

Available data resources for epidemiological study in Sweden

Weimin Ye, M.D., M.Sc., Ph.D.
Department of Medical Epidemiology and Biostatistics
Karolinska Institutet

Major Swedish Registries

Register	Year of start	No. Included/year
Causes of Death	1961	90,000
Cancer	1958	40,000
Inpatient	1964	1,700,000 (1993)
Medical birth	1973	90,000
Education	1985	NR
Fertility	1979	NR
Malformations	1965	1500
Cancer Environment	NR	Population census
Multi-generation	first-degree relatives for residents born in Sweden 1932 or later	
Total population		More than 8 m

Inpatient Registry

- Completeness

 - 1969 60% of the Swedish population

 - 1978 75%

 - 1983 85%

 - 1987 100%

- Approximately 1.7 m admissions/year since 1987

- Both somatic and psychiatric care

Information included in the Inpatient Registry

- NRN, gender, age, county, hospital, department, main diagnosis + 5–7 additional diagnoses, up to 6 operation codes, dates of admission and discharge, acute/planned care, way of admission, way of discharge, etc.
-

Quality of the Inpatient Registry

□ Incorrect or missing NRN

1970s	7%
1983	2%
1993	1.2%

Quality of the Inpatient Registry

Incorrect main diagnosis by coding level		
Coding level	Stringent criteria	Liberal criteria
5-digit level	17%	14%
4-digit level	14%	11%
3-digit level	12%	10%

Nilsson et al, 1994

Cancer risks followed by hip replacement

Follow-up via

- ❑ Cancer registry
- ❑ Causes of death registry
- ❑ Migration registry
- ❑ Total population registry

Signorello LB, Ye W, Fryzek JP, Lipworth L, Fraumeni Jr.JF, Blot WJ, McLaughlin JK, Nyren O. Cancer risk among hip replacement patients. J Natl Cancer Inst. 2001; 93:1405-1410.

Cancer risk after knee replacment

Fryzek JP, Ye W, Signorello LB, Lipworth L, Blot WJ, McLaughlin JK, Nyren O. The incidence of cancer among patients with knee implantations in Sweden, 1980–1994. *Cancer*. 2002;94:3057–3062.

Quality register existing in Sweden

- About 70–80 quality registers existing in Sweden
 - Usually initiated by clinicians
 - Now National Board of Health and Welfare is involved
 - Active or passive follow-up
-