Using administrative registers to measure equity in access to health care

Ilmo Keskimäki
National Institute for Health and Welfare
Health and Social Services

THL

NATIONAL INSTITUTE FOR HEALTH AND WELFARE, FINLAND

Structure of the presentation

- Administrative registers in Finland
  - Examples on registers
  - Privacy legislation and register research
- Linkages of population and health registers
  - Simple and complicated linkages
  - Identification of cases
- Empirical studies on equity in health care
- Conclusions / lessons to shear
  - Strengths and limitations of register research
  - Finnish experiences

Administrative registers in Finland

Examples on Finnish administrative registers

- Population Register Centre (VRK):
  - Population information system 1970-
    - Demographic data on all Finnish residents, date on birth, death, places of residence, family relations

- Statistics Finland (Tilastokeskus):
  - Register of causes of death 1969-
    - Based on information from death certificates
  - Longitudinal database of population censuses (1970-) and employment statistics (1990-)
    - Census: Every fifth year
    - Employment statistics: Annually
    - Data on several socio-economic variables, such as socio-economic position, employment, income, family position, living conditions

Examples on Finnish administrative registers

- National Institute for Health and Welfare (THL):
  - Health Care Register HILMO [earlier Hospital Discharge Register]
    - Data on all inpatient hospital admissions 1967-
    - Outpatient day surgery, inpatient care at social welfare institutions (1994-)
  - Cancer Register
    - Data on all diagnosed or suspected cases of cancer 1953-
    - Technically administered by the Finnish Cancer Society

- Social Insurance Institution (KELA):
  - Special reimbursement register 1964-
    - Disease based entitlements for receiving higher compensation for medication costs of some serious chronic diseases from KELA
  - Prescription register 1994-
    - Purchases of medication prescribed by doctor and paid partly by KELA

Administrative health and social registers in Finland

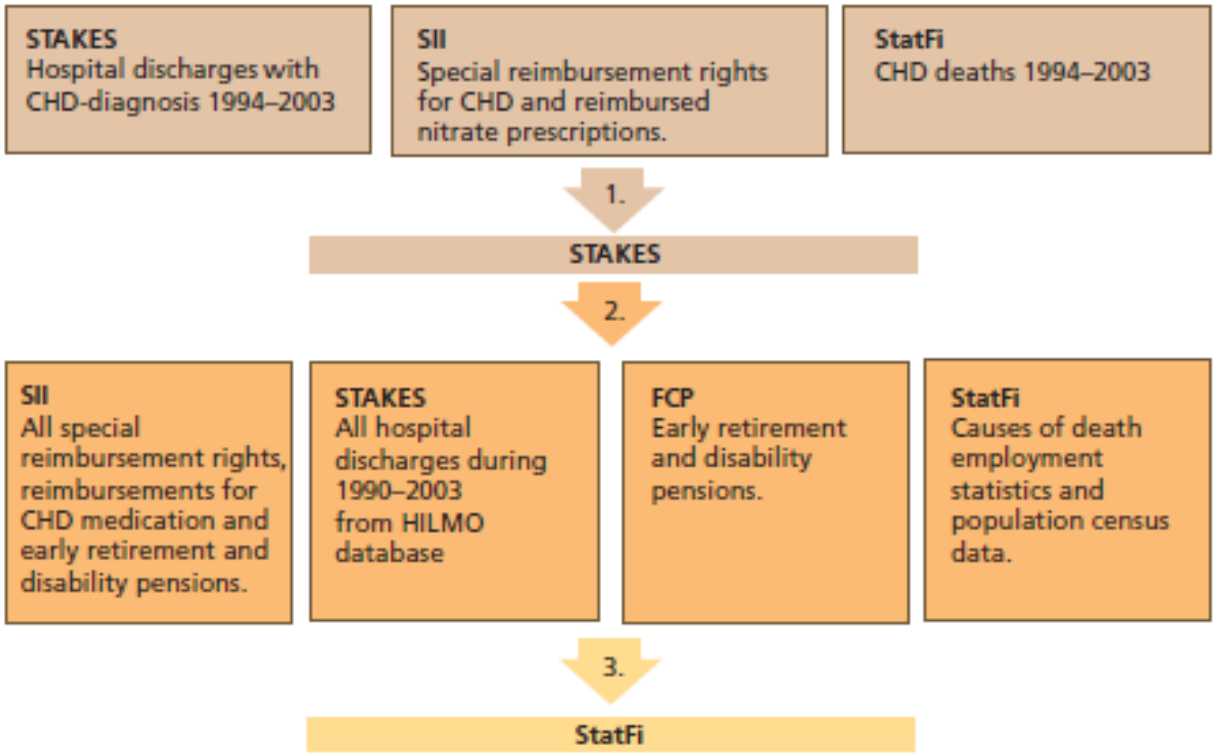
- Cancers 1953
- Health care personnel 1955
- Tuberculosis care 1956
- Psychiatric care 1957
- New cases of tuberculosis 1958
- Sexually transmitted diseases 1958
- Care at general hospitals 1960
- Malformations 1963
- Occupational diseases 1964
- Adverse drug reactions 1966
- Hospital discharges 1967
- Cervical and breast cancer screenings 1968
- Causes of death 1969
- Induced abortions and sterilizations 1977
- Exposure to cancer-hazardous material 1979
- Orthopedic endoprostheses 1980
- Drug surveillance 1982
- Visual impairments 1983
- Births 1987
- Infectious diseases 1989
- Dental implants 1994
- Outpatient surgical operations 1994
- Outpatient hospital visits 1998
- Pensions 1962
- Drug reimbursements 1964
- National pensions 1970
- Survivors' pensions 1970
- Subsidies for children with disabilities 1970
- Sickness allowances 1971
- Private health care visits 1971
- Rehabilitations 1978
- Conscripts' allowance 1985
- Unemployment benefits 1985
- Social assistance 1985
- Children and adolescents took into care 1991
- Family allowances 1993
- Child care assistances 1993
- Maternity grants 1994
- Labour market allowances 1994
- Housing allowances 1994
- Discharges from social welfare institutions 1994
- Prescriptions 1994
- Private health care operations 1996
- Financial aid for students 1997

Privacy protection and permissions to use register data in Finland

- Gathering and maintaining administrative (individual level) registers require a legal justification
- By law, all individual based register data are confidential information
- Legislation allows the use of register data (collected for administrative and statistical purposes) for scientific, historical, and statistical research purposes
- Strict regulations on permissions to apply, hand over and use data
- Personal consent not required if all data are obtained from registers
- The permission can usually be applied from the authority maintaining the register
- Statistical authorities usually release data only in anonymised form
- Indirect identification?

Linkages of population and health registers

Data compilation process for a coronary heart disease study



The purpose in data collection to identify a total CHD population in Finland in 1994–2003 to enable research on health care use and outcomes of CHD

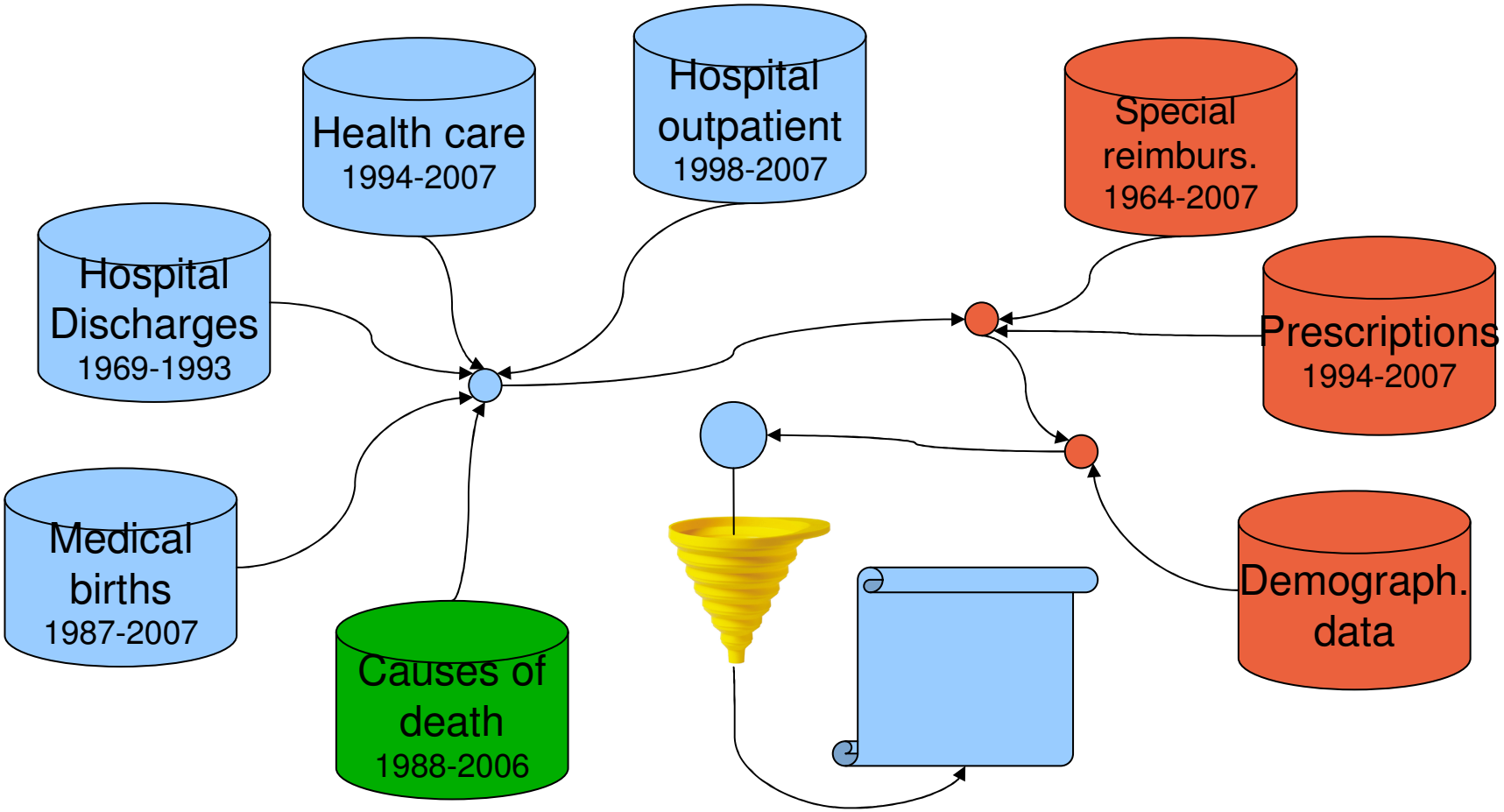
1. Personal IDs collected from all relevant register authorities. IDs from different register sources merged at STAKES

2. IDs sent to register authorities for compliation of relevant data for the research questions

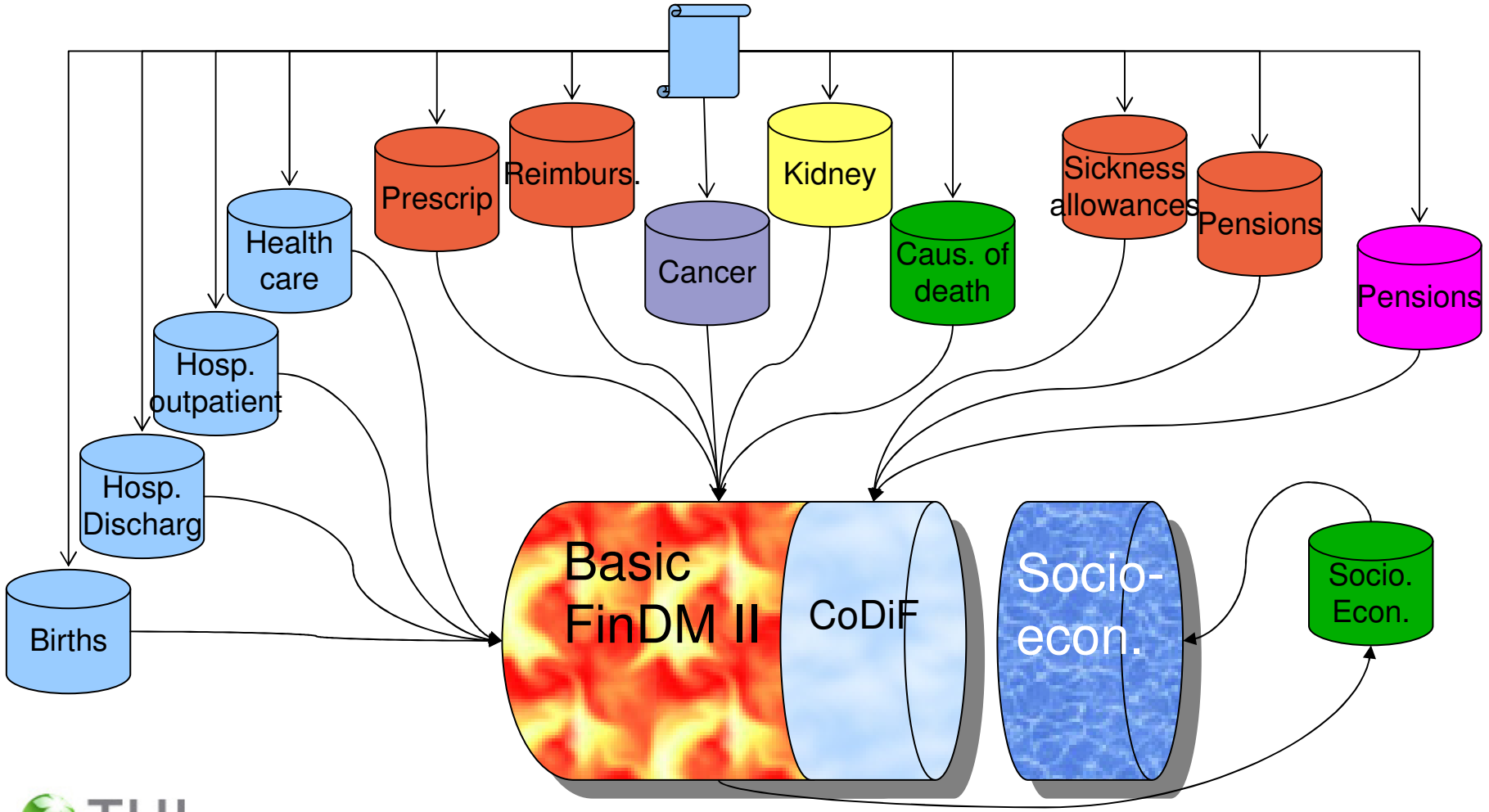
3. Register authorities send the relevant data to StatFi, where IDs replaced by artificial research numbers

Kajantie et al. 2006

Identifying the FinDM diabetes cohort



Follow-up data for the FinDM cohort



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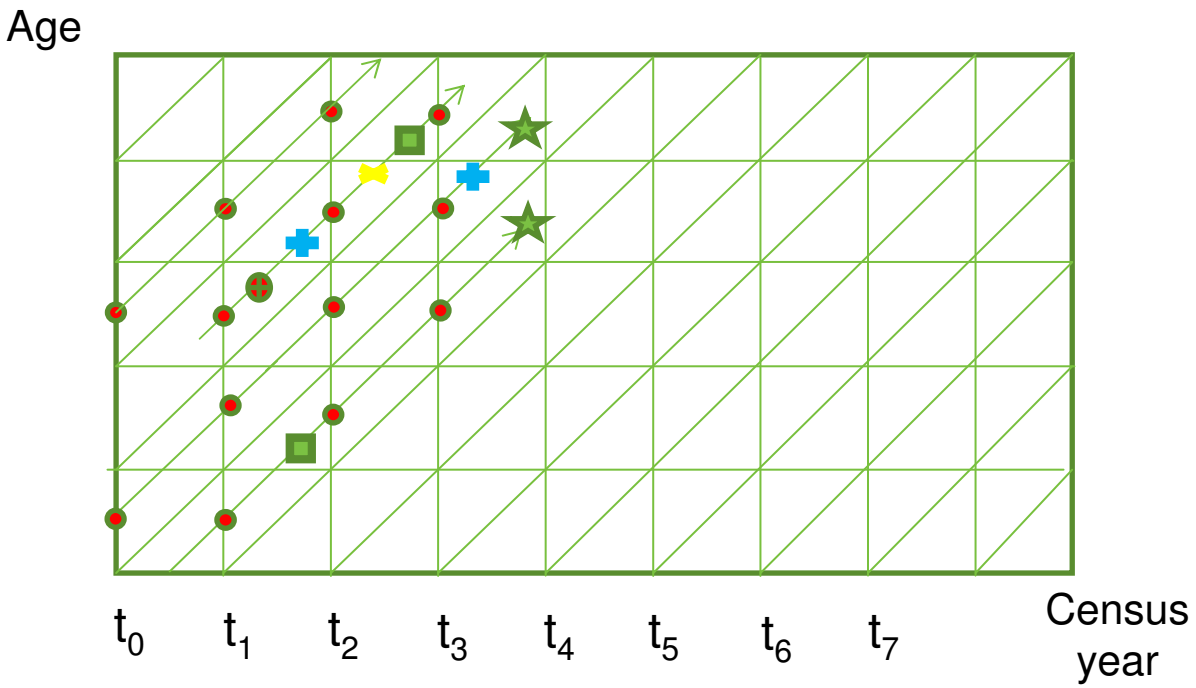
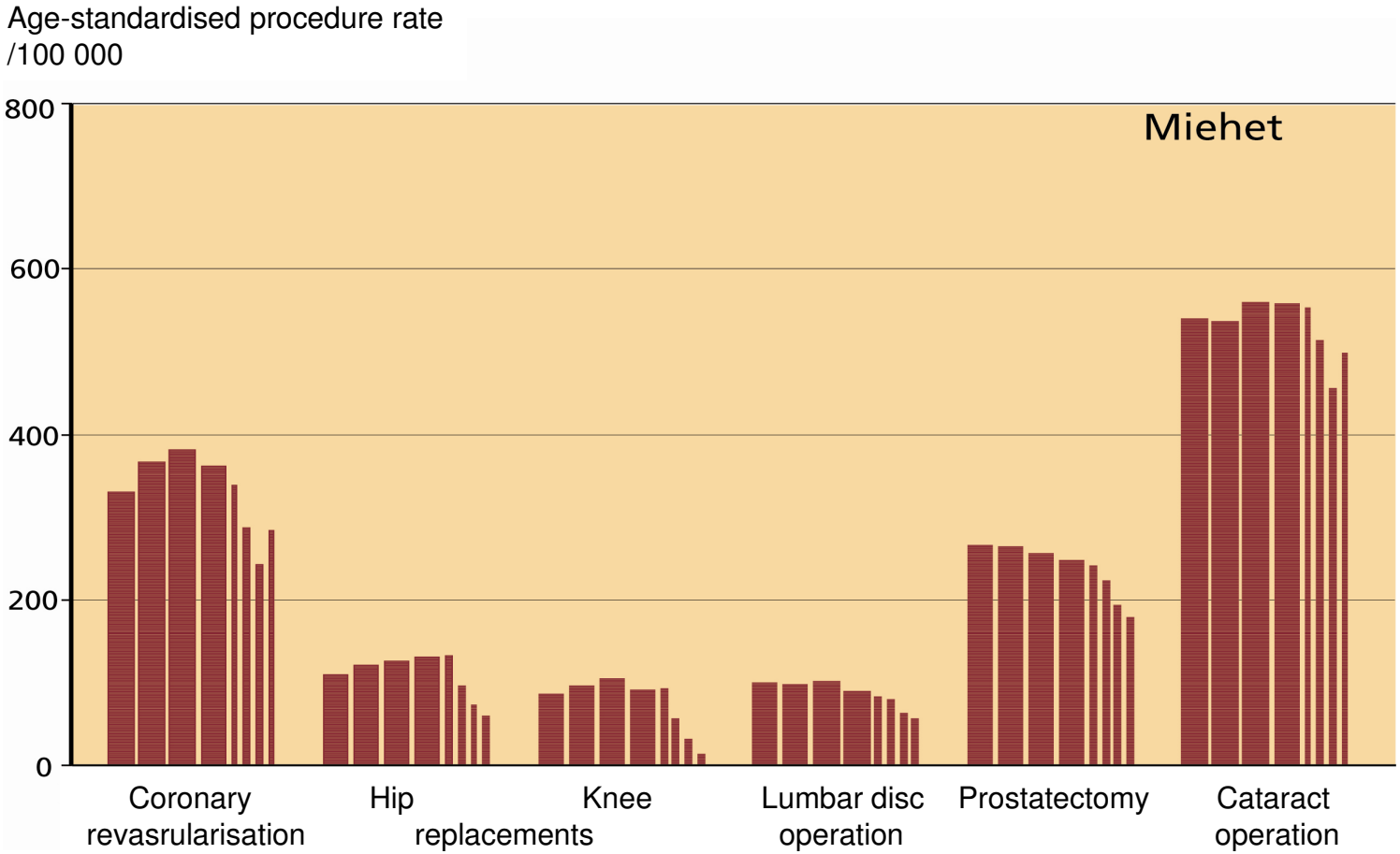
Event time diagram on register based data



Empirical studies on equity in health care

First elective procedure among 25-74 year-old men by income in 2003 /100 000



Manderbacka et al. 2008

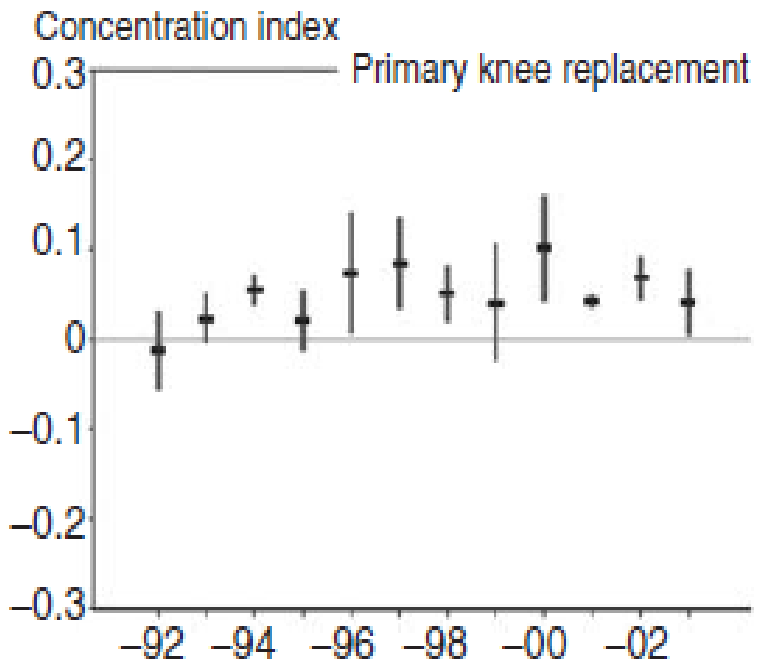
Access to six elective procedures by type of disadvantage among men aged 25-64 years in 2003

	Lowest income decile	Living alone	Long term unemployment	Living in sparsely populated area
Cataract operation	1.06 (0.96, 1.17)	1.10 (1.04, 1.16)	1.30 (1.18, 1.43)	0.97 (0.90, 1.05)
Prostatectomy	0.57 (0.50, 0.66)	0.87 (0.82, 0.93)	1.06 (0.96, 1.18)	0.94 (0.86, 1.02)
Lumbar disc op.	0.74 (0.66, 0.83)	0.79 (0.74, 0.84)	0.73 (0.64, 0.84)	1.54 (1.42, 1.68)
Endoproth. of hip	0.79 (0.68, 0.92)	0.88 (0.82, 0.95)	0.66 (0.55, 0.79)	1.24 (1.13, 1.37)
Endoproth. of knee	0.43 (0.34, 0.54)	0.86 (0.78, 0.94)	0.76 (0.61, 0.95)	1.62 (1.46, 1.81)
Revascularisation	0.88 (0.81, 0.96)	0.88 (0.84, 0.92)	0.93 (0.86, 1.00)	1.28 (1.21, 1.35)

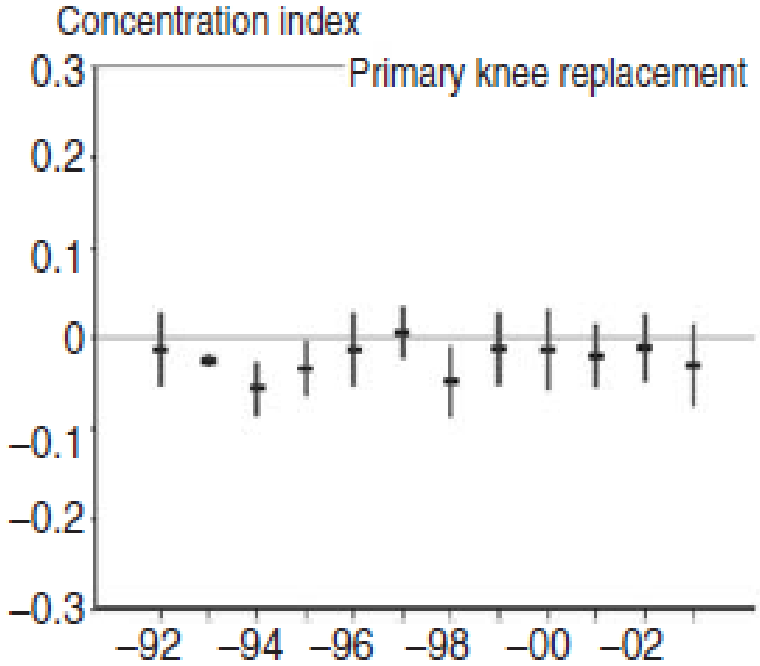
Manderbacka et al. 2008

First primary knee replacements in Men and Women, Concentration Indices and 95% CIs, Finland 1992-2003

Men

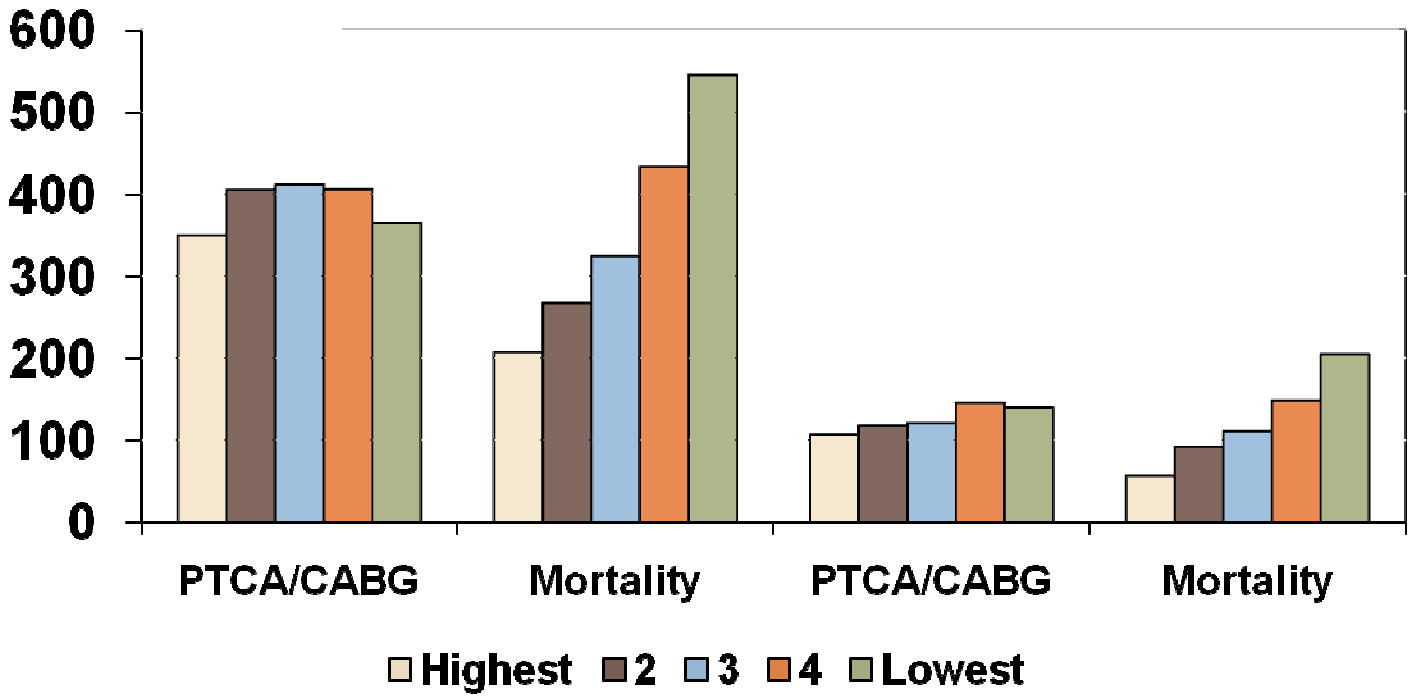


Women



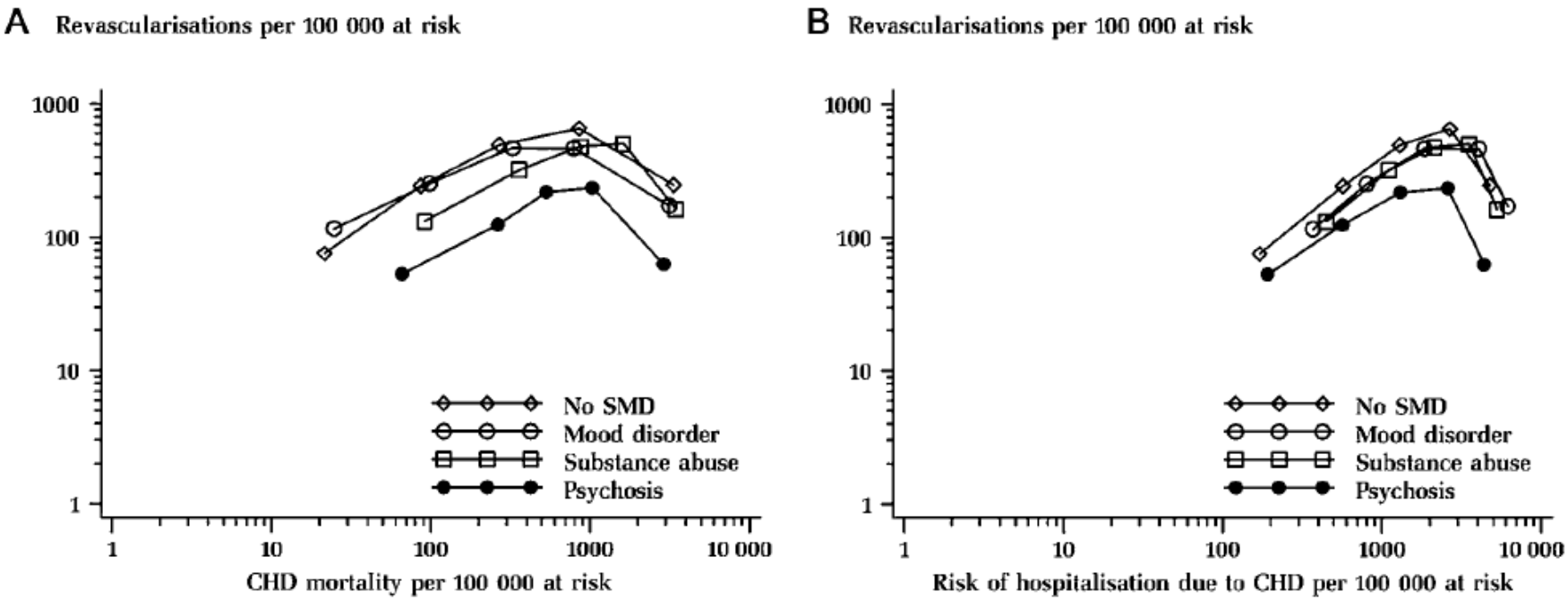
Manderbacka et al. 2009

Income group, coronary procedures (PTCA or CABG) and coronary mortality in 2003 in Finland 25-84 -year old men and women



Unpublished results from the Finnish Care Register

Effect of severe mental disorders on the rates of coronary revascularisation and mortality and hospitalisation due to CHD by 10-year age band across the age groups among men and women aged 40+. Finland 1998-2009



Manderbacka et al. 2012

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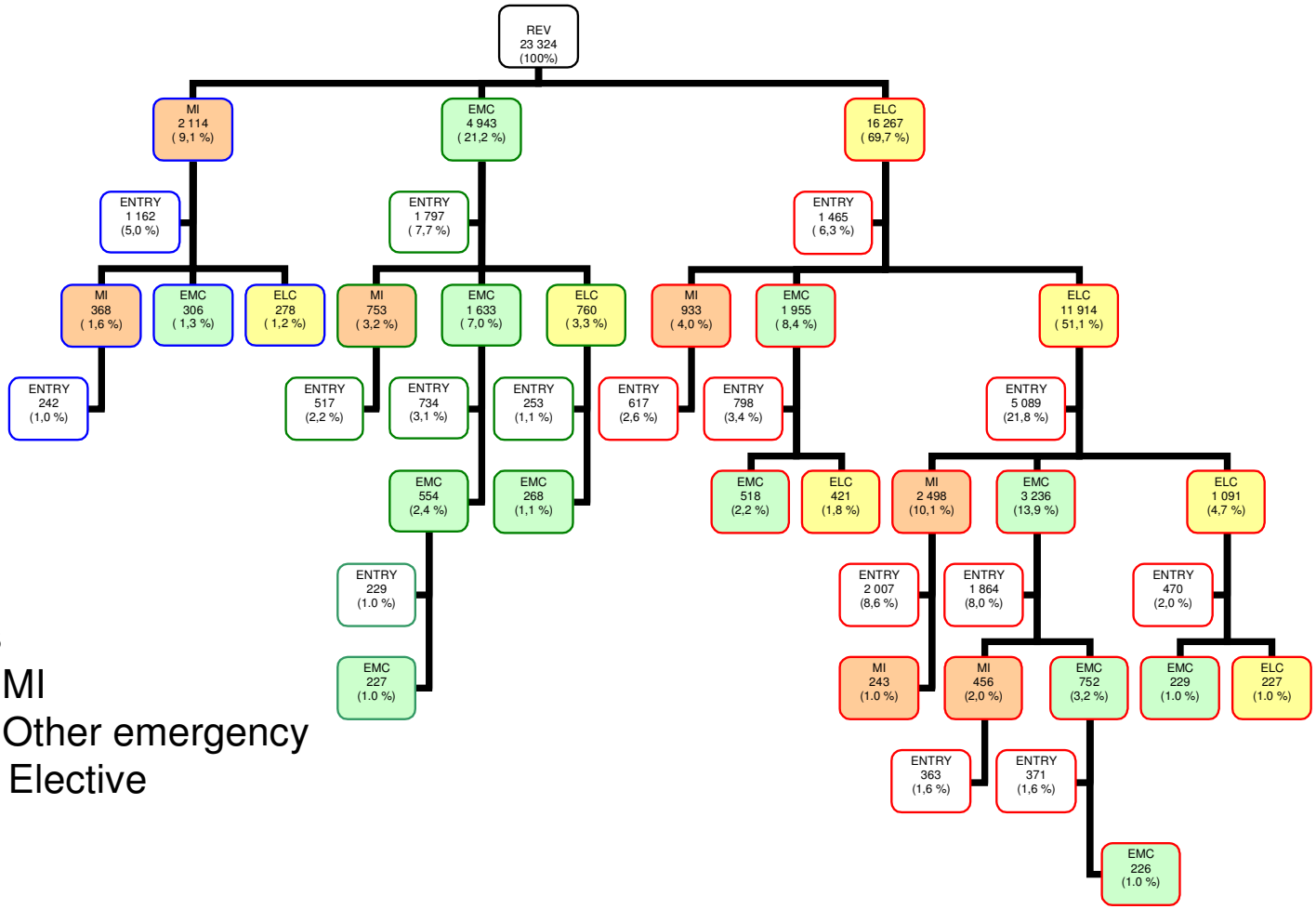
Pathways to revascularisation in 1996-1998



Admissions
- Orange = MI
- Green = Other emergency
- Yellow = Elective

Kajantie 2007

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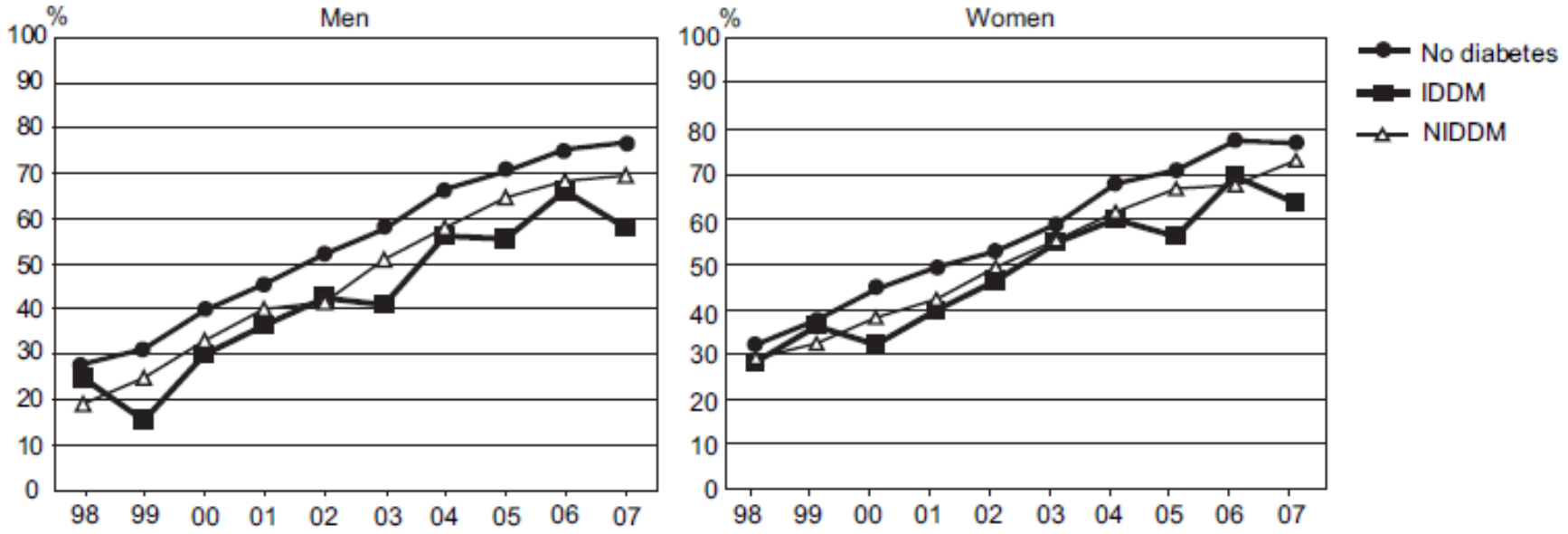
Odds Ratio (OR) for optimal pathway to revascularisation among CHD patients undergoing their first revascularisation in 1995-98

		No emergency admissions		One emergency admission	
		OR	95% CI	OR	95% CI
Education	Higher	1.00		1.00	
	Secondary	0.76	0.69 - 0.84	0.78	0.71 - 0.87
	Basic	0.74	0.68 - 0.80	0.73	0.67 - 0.80
Income	Highest	1.00		1.00	
	Middle	0.81	0.75 - 0.86	0.85	0.79 - 0.92
	Lowest	0.71	0.65 - 0.76	0.69	0.64 - 0.75

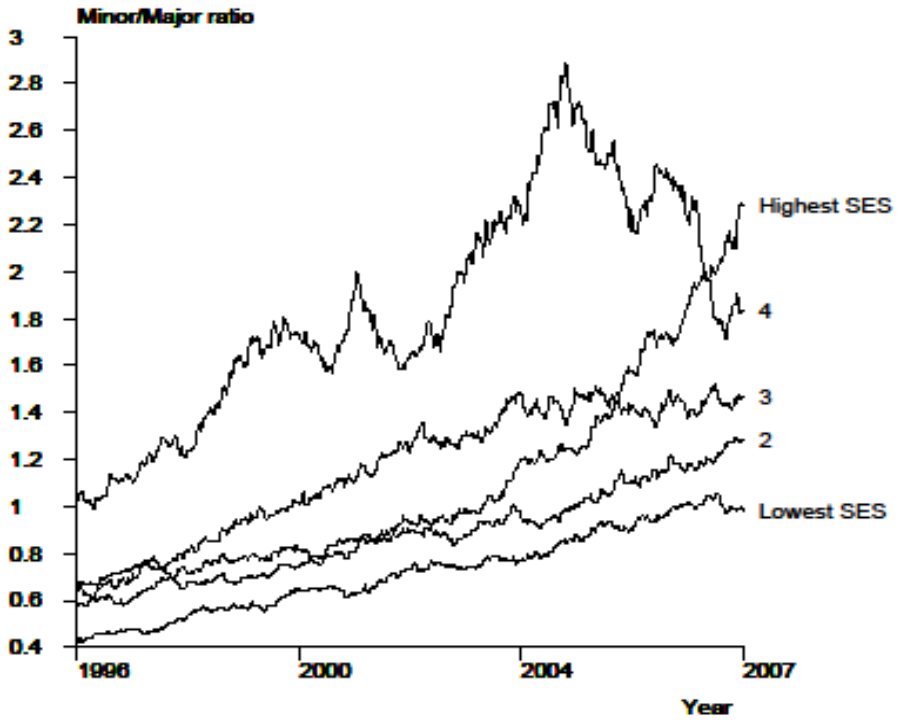
Kajantie 2007

Trends in coronary revascularisation performed at the first treatment period in 1998-2007



Vehko et al. 2011

Ratio of minor to major leg amputations among diabetic people by income, Finland 1996-2007



Venermo et al. 2012 (forthcoming)

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Concluding remarks

Strengths of Finnish administrative registers

- Valuable research infrastructure due to legislation allowing linkages & an Universal linkage key
- For researchers a relatively inexpensive way to collect data
- Allow large datasets
  - Representative data on the population
  - Easy to reach a high power for analyses
  - Allows research on relatively rare events and interactions
- Adds pay-off of administrative data gathering

Limitations of register research

- Register data = Secondary data
  - Not planned for research purposes
  - Lots of data but not so much information
  - Data drawn on administrative decisions, invoicing, accounting…
- Coverage of registers
  - Population Registers:
    - No / poor coverage for some groups: e.g. illegal immigrants
  - Health registers:
    - Entries based on contacts with health care
- Validity / reliability of register data?
  - Accuracy dependent on data collection process

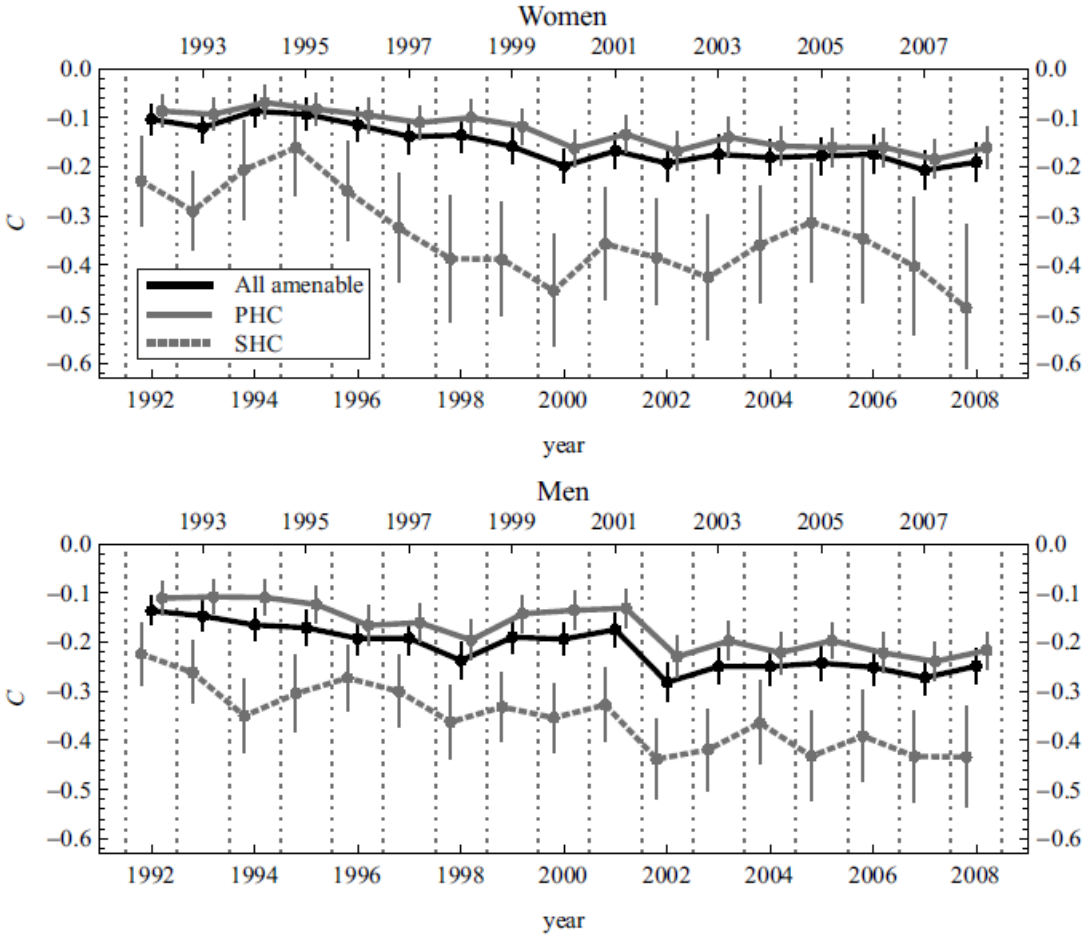
Experiences from Finland

- Costs of data
  - General principle: only extraction or other extra costs are requested but are often high for complicated linkages
- Inconsistency in laws regulating data accessability
  - Data confidentiality regulations and laws on different administrative registers are conflicting
- No clear regulations or procedures for international collaborative use of administrative registers
- Finland: a small and homogeneous country – transferability of experiences?

Contact:

Ilmo Keskimäki
National Institute for Health and Welfare / THL
email: ilmo.keskimaki@thl.fi

Relative income differences in amenable mortality in1992-2008 in Finland



Lumme et al. 2012 (forthcoming)

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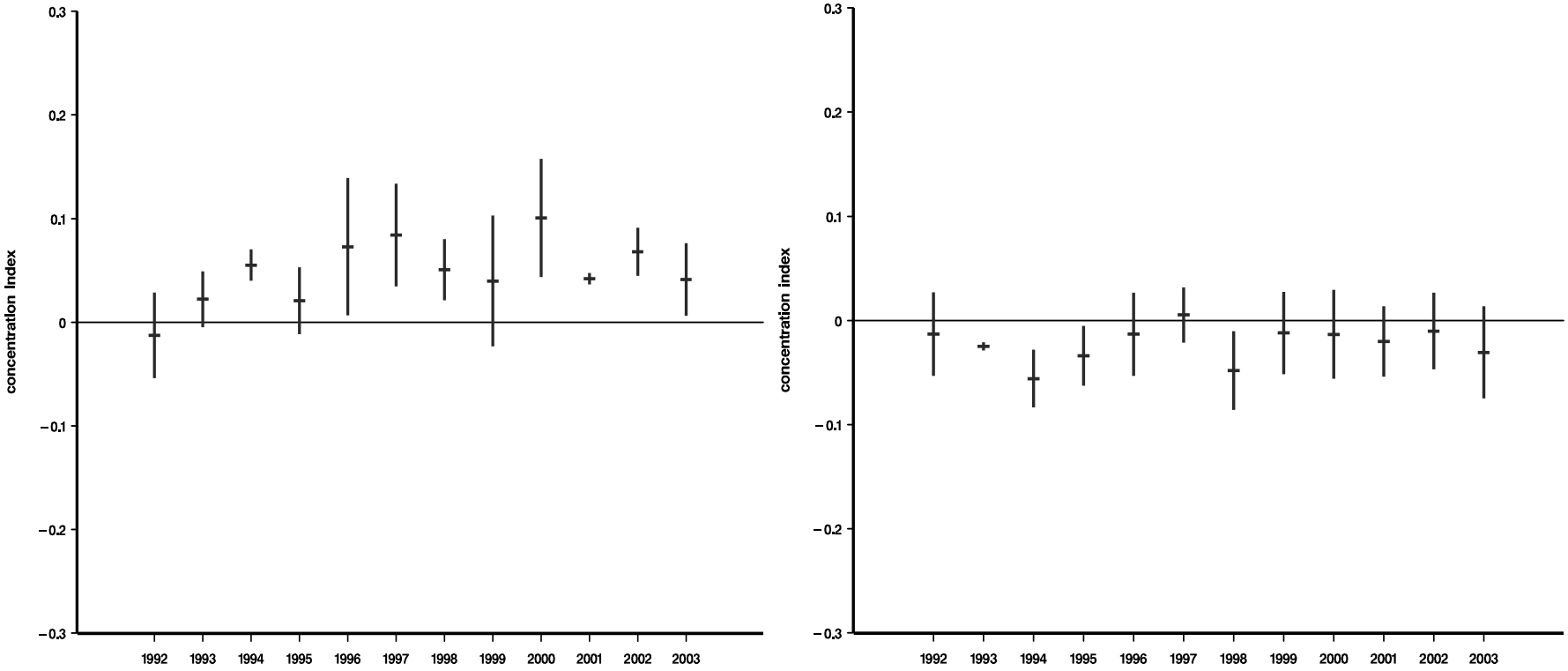

Manderbacka et al. 2006

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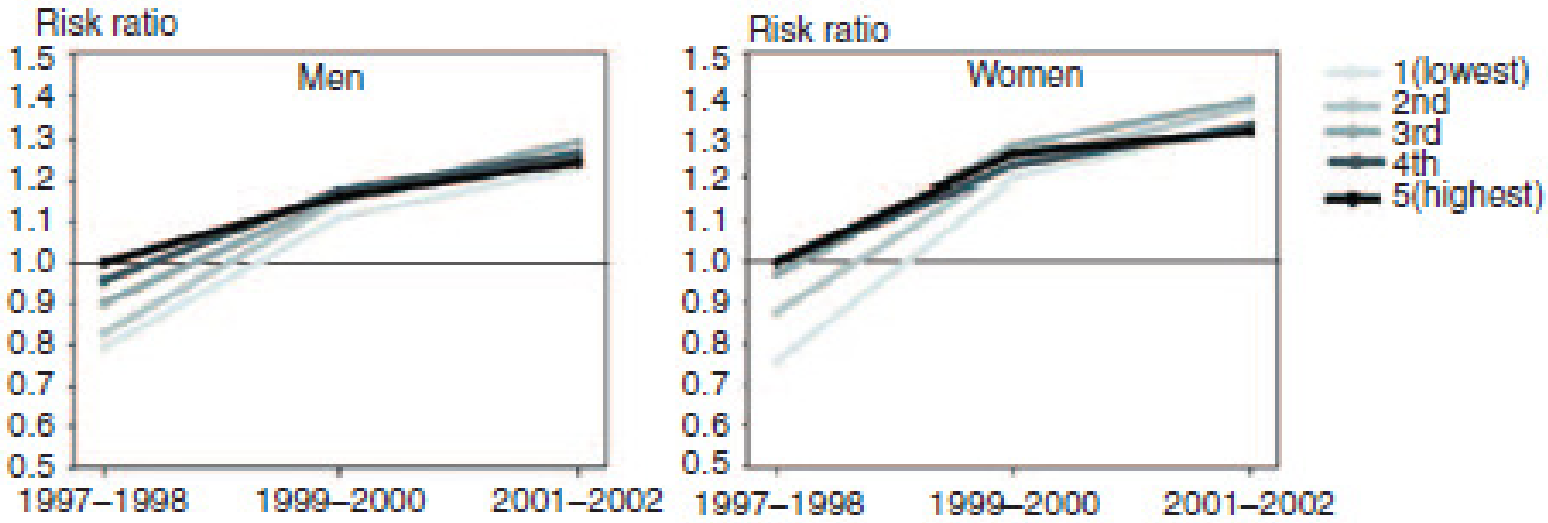
Adiminstrative registers in Finland

- Composed and maintained for administrative or statistical purposes; some examples:
- Social Insurance Institution (KELA)
  - Pays different kinds of social benefits to Finnish citizens and needs individual based registers for this purpose
- National Institute for Health and Welfare (THL)
  - Is a register and statistical authority and collects individual based data for these purposes, e.g. Finnish Hospital Discharge Register
- Statistics Finland (Tilastokeskus)
  - Is a statistical authority and collects individual data for compilation of different statistics contain personal data and individual level data on health and socio-economic situation etc.

Use of lipid lowering medication among newly diagnosed CHD patients with diabetes



Vehko et al. 2010

Personal identification number

- Introduced in 1964
- Assigned to all Finnish residents
- Used comprehensively to identify persons in hospitals, administrative registers, banks…

- E.g. “131052-308T” [generated PID, no one has this]
- ‘131052’: birthdate [ddmmyy]
- ‘-’ [can be also ‘+’ or ‘A’]: century of birth:
- 1800 (+), 1900(-), 2000(A)
- 308: three-figure individual number
- odd for males, even for females
- ‘T’: control character, calculated using special algorithm