

# How research based on Swedish registries improve health: an international perspective?

**Hans-Olov Adami**

Department of Epidemiology  
Harvard School of Public Health

Department of Medical Epidemiology and Biostatistics  
Karolinska Institutet

Eugeniahemmet, Karolinska University Hospital, Solna

25 april, 2013

# Overview

- Are we spoiled?
- Has research based on Swedish registries improved (public) health in Sweden and beyond?
- Do we need to change our view of "register-based" research?

# Are we spoiled?

Look at a few indicators:

- **Cancer registration**
- Cohort research
- Health Demographic surveillance sites (HDSS)
- Opportunities for follow-up

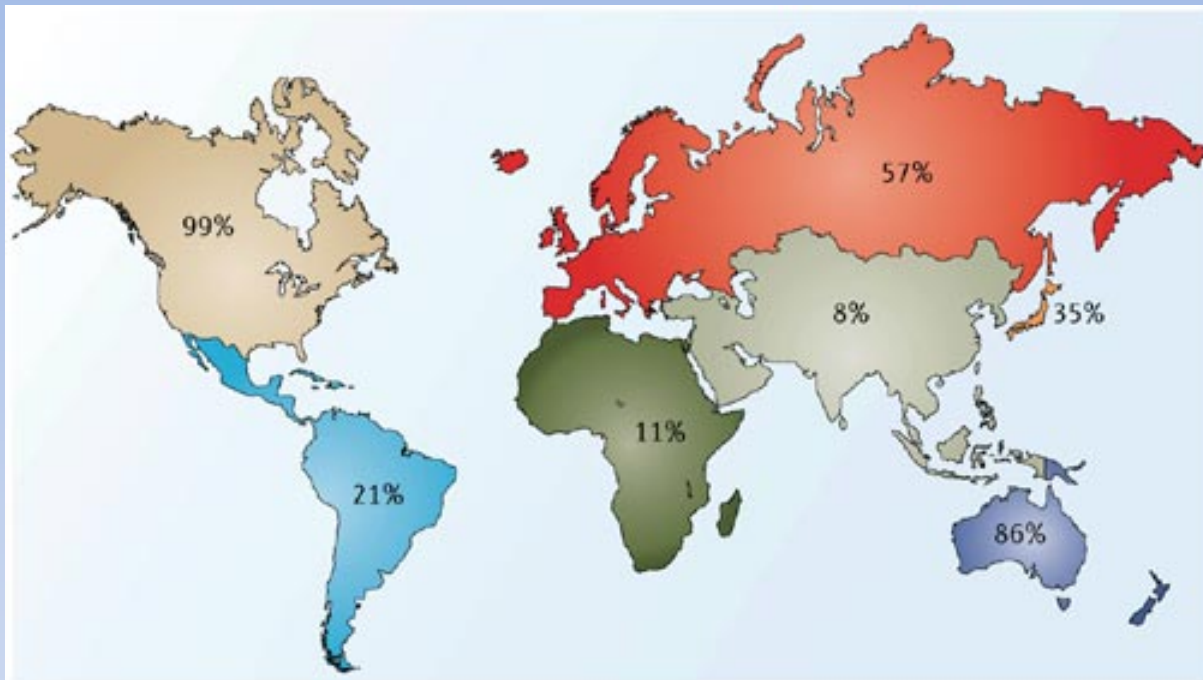
# Cancer registration

Cancer registration can be used to:

- describe cancer patterns and trends
- calculate survival
- plan and evaluate cancer control activities
- plan and monitor care of individual cancer patients
- indentify incident cancer cases in etiologic/epidemiologic studies (case-control and cohort)

# Cancer registration

- aims to record all new cases in a defined population
- this is a complex activity which need a sophisticated infrastructure



Copyright © 2006 Nature Publishing Group  
Nature Reviews | Cancer

Parkin *Nature Reviews Cancer* 6, 603–612 (August 2006) | doi:10.1038/nrc1948



Parkin *Nature Reviews Cancer* **6**, 603–612 (August 2006) | doi:10.1038/nrc1948

<b>Volume</b>	<b>Year</b>	<b>Registries</b>	<b>Populations*</b>	<b>Countries</b>	<b>Period (approximate)</b>
I	1966	32	35	29	1960–1962
II	1970	47	58	24	1963–1967
III	1976	61	79	29	1968–1972
IV	1982	79	103	32	1973–1977
V	1987	105	137	36	1978–1982
VI	1992	137	166	49	1983–1987
VII	1997	150	183	50	1988–1992
VIII	2002	186	214	57	1993–1997

\* Populations defined in several ways, for example, ethnicity, birthplace and urban or rural.

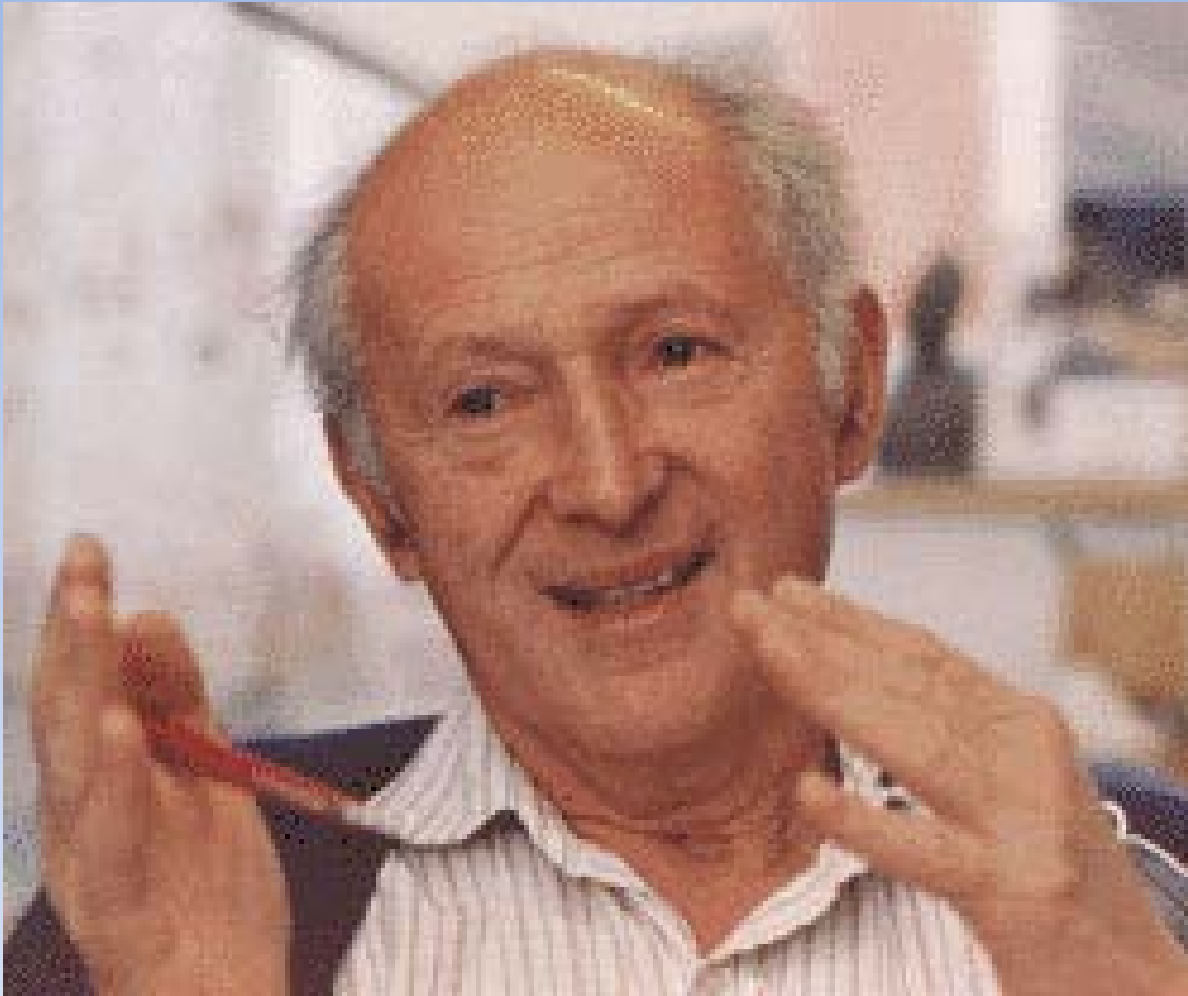
Parkin *Nature Reviews Cancer* 6, 603–612 (August 2006) | doi:10.1038/nrc1948



# Are we spoiled?

Look at a few indicators:

- Cancer registration
- **Cohort research**
- Health Demographic surveillance sites (HDSS)
- Opportunities for follow-up




Sweden 🇸🇪

Ranked #7 – Life Expectancy

Average age = 81 years



Nigeria 

Ranked #182 (30% below world average)

Life Expectancy

Average age = 46 years

# Chronic Diseases



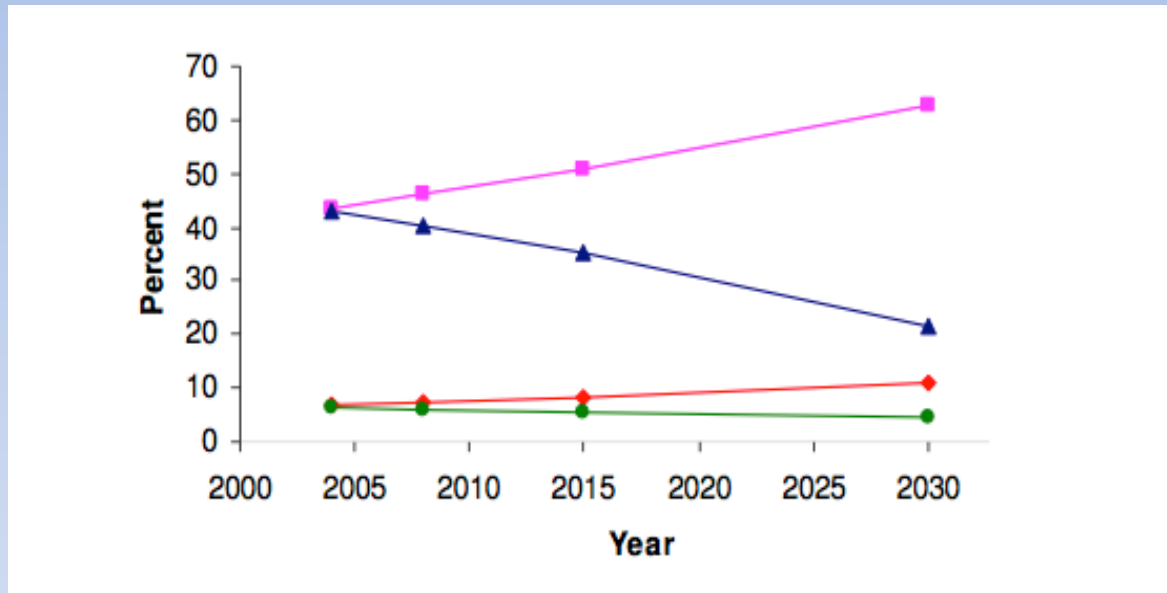
NCDs disproportionately affect the poor- further deepening inequalities

The poor are more likely to live in settings where policies are inadequate to address and manage NCDs

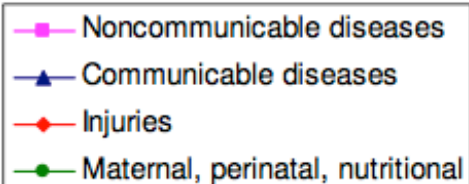
NCDs lend to continued expenditures that trap poor households in cycles of illness, debt, and stress

NCDs diminish household earnings and a family's ability to provide for and educate children

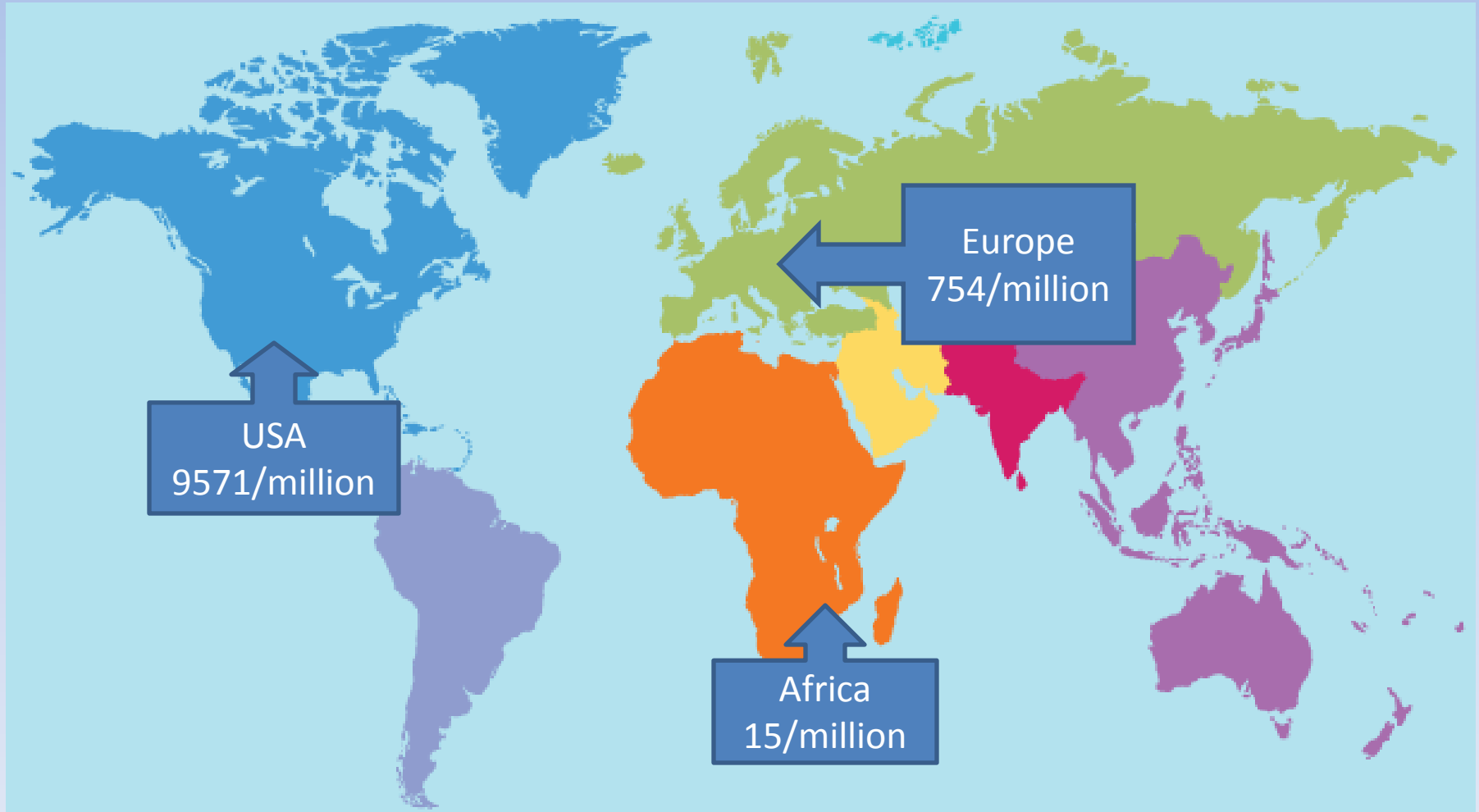
# Cause of Mortality



Estimated proportions of age-standardized mortality rates by cause in sub-Saharan Africa



# Disparities in cohort studies

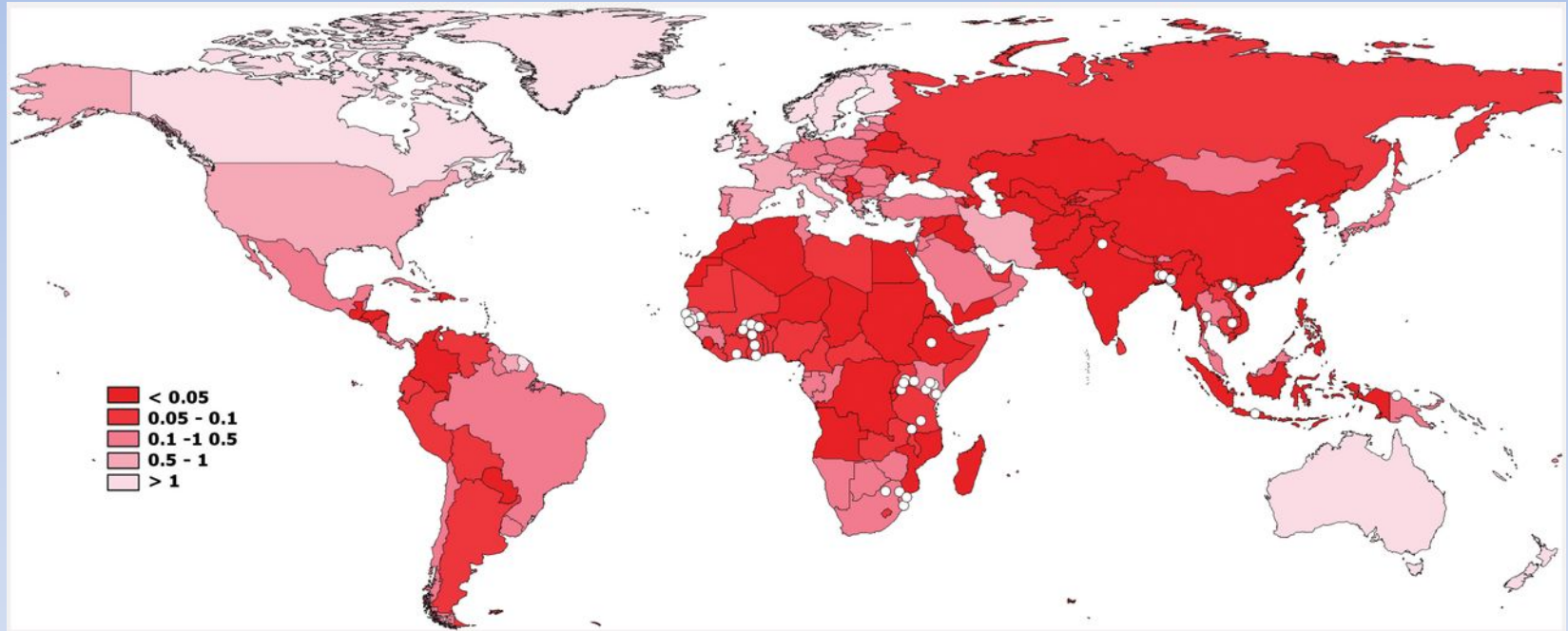


# Are we spoiled?

Look at a few indicators:

- Cancer registration
- Cohort research
- **Health Demographic surveillance sites (HDSS)**
- Opportunities for follow-up

Countries of the world classified by PubMed citations for ('epidemiology' and <country>) per 1000 population, also showing the location of 43 HDSS site members of the INDEPTH Network (white dots).



Sankoh O , and Byass P Int. J. Epidemiol. 2012;41:579-588



# Are we spoiled?

Look at a few indicators:

- Cancer registration
- Cohort research
- Health Demographic surveillance sites (HDSS)
- **Opportunities for follow-up**

# The unique prerequisites that prevail in Sweden

- offer endless opportunities and
- ethical obligation to use them

# Overview

- Are we spoiled?
- **Has research based on Swedish registries improved (public) health in Sweden and beyond?**
- Do we need to change our view of "register-based" research?

# Has research based on Swedish registries improved (public) health in Sweden and beyond?

## Answer 1:

- The immediate goal of scholarly work – including research based on registers – is to make discoveries
- We can never predict if these discoveries will or will not improve public health

**Has research based on Swedish registries improved  
(public) health in Sweden and beyond?**

**Answer 2:**

There is no simple and valid approach to  
measure improvements in public health

# Has research based on Swedish registries improved (public) health in Sweden and beyond?

## Answer 3:

Let me offer a few examples of research using registers that might have been of benefit:

### Example 1:

Hormone replacement therapy increases the risk of breast cancer

N Engl J Med 1989;321:293-7

Int J Cancer 1999;81:339-44

### Registers used:

Prescription; cancer; death

# Has research based on Swedish registries improved (public) health in Sweden and beyond?

## **Example 2:**

Hormone replacement therapy increases the risk  
of endometrial cancer

J Natl Cancer Inst 1999;91:1131-7

Lancet 1999;353:1824-8

## **Registers used:**

Population; cancer

# Has research based on Swedish registries improved (public) health in Sweden and beyond?

## **Example 3:**

Reflux is a predominant cause of esophageal adenocarcinoma

N Eng J Med 1999;18;340:825-31

## **Registers used:**

Cancer



**Has research based on Swedish registries improved  
(public) health in Sweden and beyond?**

**Example 4:**

Snus increases the risk of pancreatic cancer

Lancet 2007;369:2015-20

**Registers used:**

Construction workers cohort; cancer; death

# Has research based on Swedish registries improved (public) health in Sweden and beyond?

## **Example 5:**

Radical prostatectomy reduces mortality in patients with early prostate cancer

N Engl J Med 2002;347:781-9

N Engl J Med 2005;352:1977-84

J Natl Cancer Institute 2008;100:1144-54

N Eng J Med 2011;364:1708-17

## **Registers used:**

Randomized trials; death

# Has research based on Swedish registries improved (public) health in Sweden and beyond?

## **Example 6:**

Low carbohydrate, high protein (Atkin's) diet increases risk of cardiovascular disease.

BMJ 2012; 344:e4026.

## **Registers used:**

Analytic cohort; death; migration; in-patient

# Overview

- Are we spoiled?
- Has research based on Swedish registries improved (public) health in Sweden and beyond?
- **Do we need to change our view of “register-based” research?**

**Do we need to change our view of  
"register-based research"?**

**Answer 1:**

**There is no such thing as  
"register-epidemiology" or  
"register research"!**

# Do we need to change our view of “register-based research”?

Registry data can be used in both etiologic and clinical research to:

- Calculate person-time
- Calculate survival
- Monitor disease control activities
- Undertake economic analyses
- Generate descriptive information (incidence, prevalence, mortality)
- Sample study participants
- Ascertain exposure, confounders, effect modifiers and outcomes

# Do we need to change our view of “register-based research”?

## Answer 2:

- Register information can be used in studies of all possible designs
- Methodologic issues are no less challenging than in any other scholarly activity and can only be underestimated

# Do we need to change our view of “register-based research”?

## Answer 3:

The terminology “register research” misleads:

- Decision makers
- Funders
- Colleagues (particularly basic researchers)
- Perhaps ourselves



# Overview

- Are we spoiled? **Yes**
- Has research based on Swedish registries improved (public) health in Sweden and beyond? **Probably**
- Do we need to change our view of "register-based research? **Indeed**

**Thank you for  
listening!**