

Det Koordinerende Organ for Registerforskning

Henrik Toft Sørensen, formand for KOR



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ATLAS COLORIÉ

de

SPEDALSKHED

(Elephantiasis des Grecs)

par

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et

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Les planches dessinées par J.L. Loxting.

BERGEN EN NORVEGE

1847.



OR

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Et historisk overblik

1645 Church files

1787 The First Census

1856 The First Disease Registry -*The Leprosy Registry in Norway*

1924 National Population Registry

1925 The Registry of Cerebral Paresis

1937 The Registry of Tuberculosis

1943 The Cancer Registry

1943 The Registry of Causes of Death

1953 The Central Psychiatric Registry

1968 The Civil Registration System

1973 The Medical Birth Registry

1977 The National Registry of Patients

1995 The National Prescription Registry

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 abortion 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 socioeconomic data on jobs and salaries.

What makes the databases a powerful 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 Board of Health and public hospitals, their use of 120 demographic databases overseen by the agency Statistics Denmark is tightly restricted. Statistics Denmark won't allow researchers to remove from its premises data coded by CPR, and the procedures for accessing information at all are unwieldy and expensive.

Statistics Denmark officials are reluctant to release data tied to CPRs, citing privacy concerns. "The public should have confidence that information identifying them as individuals does not reside outside of this institution," says the agency's Otto Andersen.

Last month, Danish research minister Birte Weiss formed a committee to break the impasse. Denmark's databases are "a resource which can be used more optimally," she told *Science*. "This should be a scientific flagship."

Working the health databases can yield powerful results. For years the U.S. National Institutes of Health has supported a study following z twins, hoping to tease out the relative contributions of genes and lifestyle to aging. Led by University of Southern Denmark gerontologist Kaare Christensen, the project has tapped the Danish Twin Register, which includes 110,000 pairs of twins born since 1870. After follow-

ing more than 2000 pairs of twins aged 70 or older, Christensen's group has so far tied to 0 genes about a quarter of the variation in human longevity. "The project is made possible by the unmatched age and completeness of the Danish twin Register," he says.

The health databases have proven invaluable for probing contradictions raised by smaller studies and following disease pro-



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Hvorfor er Danmark en kohorte?

- ▶ Etableringen af Det Centrale Person Register i 1968
- ▶ Lang tradition for offentlig registrering
- ▶ Offentligt sundhedsvæsen



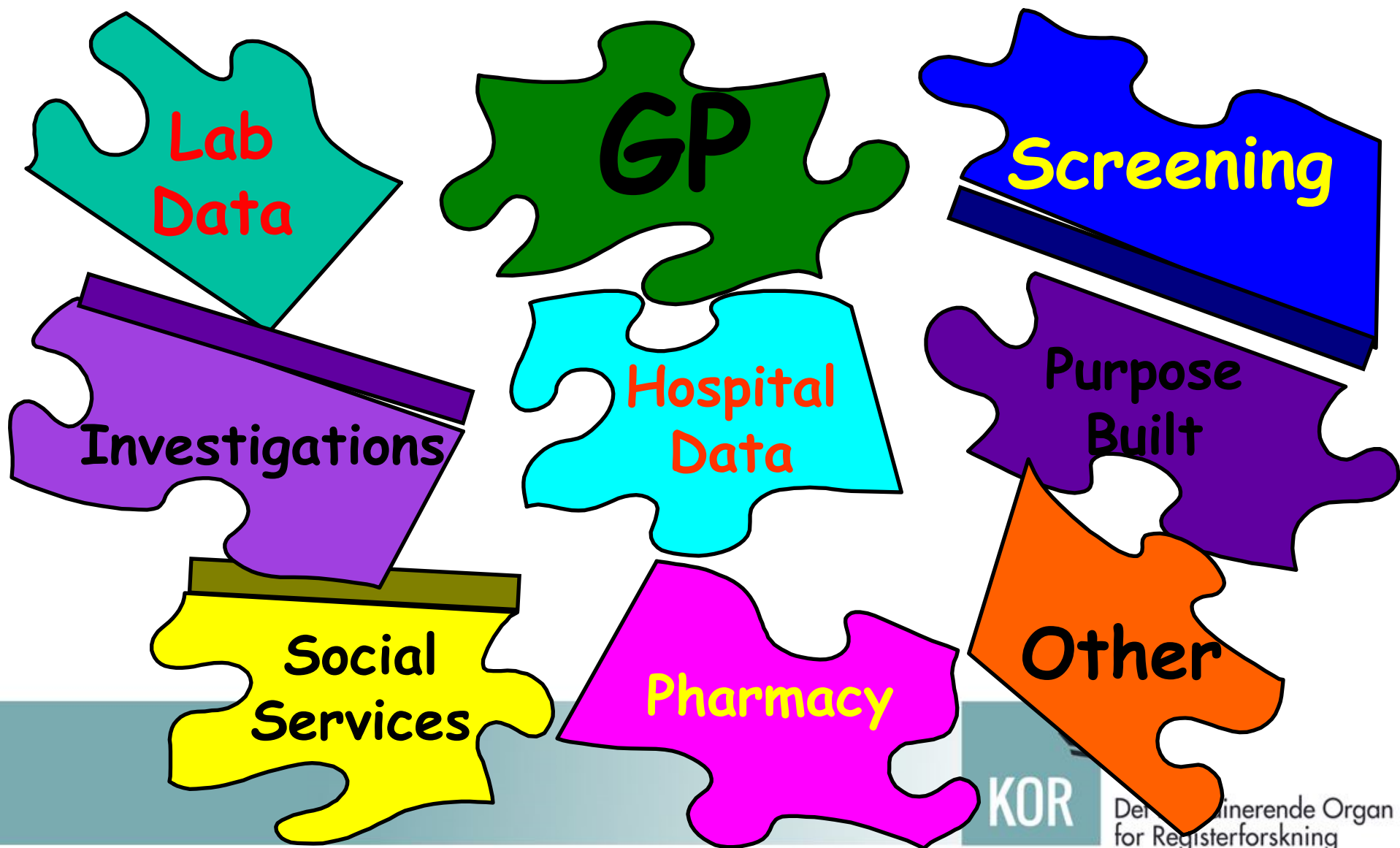
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		Rubrik	Beløb i kroner	Felt nr.
Personlig indkomst, hvorfra der skal betales AM-bidrag (8 %) og SP-opsparing (0 %)	Lønindkomst, bestyrelses honorar, fri bil mv. før fradrag af AM/SP-bidrag	11		202
	Honorarer og vederlag i form af visse goder mv. før fradrag af AM/SP-bidrag	12		210
	Jubilæumsgratiale og fratrædelsesgodtgørelse mv. før fradrag af AM/SP-bidrag	14		243
	Anden personlig indkomst som fx fri telefon, privat dagpleje og hushjælp mv. før fradrag af AM/SP-bidrag	15		207
Personlig indkomst, hvorfra der ikke skal betales AM-bidrag og SP-opsparing	Pensioner, dagpenge mv. og stipendier fra SUstyrelsen	16		204
	Uddelinger fra foreninger og fonde mv. Gruppelivs-forsikring betalt af pensionskasse. Visse personalegoder	17		229
	Hædersgaver	18		256
	Modtaget underholdsbidrag	19		212
	Anden personlig indkomst	20		250
Fradrag i personlig indkomst	Bidrag og præmie til privattegnet pension med løbende udbetalinger og ratepension	21		416
	Bidrag og præmie til privattegnet kapitalpension (højest 43.100 kr.)	22		433
	Tilbagebetalt kontanthjælp, introduktionsydelse mv.	23		477
	Øvrige fradrag i den personlige indkomst	29		425
Kapitalindkomst <i>Fradragsberettigede tab angives med minus</i>	Renteindtægter af indestående i pengeinstitut, obligationer og pantebreve i depot mv. samt udlodning fra obligationsbaserede investeringsforeninger	31		233
	Reservefondsudlodninger og kapitalværdistigninger af pensionsordninger	33		249
	Udlodning fra investeringsselskab/-forening, hvor der er indeholdt udbytteskat	34		247
	Over-/underskud ved visse skibsprojekter (underskud angives med minus). Overskud ved anden anpartsvirksomhed	35		217
	Fortjeneste/tab ved ophør af visse skibsprojekter. Fortjeneste ved ophør af anden anpartsvirksomhed	36		254
	Lejeindtægt ved udleje af helårsbolig en del af året samt sommerhus- og værelsesudlejning. Gælder kun, hvis du selv ejer boligen	37		218
	Renter af pantebrev ej i depot. Gevinst/tab på bevis i investeringsselskab, og i udloddende blandet og obligationsbaseret investeringsforening.	38		239
	Anden kapitalindkomst, som fx finansielle kontrakter, aftaler mv.	39		214
Fradrag i kapitalindkomst	Renteudgifter af gæld til realkreditinstitutter og reallånefonde samt fradragsberettigede kurstab ved omlægning af kontantlån	41		483
	Renteudgifter af gæld til pengeinstitutter, pensionskasser, forsikrings- og finansieringsselskaber, kontokortordninger samt af pantebreve i depot	42		481
	Renteudgifter af studielån fra SUstyrelsen	43		489
	Renteudgifter af anden gæld, herunder af statsgaranterede studielån i et pengeinstitut samt af pantebreve der ikke er i depot	44		485

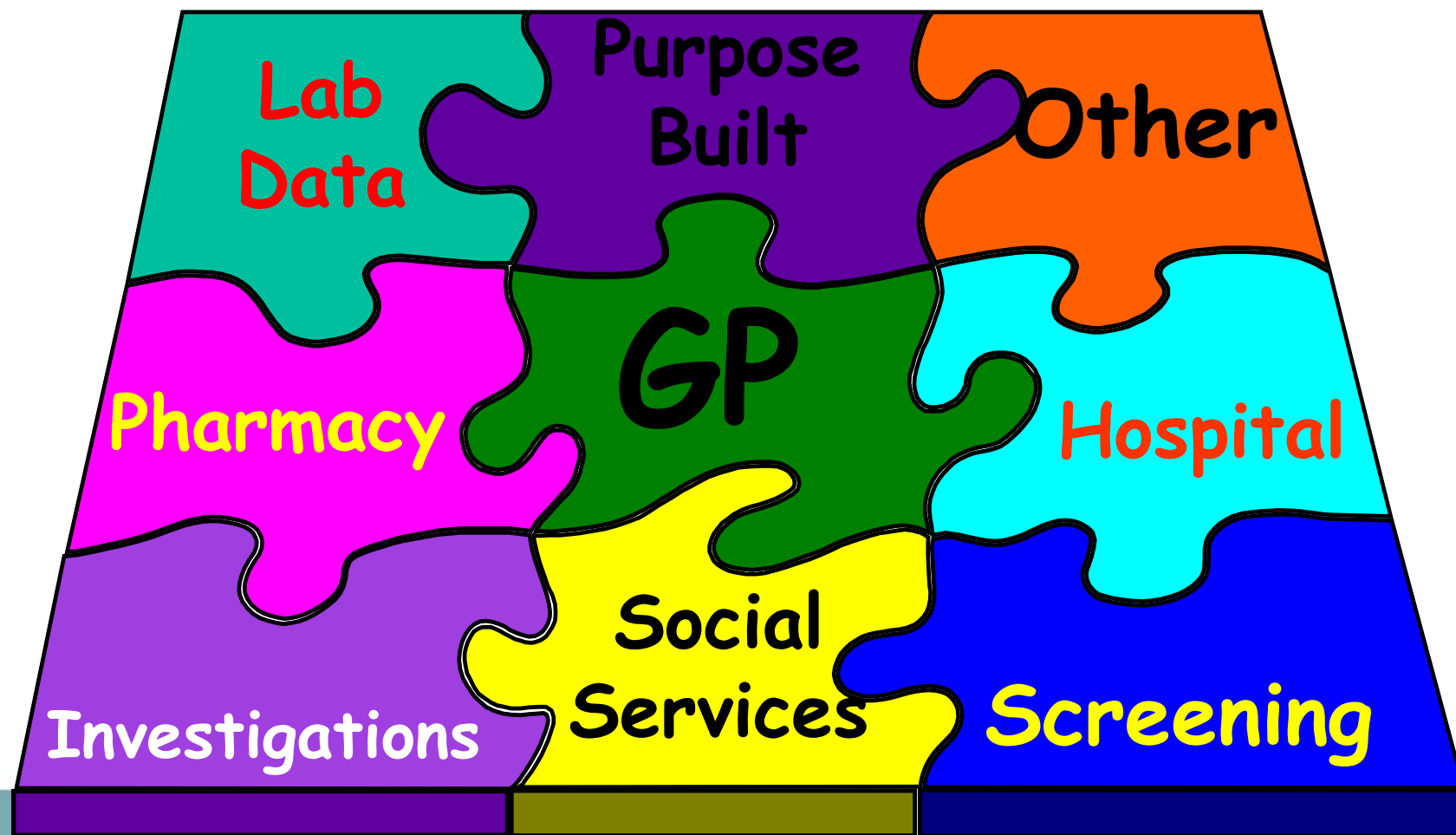
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Data, Data everywhere.... But not much of it linked



Record-Linked Data

Completing the Jigsaw



KORs formål

Er et rådgivende organ under Uddannelses- og Forskningsministeriet, formålet er at stimulere og styrke dansk registerforskning.

Startet i 2002 for at støtte adgang til registerdata og bedre metadata

Styrket 2013 med flere medlemmer, sekretariat, midler til selvstændige projekter



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KORs opgaver

- ▶ Rådgive Forskningsministeriet
- ▶ Skabe sammenhæng og koordination i miljøer
- ▶ Støtte forskerserviceenhederne
- ▶ Projekter
 - Register over statslige registre
 - Pilot for multigenerationsregister
 - Høj kvalitetsdokumentation af centrale variabler
 - European Social Survey round 7
 - Referencegruppe for registerforskning
 - Kortlægning af datawarehouses



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KORs medlemmer

- ▶ Professor, overlæge Henrik Toft Sørensen, Aarhus Universitet (formand)
- ▶ Forskningschef Hans Hummelgaard, KORA
- ▶ Professor Preben Bo Mortensen, Aarhus Universitet
- ▶ Professor Lisbeth B. Knudsen, Aalborg Universitet
- ▶ Professor Marianne Simonsen, Aarhus Universitet
- ▶ Professor, speciallæge Mogens Vestergaard, Aarhus Universitet
- ▶ Klinisk professor, overlæge Merete Osler, Københavns Universitet
- ▶ Instituttleder, professor Kirsten Ohm Kyvik, Syddansk Universitet
- ▶ Klinisk professor, overlæge Niels Obel, Københavns Universitet
- ▶ Professor Lotte Bøgh Andersen, Aarhus Universitet
- ▶ Professor Morten Grønbæk, Syddansk Universitet



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KORs budget

Finanslovs bevilling for Registerforskning finansierer 1 / 3 af forskerserviceordningerne

- ▶ 6,7 mio. DKK til Danmarks Statistik
- ▶ 2,9 mio. DKK til Sundhedsdatastyrelsen

Bevilling fra Forskningsinfrastrukturpuljen

- ▶ 15,3 mio. DKK fordelt over år 2014–2017



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Referencegruppen

Formålet er at koordinere tiltag og diskussioner på registerområdet blandt organisationer der bruger register data i forskning, analyser kvalitetsudvikling etc.

Tema om Registerforskningens impact på det danske samfund blev vedtaget på sidste møde

Tre vinkler

1. Demokrati
2. Økonomi
3. Borgerne



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Hovedspørgsmål

- ▶ Adgang til data
- ▶ Hvilke og hvor mange data der kan udleveres til forskerne
- ▶ Kan data udleveres til private organisationer
- ▶ Kan data udleveres til private firmaer
- ▶ Diskussion om informeret samtykke