

Helseregistre i de nordiske lande

Danmark

– nytte av helseregistre

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I dag

Organiseringen af sundhedsregistre i Danmark

Hvad kræves for adgang

Eksempler på brug af registre (forskning, kvalitetssikring, overvågning)

Registre: Lang historie

Meget lang endda...

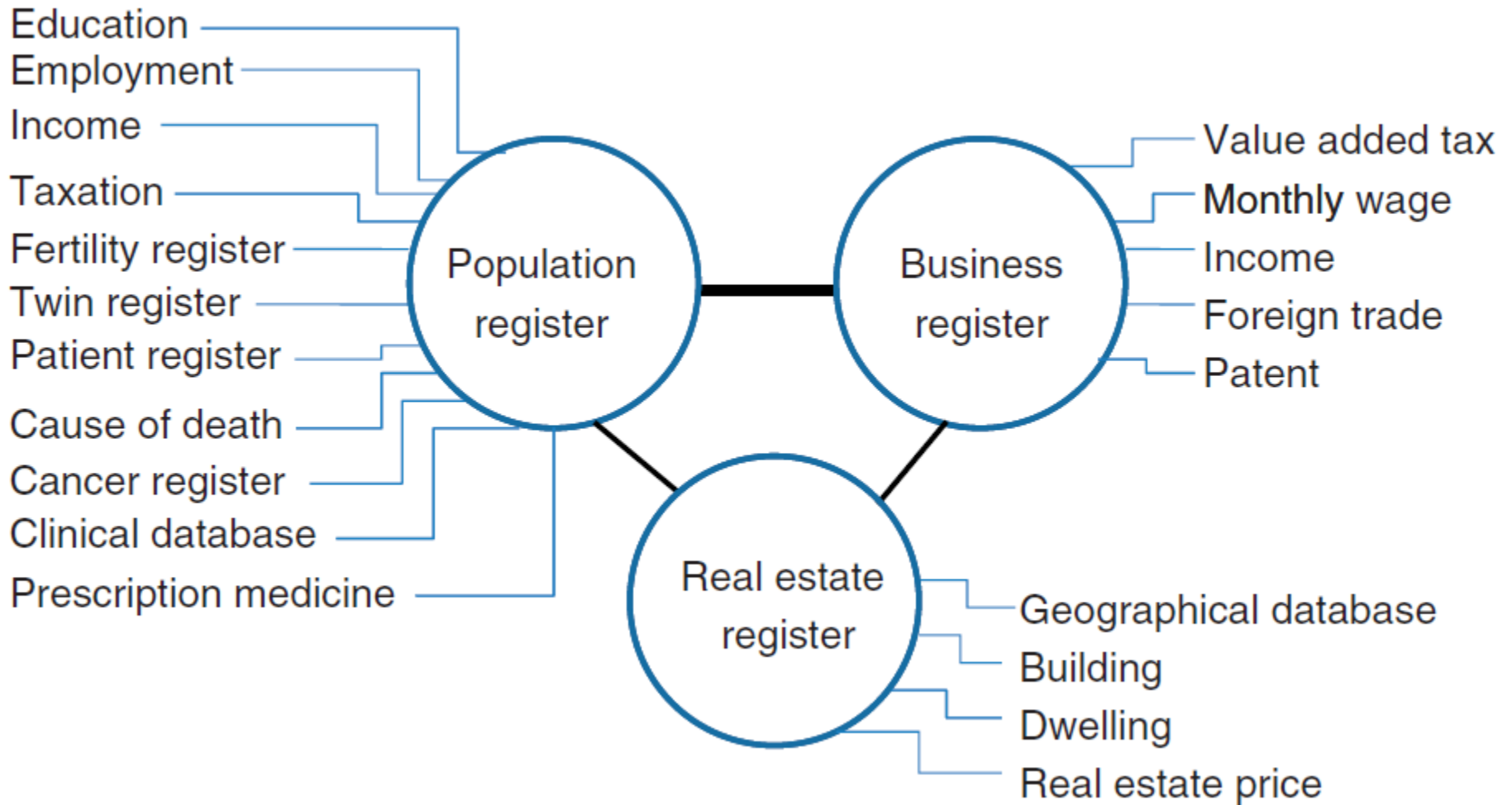
Første folketælling 1769

CPR-nummeret 2. april 1968

Stadig flere registre

...som i de andre nordiske lande

Organisation: Basisregistre



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, on 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 registries allow for instant, large cohort studies that are impossible in most countries."



Beasty 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 databases for access and e Statistics D to release data concerns. "The dence that inf individuals doe stitution," says

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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.

Adgang til data

Balance mellem databrug og fortrolighed

Hensyn både til almenvældet eller individet

‘Need to know’-princippet (ikke ‘nice-to-know’)

Organisation af registre

To væsentligste institutioner:

- **Danmarks Statistik**
- **Sundhedsdatastyrelsen**

Stor datamængde

Online aggregerede data

Mikrodata: To modeller

Danmarks Statistik

Online adgang til mikrodata

Specifikke autoriserede miljøer

Alle mikrodata bliver hos Danmarks Statistik

‘One way street’

Anonymiseret af projekt-specifik nøglevariabel

Ingen print af records eller download

Sundhedsdatastyrelsen

1.

Klassisk: Ansøgning → udtræk → modtage data (med CPR)

2.

Forskningsserver: Ligesom Danmarks Statistik
Nyeste opdatering af registre
(Ikke fuldstændig) “one way street”

Ansøgning

Godkendelse datatilsynet

Projektbeskrivelse

Udtræksbeskrivelse

(protokol, følgebrev)

Proces

Opfølgende spørgsmål

Dataspecifikation

Fremsende CPR-numre

Modtager datasæt eller lagt på server

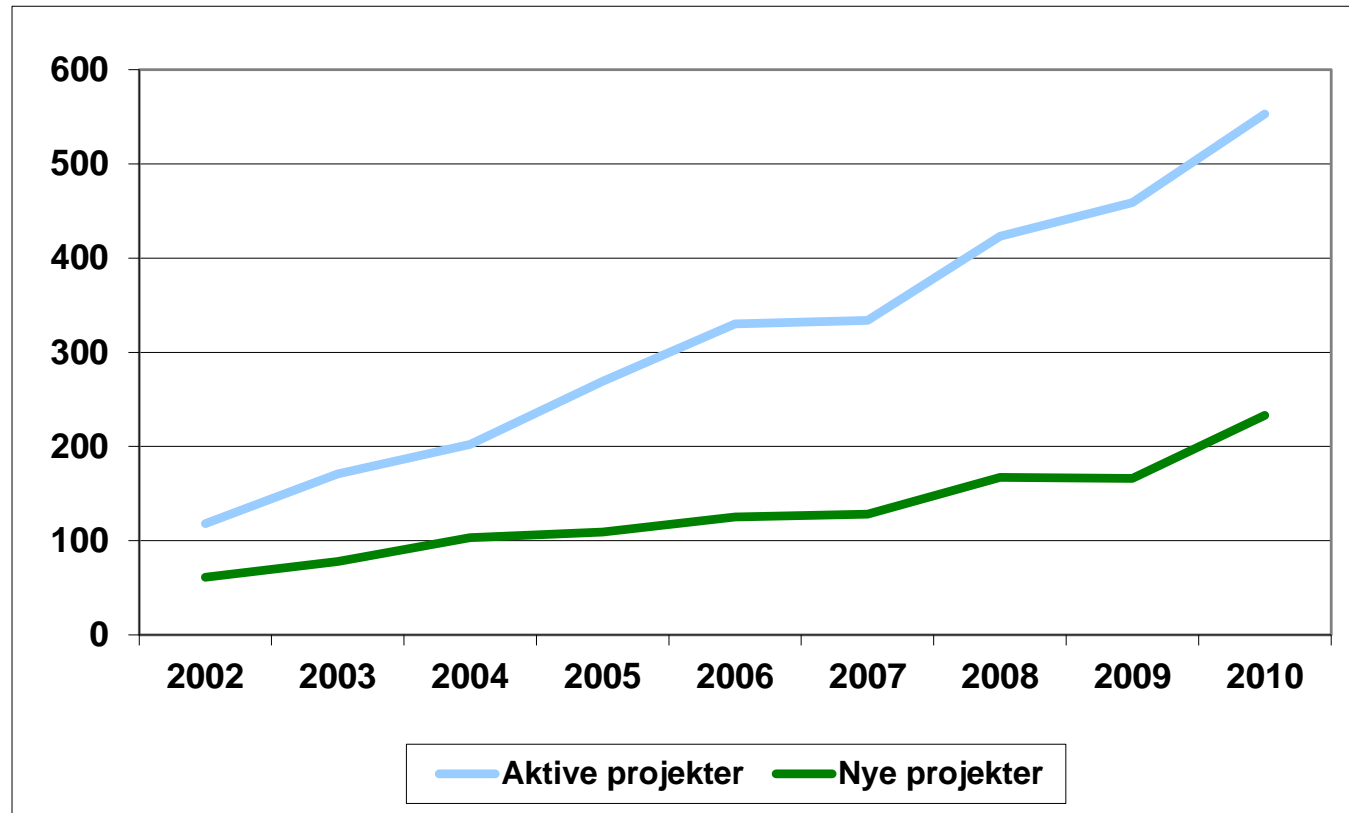
Eksempler - forskning

Registerforskningen: Størstedelen af danske publikationer i de bedste medicinske tidsskrifter

Udviklingen går kun en vej

Udviklingen

Nye og aktive projekter



Fra Danmarks Statistik (Ivan Thaulow)

Eksempler - forskning

Aktive projekter Danmarks Statistik (www.dst.dk):

- 2010: 548
- 2011: 710
- 2012: 823
- 2013: 967
- 2014: 1129

Dansk forsknings guldæg

MMR vaccination and autism (NEJM 2002)

Induced abortion and breast cancer (NEJM 1997)

Statins and cancer-related mortality (NEJM 2012)

Eksempler - Kvalitetssikring

Kliniske kvalitetsdatabaser

Måle kvalitet af klinisk behandling

Behandelende hospitalsafdeling
indrappporterer

Oplysninger om behandlingsforløbet

Eksempel: DCCG

Behandlingskvalitet - indikatorer:

- Indikator 3. Anastomoselækage ved rektumcancer kirurgi ($\leq 10\%$)
- Indikator 4. Postoperativ død efter elektiv kirurgi ($\leq 3\%$)
- Indikator 7. Specialistoperation ved elektiv koloncancer kirurgi ($\geq 90\%$)

Kliniske retningslinier

Forskning

Kliniske kvalitetetsdatabaser

Både nationale og regionale databaser

Udfordring:

Decentral organisering

69 godkendt (8. marts 2016)

Eksempler - Sundhedsberedskab

Smitteberedskab - Statens Serum Institut

Overvågning af smitsomme sygdomme,
mikroorganismer og vaccinationstilslutningen

Danske overvågningsregistre har høj kvalitet
og bruges også i forskningsprojekter

Rapporter

Mange sygdomme

Cancer

- Incidens og overvelse
- NORDCAN

Næste skridt?

Tvæer-nationale studier

Eksempler på tvæer-nordiske studier

Farmakoepidemiologi

Cancerepidemiologi

Sjældne eksponeringer og udfald

Udfordringer:

Data et sted – en løsning?

Harmonisering

Forskellig tid til søgning af data

Scandinavian Journal of Public Health

“Danish population-based registers for public health and health-related welfare research

A description of Danish registers and results from their application in research”

July 2011; 39 (7 suppl)

