

Register-based research — pros and cons a register-based researcher's view

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Presenter Disclosure Information

Register-based research — pros and cons

- I will not discuss off label use in my presentation.
- I have no financial relationships to disclose.
- I have nothing to disclose.

Main points

- Population-based registers are important for evaluating the effectiveness of healthcare systems.
- Register-based research can provide knowledge that can improve human health, for example, through identifying opportunities for disease prevention and improved treatment.
- Registers are not perfect; Register-based research is not easy!
- Intricate knowledge of the registers is required.
- Important to have a well-defined hypothesis.
- Combining register data and clinical data (e.g., Caroline Weibull's study) can be advantageous.
- Register-enhanced trials have exciting potential.

Validating the Swedish Cancer Registry [1]

The completeness of the Swedish Cancer Register 29

Table I. Number of malignant cancer cases, according to ICD-10: C00-C96 except C77-C79, in the Swedish Cancer Register in 1998. Number of cancer cases in the Hospital Discharge Register in 1998 and the number of cancer cases that were not registered in the Swedish Cancer Register in 1958–1998.

Site	Reported to the Cancer Registry in 1998		Reported to the Hospital Discharge Registry in 1998	Reported to the Hospital Discharge Registry only	Ratio (%) ¹
	Number of tumours	Number of persons	Number of persons	Number of persons	
Head and neck	988	982	1 140	99	10.1
Digestive organs	8 715	8 579	9 979	863	10.1
Lung	2 997	2 982	3 470	329	11.0
Soft tissue	1 316	1 312	1 527	165	12.6
Skin	4 232	4 092	1 653	398	9.7
Breast	6 225	6 091	6 118	84	1.4
Female genital organs	2 936	2 909	3 354	100	3.4
Urology	9 996	9 865	8 207	509	5.2
Nervous system	1 410	1 407	1 376	195	13.9
Leukemia and lymphoma	3 171	3 157	3 884	534	16.9
Other sites	784	784	1 302	153	19.5
Total	42 770	42 160	42 010	3 429	8.1

¹Ratio in per cent of the number of persons with a tumour reported to the Swedish Cancer Registry.

46% of cases in HDR only should have been reported to SCR.

Validating the Swedish Cancer Registry [2]

CANCER INCIDENCE IN SWEDEN 2011

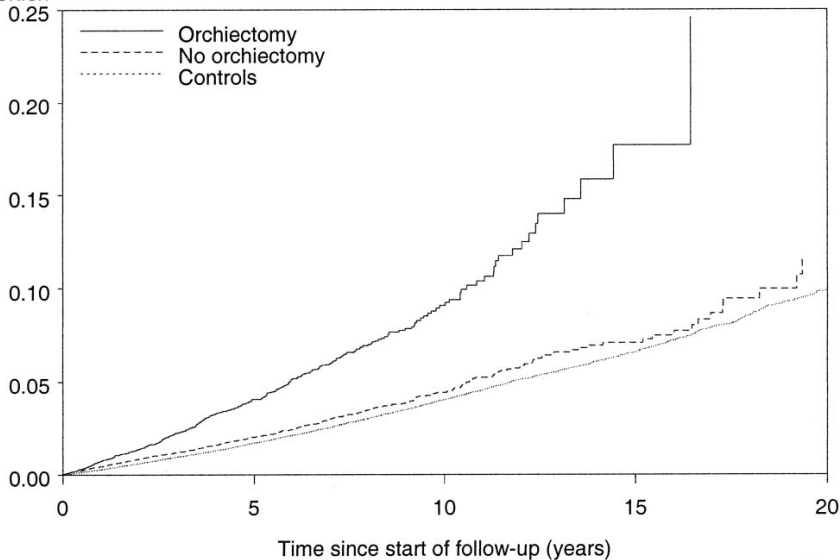
Table A1. Main cancer sites in not autopsied cases in the Cause of Death register 2011, but not in the Cancer Register 1958-2011

ICD-10	Site	Sex	All ages	Age at death		
				0-49	50-74	75+
C00-C97	All sites	M	1 289	25	391	873
		F	1 349	21	223	1 105
C16	Stomach	M	17	1	3	13
		F	22	1	3	18
C18-C21	Colon and rectum	M	100	3	26	71
		F	142	1	16	125
C22	Liver and intrahepatic bile ducts	M	105	2	49	54
		F	62	1	10	51
C23-C24	Gallbladder and biliary tract	M	30	0	6	24
		F	94	0	16	78
C25	Pancreas	M	174	3	60	111
		F	216	1	34	181
C26	Other and ill-defined digestive organs	M	18	0	5	13
		F	27	0	0	27
C34	Bronchus and lung	M	233	3	81	149
		F	204	2	52	150

A typical register-based study [3]; androgen deprivation and risk of hip fracture

- Compare incidence of hip fracture among,
 - 17,731 men diagnosed with prostate cancer treated with bilateral orchiectomy.
 - 43,230 men diagnosed with prostate cancer not treated with bilateral orchiectomy.
 - 362,354 men randomly selected from the general population.
- Cancer patients identified from the cancer registry.
- Matched controls identified from the total population register.
- Exposure (orchiectomy) and outcome (femoral neck fracture) identified from inpatient register.

Incidence
Proportion



Caroline Weibull's study

- Population-based registers were not sufficient; information on treatment and date of relapse were crucial.
- We used data collected by Ingrid Glimelius, where additional information (e.g., treatment and relapse) was obtained from medical records.
- Matching with the medical birth register provided good data on pregnancies.

Enhancements

- Supplement the register data with collections of additional clinical data.
- Registry-based randomized controlled trials [4], also called 'pragmatic trials' [5].
- Still need to consider the strengths/weaknesses of the registers and only use such studies to answer suitable research questions.
- Registry-based randomized controlled trials are usually performed to address comparative effectiveness research questions in real-world settings when high-quality registries are available.
- Also useful for studying treatment side-effects in a real world setting.

References

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- [4] Li G, Sajobi TT, Menon BK, Korngut L, Lowerison M, James M, *et al.*. Registry-based randomized controlled trials- what are the advantages, challenges, and areas for future research? *J Clin Epidemiol* 2016;.
- [5] Thabane L, Kaczorowski J, Dolovich L, Chambers LW, Mbuagbaw L, *CI*. Reducing the confusion and controversies around pragmatic trials: using the cardiovascular health awareness program (CHAP) trial as an illustrative example. *Trials* 2015;**16**:387.