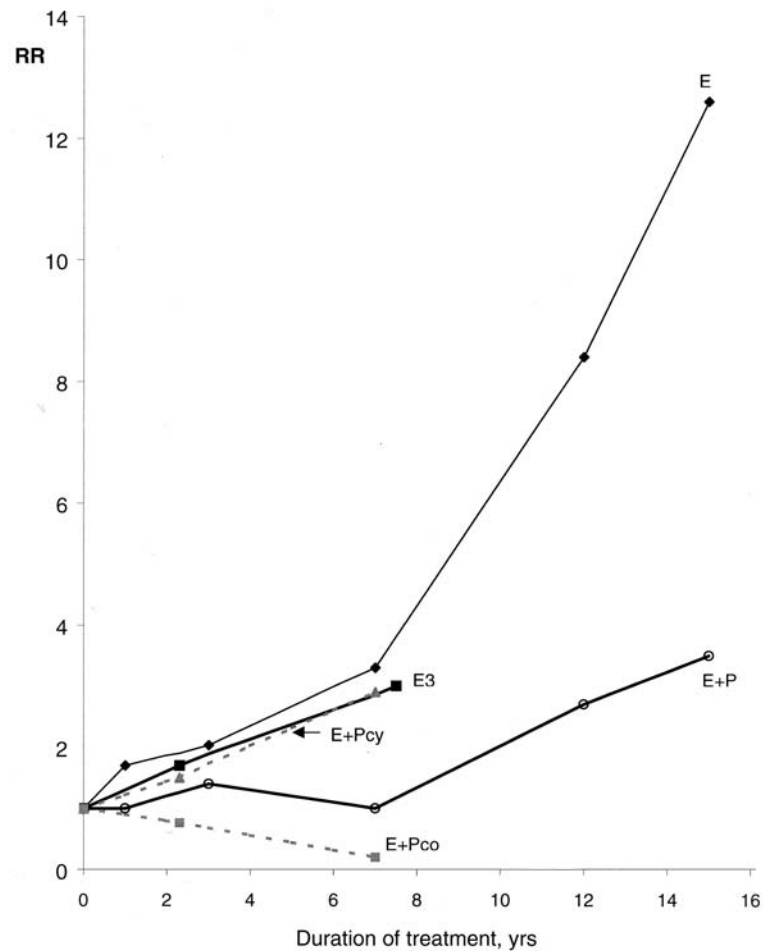


Figure 18-3. Relative risk (RR) of developing invasive endometrial cancer following postmenopausal Hormone replacement with weak estrogens (E3-estril, 1-2 mg/day) and medium-potency estrogens (E) Or combined with progestins (E+P). In the latter category, separate analyses were also carried out For estrogens combined with progestins cyclically for less than 16 days per cycle (E+Pcy) or Continuously (E+Pco). (Source: Weiderpass et al, 1999a, 1999b)

Weiderpass E et al. Risk of endometrial cancer following estrogen replacement with and without progestins. J Natl Cancer Inst 1999;91:1131-1137

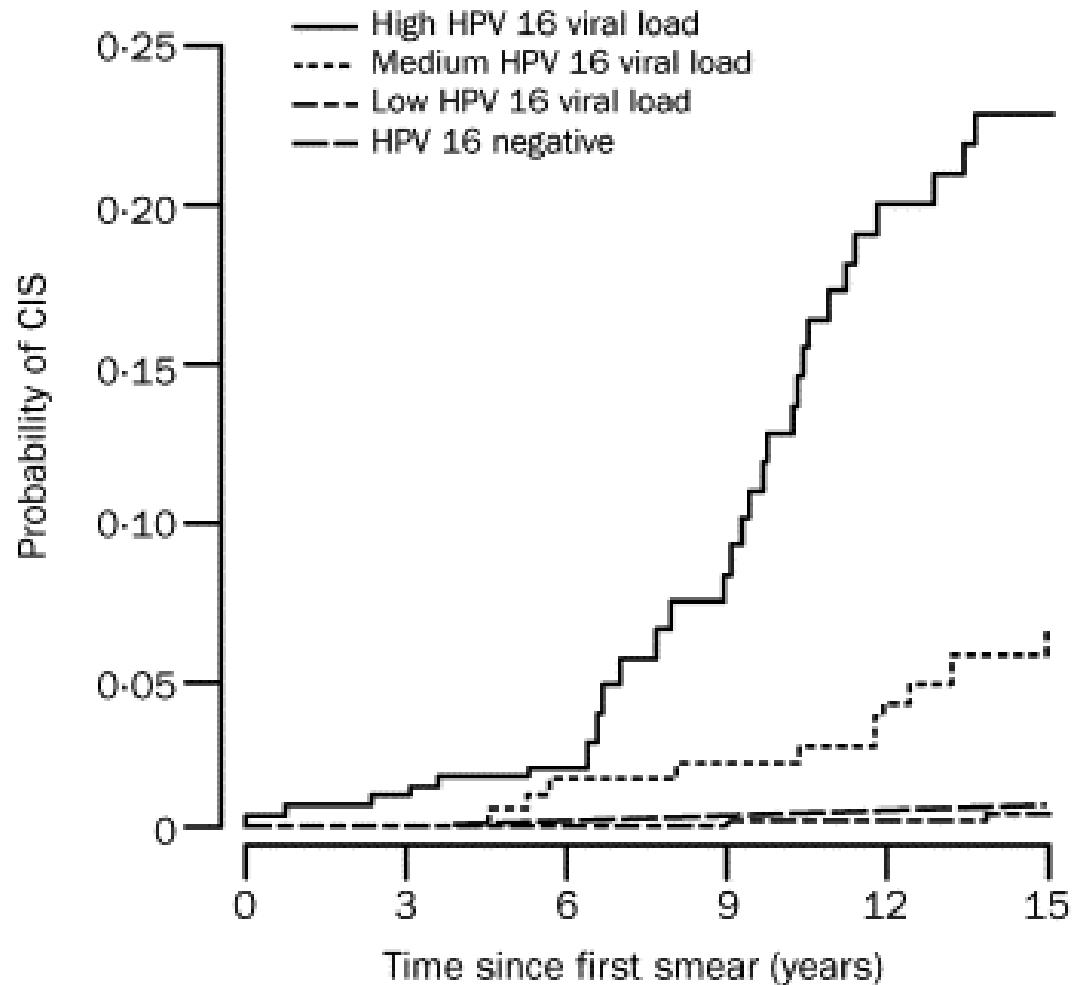


Figure 17-4. Probability of developing cervical carcinoma in situ in relation to HPV 16 viral load of first smear among women younger than 25 years at time of first smear. CIS = cervical carcinoma in situ. (Source: Ylitalo et al, 200b).

Ylitalo et al. Consistent high viral load of human papillomavirus 16 and risk of cervical carcinoma in situ: a nested case-control study. Lancet 2000;355:2194-2198

Outline (Abstract)

- Explain why, as a continent, Europe is even more heterogenous than North America
- Describe the specific attributes of (but also the heterogeneity among) Scandinavian countries
- Introduce you to the endless opportunities for record linkage studies in Scandinavia
- (Try to) demonstrate that population-based, case-control studies can still be conducted with high validity
- **Emphatically convey that the sky is the limit if we combine methodologic skills, intellectual power, critical mass, and financial resources in the US (UW?) with opportunities and prerequisites in Scandinavia**

Thank you!