

NordForsk PhD course in Register-Based Epidemiology

Introduction to the Nordic register system

Introduction

As part of the information technology increase, increasing use of registers

Many research questions answered fast and efficiently

Other possibilities increasingly difficult

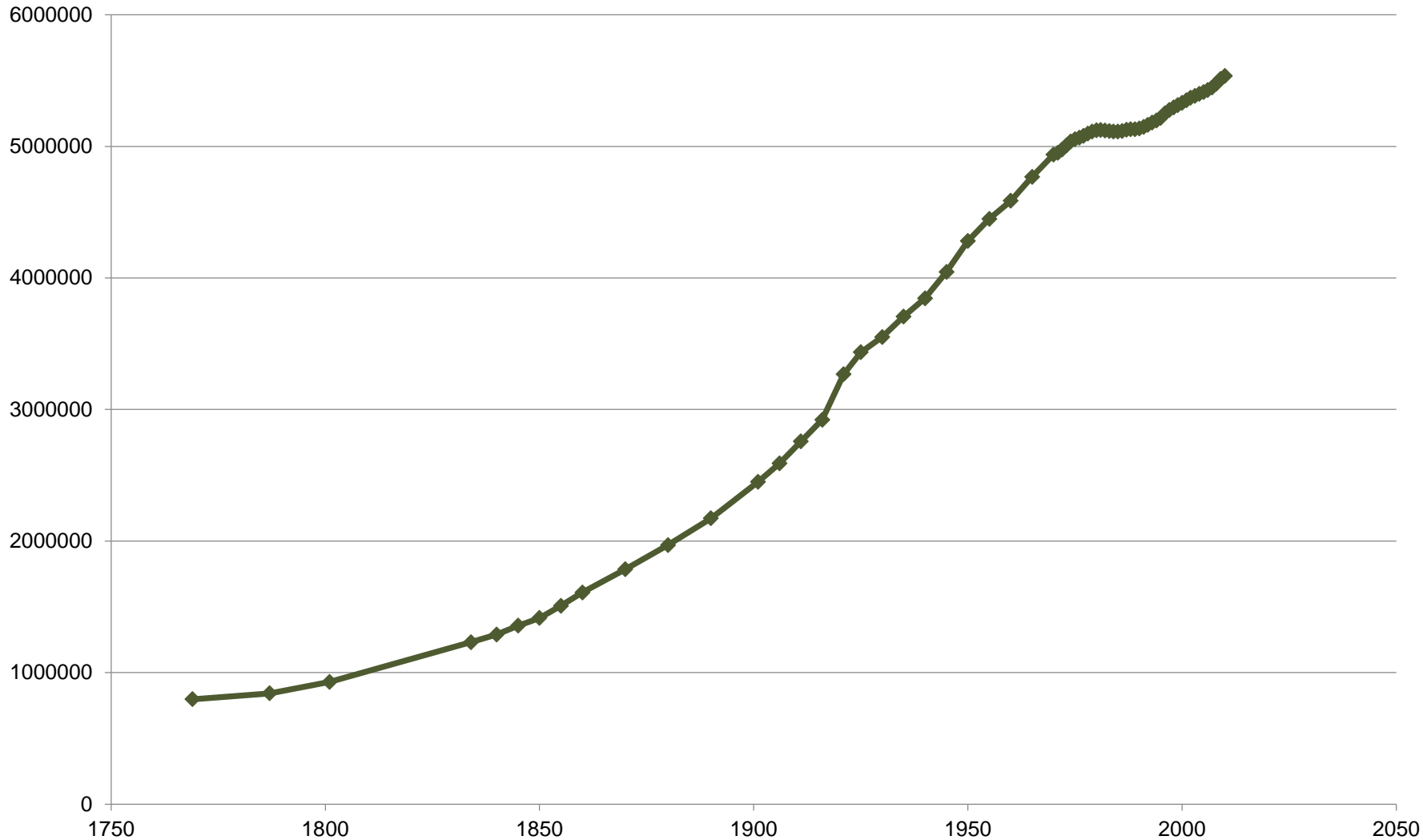
- Decreasing participation rates
- Privacy restrictions in many countries (e.g. moving persons (flytteblanketten) in Denmark)
- Clinical trials more expensive

History

The Nordic tradition for registers

- In Denmark all births and deaths has been registered in church records since 1645
- First census
 - Denmark: 1769
 - Finland: 1634-1651
 - Norway: 1430
 - Sweden: 1751
- First disease register: Norwegian Leprosy Register in 1856

Population size - Denmark



Nr	Dødsdagen (Aar og Datum) og Dødsstedet. (Paa Landet: Byen, Sognet og Herredet. I Købstad: Købstaden og tillige Sognet, hvis der i Byen er mere end 1 Sogn).	Begravelsesstedet (Kirkegaardens, Sognets og Herredets (Købstadens) Navn) og Begravelsesdagen (Aar og Datum).	Den afdødes fulde Navn (saa vidt muligt efter forevist Daabs- eller Fødselsattest eller ved Eftersyn i Kirke- bogen).	Den afdødes Stilling og Bopæl (s: sidste faste Opholdssted, betegnet paa Landet ved Byen, Sognet og Herredet, i Køb- stad ved Købstaden, Gaden og Husnummeret) samt, for saa vidt Oplysning derom kan erholdes, tillige den afdødes Fødested og Forældrenes (ved nægte fødte Moderens) fulde Navn, Stilling og Bopæl. Hvis den afdøde var eller vides at have været gift, an- føres tillige dette samt, saa vidt muligt, Ægtefællens fulde Navn og deres sidste fælles Bopæl.	Alder. (Naar den afdøde var over 1 Aar, angives Alderen med det fulde Aar).	Af hvilken Præst Begravelsen er forrettet.	Anmærk-
0	1906 - 22 November. Slukkerup, Kallemandsogn, Vester Flakkebjerg Herred.	29 November 1906.	Karen Mikaelsdatter	Opholdt sig midlertidig i Sørbørg, Vestergaard, Vester Flakkebjerg Herred, født i Ejlslevsøge, Ekte efter Peder Hans Jensen Vissrup.	86 Aar	Pastor Petri	
1907 1	1907 - 19 januar. Allehus, Holsteinborg Sogn, Vester Flakkebjerg Herred.	Holsteinborg Kirke- gaard 24 januar 1907.	Anna Margrethe Brodthagen.	Ekte efter afdøde Kjellermand, Albrecht Danischer Ingeniør og Dische af Allehus ved Holsteinborg, Holstein- borg Sogn, Vester Flakkebjerg Herred. født i Nyrup, Fjerrendal Sogn. Datter af Gymnasistlærer Lars Brodthagen af Nyrup.	89 Aar	Pastor Petri	
2	1907 - 29 Marts Bissrup, Holsteinborg Sogn, Vester Flakkebjerg Herred.	Holsteinborg Sogns Kirkegaard. 1907 - 4 April	Karen Marie Jørgensen.	Ekte efter afdøde Kvarmand Peter Larsen i Bissrup, Holsteinborg Sogn, Vester Flakkebjerg Herred, født i Nyrup, Fjerrendal Sogn. Datter af regitte Karen Hansdatter af Nyrup.	75 Aar	Pastor Petri	
7	1907 - 15 Juni. Bissrup, Holsteinborg Sogn, Vester Flakkebjerg Herred	Holsteinborg Sogns Kirkegaard 21 Juni 1907.	Karen Jensen datter.	Ekte efter afdøde Kvarmand og Dischekarer Christian Jensen Bissrup, Holsteinborg Sogn, Vester Flakkebjerg Herred, født i Bissrup, Datter af Kvarmand Jøns Jørgensen og Kvarter Anne Olddatter, Bissrup.	81 Aar	Pastor Petri	
8	1907 - 13 April Bissrup, Holstein- borg Sogn, Vester Flakke-		Karoline Lofie Nielsen.	Gift med Badermand Peter Jørgensen i Bissrup	35 Aar.		

HOVED LISTE

Byraas eller Stedernes Navne med Angivelse af Gaardens, Husenes osv. Matr.-Nr.	Familierets Lebe-Navne Søn "Familie" haves ogsaa som "familie" haves, men ikke Logerende. - Paa Logerende (alene) og Paa Logerende (alene) indføres (uden Modtælling) kun den m. Familien med tilhørende Lebe-Navne.	Samtlige Personers Navn		Kønnet Mandkøn (M) Kvindkøn (K)	Fødsels-dag	Fødsels-år	Fødested Der angives: København, Frederiksberg, Købstadens eller Sognets og Amtets Navn. For dem, der er født udenfor det egentlige Danmark, skrives f. Eks. Pærerne, Grønland, Island eller vedkommende fremmede Lands Navn.	Statsborgerforhold Personer, der har dansk Indfødsret, skrives „dansk“; andre anføres her Navnet paa det Land, hvori de har Statsborgerret (Island, Sverige, Tyskland, Forenede Stater o. s. v.)	Ægteskabelig Silling Ugift (U) Gift (G) Bøkem. eller Enke (E) Separeret (S) Fraakl. (F)	Silling i Familien Husfader, Husmoder; Barn, Slægtning o. l.; Husassistent, Tjenestekar, - pige, Pensioner, Logerende. Hvor en Familie er indligeret hos en anden Familie, angives dette særskilt ved Betegnelsen „Indligeret Familie“. For den indligerede Families Vedkommende anføres dog desuden paa sædvanlig Maade: Husfader, Husmoder o. s. v.	Erhverv eller Livsstilling Hvis nogen har flere Erhverv, anføres disse, Hovederhvervet først. Har Husmoderen eller Datterne særlige Erhverv, anføres disse. Man angiver udtrykkeligt det Pøg, man arbejder i, og Æns Silling i Pøget. Lever man hovedsagelig af Formue, privat Understøttelse, Alderdomsunderstøttelse, Fattighjælp, anføres dette, men tillige Erhvervet. Forhenværende Næringsdrivende o. l. sættes „Ih.v.“ foran tidligere Livsstilling.	Her anføres: Bopæl d. 5. Novbr. 1924 Bopæl i Byerne angives ved: Bynavn, Gade og Hus-Nr. Bopæl paa Landet angives ved: Kommune og Postadresse.	Denne Rubrik udfyldes ikke
		Efternavn	Samtlige Fornavne O rigtigt Sidskaldes det endeligt anvendte Fornavn særskilt angives.										
5		Jenssen Hans Thord	M	17/1	1885	Holsten	D.	G.	Husf.	Holsten	Hans Thord	Alles	
		Jenssen Thord	K	23/1	1885	Thorslev	D.	G.	Husm.		Hans Thord	Alles	
		Jenssen Lars Thord	M	2/1	1911	Thorslev	D.		Barn		Hans Thord	Alles	
		Thord Lars Thord	M	23/1	1889	Thorslev	D.	G.	Husf.	Holsten	Hans Thord	Alles	
6		Jenssen Thord	M	28/1	1862	Thorslev	D.	G.	Husf.	Holsten	Hans Thord	Alles	
		Jenssen Thord	K	2/1	1865	Thorslev	D.	G.	Husm.		Hans Thord	Alles	
7		Jenssen Thord	M	28/1	1900	Thorslev	D.	G.	Husf.	Holsten	Hans Thord	Alles	
		Jenssen Thord	K	28/1	1900	Thorslev	D.	G.	Husm.		Hans Thord	Alles	
8		Jenssen Thord	M	1/1	1888	Thorslev	D.	G.	Husf.	Holsten	Hans Thord	Alles	
		Jenssen Thord	K	1/1	1889	Thorslev	D.	G.	Husm.		Hans Thord	Alles	
9		Jenssen Thord	M	17/1	1877	Thorslev	D.	G.	Husf.	Holsten	Hans Thord	Alles	
		Jenssen Thord	K	1/1	1880	Thorslev	D.	G.	Husm.		Hans Thord	Alles	
		Jenssen Thord	M	2/1	1870	Thorslev	D.	G.	Husf.	Holsten	Hans Thord	Alles	
		Jenssen Thord	M	23/1	1879	Thorslev	D.	G.	Husf.	Holsten	Hans Thord	Alles	
10		Jenssen Thord	M	2/1	1870	Thorslev	D.	G.	Husf.	Holsten	Hans Thord	Alles	
		Jenssen Thord	K	2/1	1870	Thorslev	D.	G.	Husm.		Hans Thord	Alles	
		Jenssen Thord	M	2/1	1870	Thorslev	D.	G.	Husf.	Holsten	Hans Thord	Alles	
		Jenssen Thord	K	2/1	1870	Thorslev	D.	G.	Husm.		Hans Thord	Alles	
		Jenssen Thord	M	2/1	1870	Thorslev	D.	G.	Husf.	Holsten	Hans Thord	Alles	
		Jenssen Thord	K	2/1	1870	Thorslev	D.	G.	Husm.		Hans Thord	Alles	

10-9

Midlertidigt nærværende, der har fast Bopæl andetsteds, opføres paa Skemaets Bagside.

7

History (2)

Identification number:

1947: Sweden (personnummer)	(YYMMDD-RRRC)
1953: Iceland (kennitala)	(DDMMYY-RRCA)
1964: Norway (fødselsnummeret)	(DDMMYY-RRRCC)
1964/1967: Finland (henkilötunnus)	(DDMMYY-ÅRRRC)
1968: Denmark (Greenland 1972) (CPR-num)	(DDMMYY-ÅRRC)

All persons entered in the population register get a personal identification number – slight differences between countries

Does never change (almost)

History (3)

Existence of more administrative registers

Trigger discussions on privacy issues

If public attitude becomes negative, politicians may become reluctant

Linking of administrative data - register administrator knows "everything" about every single citizen

Privacy >< precision

We all have a right to privacy

We routinely promise anonymity to study subjects

- Directly through informed consent procedures
- Indirectly through our correspondence with Institutional Review Boards

How much is enough to identify persons

Identified

Pseudonymization

Anonymization

Data may not be anonymized if you have auxiliary information

History (4)

Important that general public appreciates and understands the benefits

- Cost efficiency
- Persons, households and firms can live in peace
- Data security is better because of the reduction in the number of persons handling the data

Seem to be accepted by most citizens

A register

Definition dictionary: Etymology (register): Bring back, collect, gather
Merriam-Webster define the noun 'register' to mean

- 'a written record containing regular entries of items or details'
- 'a book or system of public records'
- 'an official record book'
- 'an automatic device registering a number or a quantity'

Others emphasize the use of registers for program administration and patient follow-up or focus on the uniformity and comprehensiveness of data collection

Last (1995) define a register as the actual listing of the cases; in formal terms, the register is the system of ongoing registration (and possibly follow-up) together with the register - this means that, conceptually, a register can just be a collection of records

Register

Definition United Nations Economic Commission for Europe (2007):

- A register is a systematic collection of unit-level data organized in such a way that updating is possible
- Each unit in the register can always be identified
- Only requirements for the content of the register

*“A register aims to be a **complete list** of objects in a specific object set or population and it should contain information the **object’s identity** to that it can be updated with new variabel values for that object.”*

- Wallgren & Wallgren (2007), p. 42.

This means:

- An anonymised register is not a register
- A sample from a register is not a register

Register versus registry

Base registers

One type of administrative registers

Of great importance for whole register system

Defines important objects

Base registers

Must be able to provide data for different populations

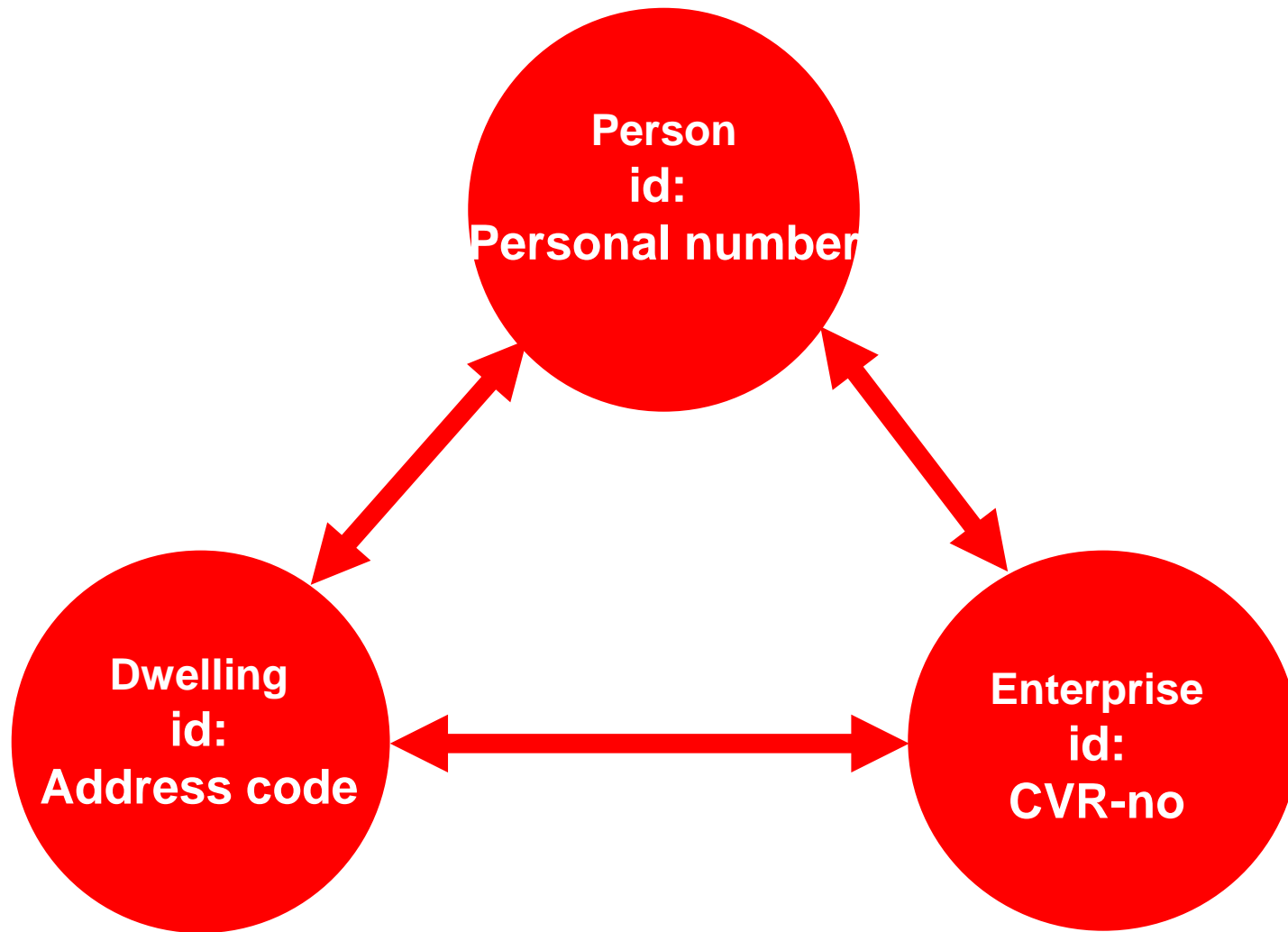
E.g., the CRS have persons resident in a country

- The CRS should, however, also give information on people working in the country but living elsewhere
- Further, even units that are no longer active should be kept in the base registers for historical reasons

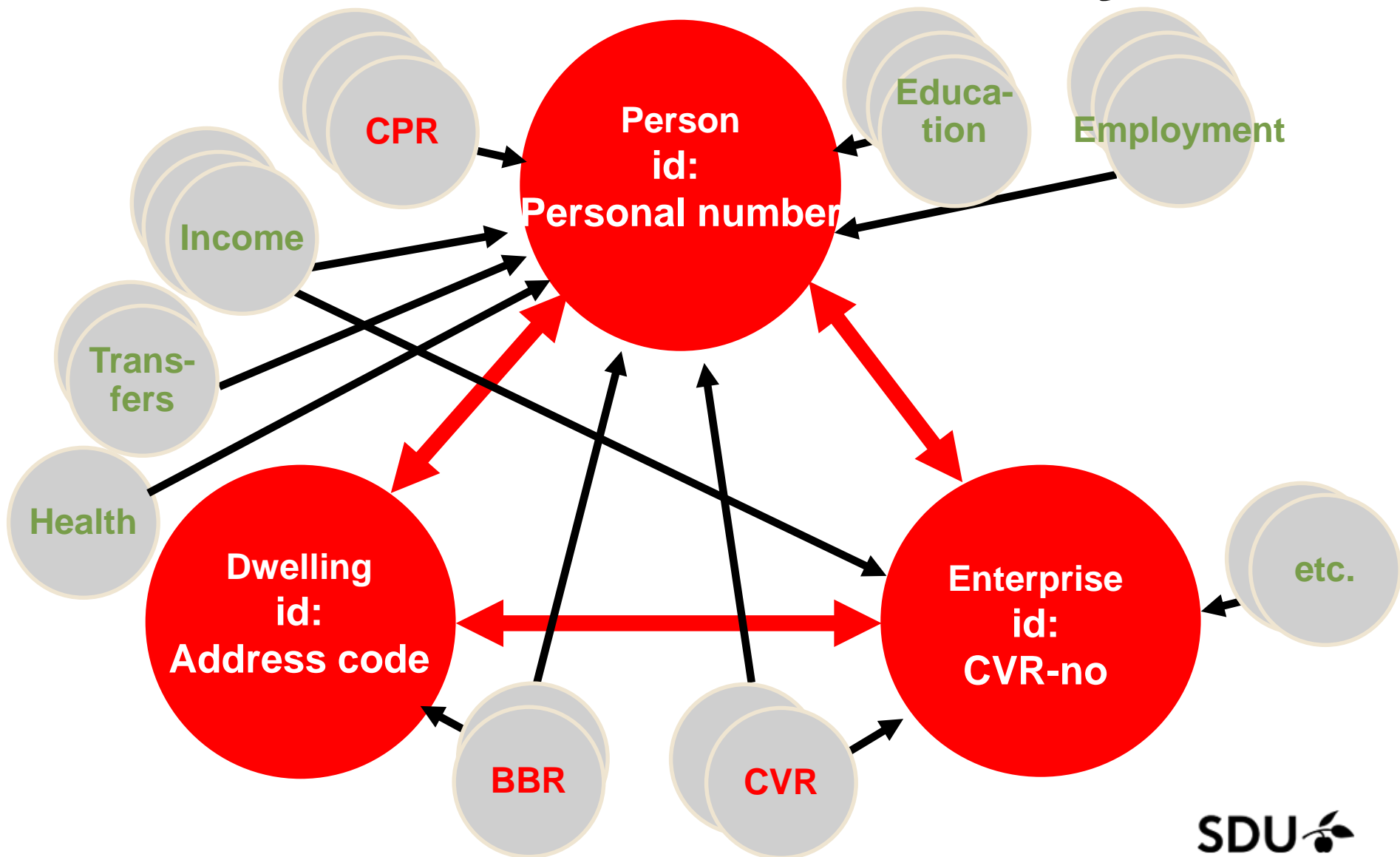
Nordic countries, at least 3 base registers are defined:

- Register on persons
- Business register
- Register on properties

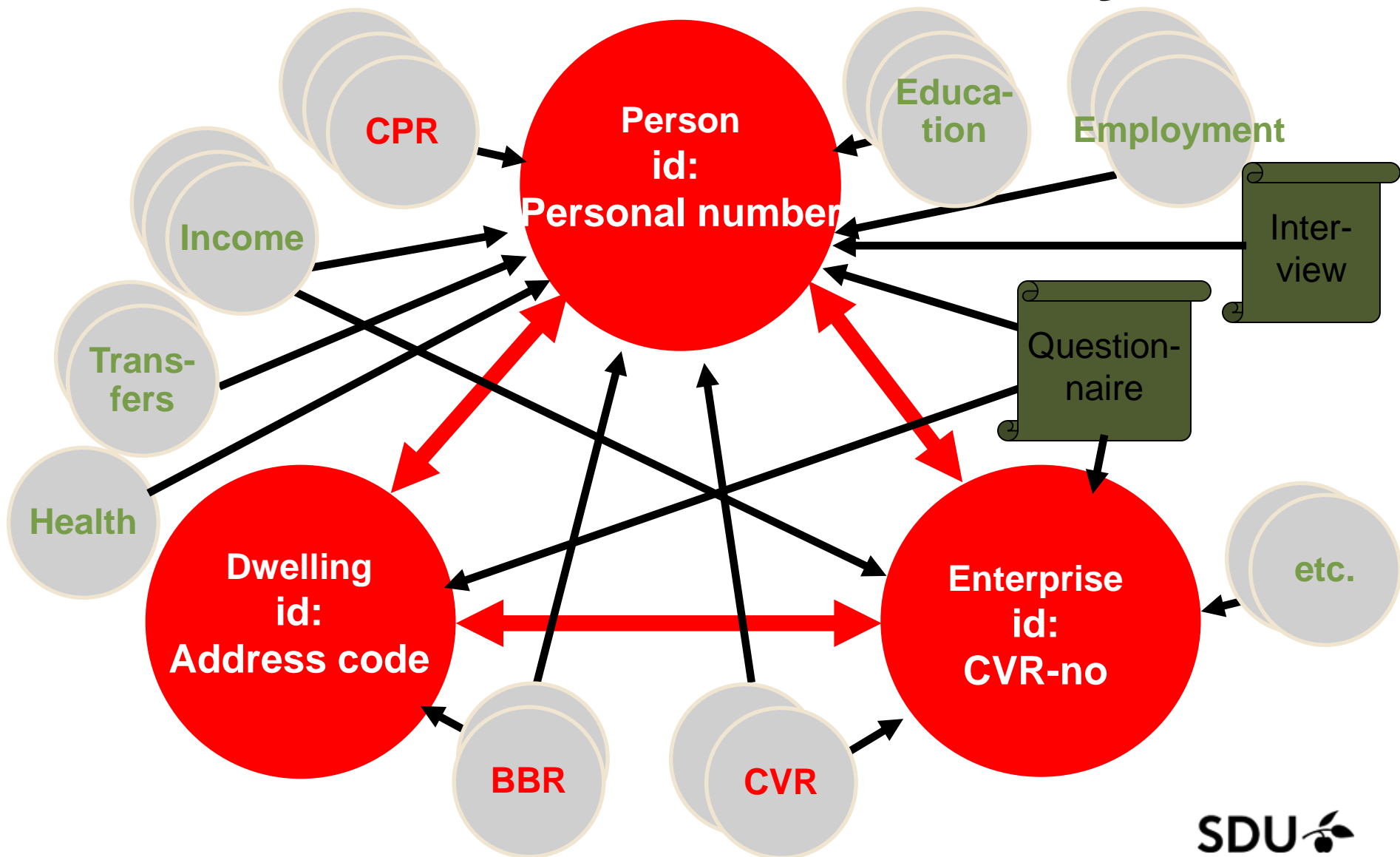
The overall statistical system



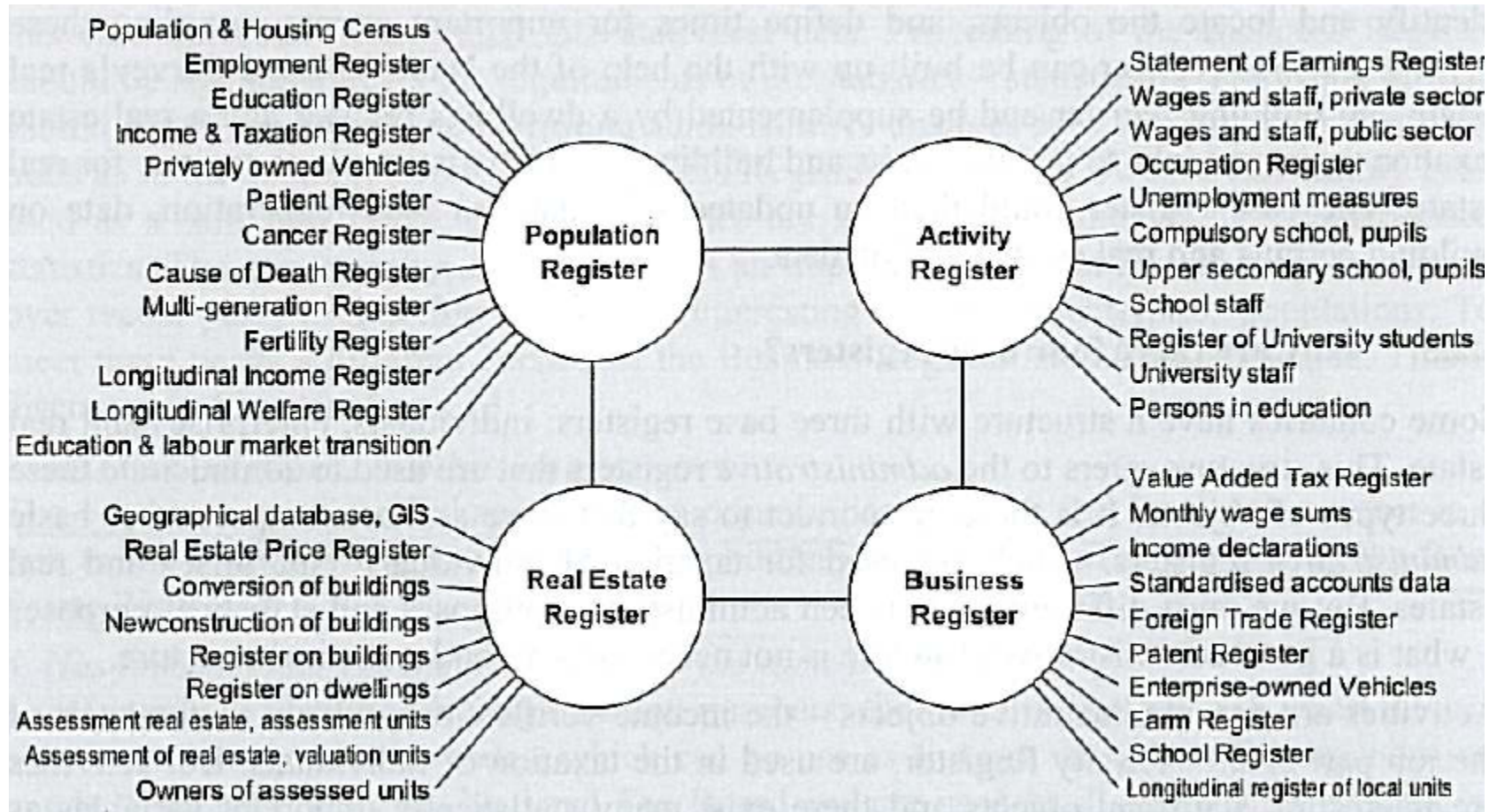
The overall statistical system



The overall statistical system



Base registers in Sweden



When an Entire Country Is a Cohort

Denmark has gathered more data on its citizens than any other country. Now scientists are pushing to make this vast array of statistics even more useful

For years, any woman who got an abortion had to accept more than the loss of her fetus. For some unknown reason, she also faced an elevated risk for breast cancer. At least that was what several small case-control studies had suggested before Mads Melbye, an epidemiologist at the Statens Serum Institute in Copenhagen, undertook the largest effort ever to explore the link. He and his colleagues obtained records on 400,000 women in Denmark's national Abortion Register, then checked how many of the same women were listed in the Danish Cancer Register. Their foray into the two databases led to a surprising result: As they reported in *The New England Journal of Medicine* in 1997, there appears to be no connection between abortions and breast cancer.

Their success underscores the value of a trove of data the Danish government has accumulated on its citizenry, which today totals about 5 million people. Other Scandinavian countries have created powerful database systems, but Denmark has earned a preeminent reputation for possessing the most complete and interwoven collection of statistics touching on almost every aspect of life. The Danish government has compiled nearly 200 databases, some begun in the 1930s, an everything from medical records to socio-economic data on jobs and salaries. What makes the databases a plum research tool is the fact that they can all be linked by a 10-

digit personal identification number, called the CPR, that follows each Dane from cradle to grave. According to Melbye, "our registers allow for instant, large cohort studies that are impossible in most countries."



Beauty in numbers. These Danish twins starred in a variety show at the turn of the 20th century; now it's their medical records, part of a database, that are in demand.

But Melbye and other scientists think they can extract even more from this data gold mine. They argue that not enough money is being spent on maintaining and expanding existing databases, and they say that red tape is hampering studies that require correlation of health and demographic data. The problem is that, while they have unfettered access to more than 80 medical databases maintained

by the Danish hospitals, their databases covers Denmark is tight mark won't also its premises dat ceases for acc unwieldy and e Statistics D to release data concerns. "Th dence that inf individuals doe situation," says Last n ter Br to be datab can b told 5 entifi W can y the U has 8 twins tive - life of Sc Kaan tappi whic twins

ing more than older, Christer genes about a man longevity by the unamb the Danish Tw The health able for prob smaller stud

The Epidemiologist's Dream: Denmark

If the planners of a U.S. study of children's health could work in an ideal world, it might be Denmark. Epidemiologists there finished enrolling a cohort of 100,000 pregnant women into a mother-and-child research project last September and expect to finish collecting data from the children over the next year. The entire survey—which is large for this country of 70,000 annual births—is to be completed in 2005 for about \$15 million, a tiny fraction of what the cost would be in the United States.

The Danes didn't design their Better Health for Mother and Child cohort study to answer specific questions or conduct long-term follow-up, as the Americans plan to do (see main text). Instead, they aim to create a databank that generations of researchers can mine and use as a starting point for studies of how medications, infections, nutrition, and even psychological factors affect pregnancy and child health.

Physicians have recruited volunteers among women making their first pregnancy visit. Participants give two blood samples during pregnancy and cord blood when the baby is born. The samples are saved for later use, including possibly for genetic studies. The mothers also answer a detailed questionnaire concerning nutrition; in an 18-month follow-up, they give information on their health and environmental exposures. The public health system is funding the study, with support from private and public foundations.

"Because the Danish population is probably the world's best registered, Denmark is the ideal place for such studies," says epidemiologist Mads Melbye, a steering group member from Statens Serum Institute

in Copenhagen. Each citizen has a personal identification number that can be used to track data in centralized health care records, disease registries, and a population registry. Even centralized school records may be used. "It's an epidemiologist's dream," says Mark Klebanoff of the U.S. National Institute of Child Health and Human Development, who says tracking subjects is one of the costliest aspects of long-term U.S. studies.

Norway, which has a system like Denmark's, is launching a mother-child study that will pool data with the Danish group's. Both benefit from streamlined management. It's difficult to get things done with too many decision-makers, says Melbye: "Running such a large study has taught us many things, but the chief lesson is that it is essential to put a very small group of people in charge."

Results are already beginning to trickle out of the Danish study. For example,

one group published an article in *The Lancet* last November that disproved the existing consensus view that a fever early in pregnancy increases the risk for miscarriage. That's just the beginning: Denmark's scientific ethics committee has so far given the green light to more than 70 research protocols based on the mother-child study.

—LORE FRANK

Lore Frank is a science writer in Copenhagen.



Ready subjects. Denmark's 18-month-long birth cohort survey will collect data from mothers and newborns for a new database.