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Combining register information with other data sources



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Outline


1. Health surveys
2. Other cohorts
3. Biobanks
4. Clinical data
5. Historic population data

Why use other data sources than the registers?

- Limited amount and type of variables
- Limited time frame
- Not all type of study questions can be answered with registers

- By combining register data with other data sources new exciting possibilities emerge

1. Health surveys – Sweden:


ABOUT US ▾
ABOUT HARMONIZATION ▾
WHAT WE OFFER ▾
PARTNERSHIPS ▾
CONTACT US
MÆLSTROM CATALOGUE

Individual Studies

Summary Report

1 - 25 of 34

Search ...

| Acronym | Name | Study Design | Participants | Country | Variables |
|------------------------|--|--------------|--------------|---------|-----------|
| AAA | Uppsala Abdominal Aortic Aneurysm | | | | - |
| BEDA | The Gothenburg BEDA study | | | | - |
| COSM | Cohort of Swedish Men | Cohort | 48,850 | Sweden | 1,575 |
| EpiHealth | Epidemiology for Health | Cohort | 300,000 | Sweden | 607 |
| GÅS-SNAC-S | Swedish National study on Aging and Care - Good Aging in Skåne | Cohort | 6,023 | Sweden | - |
| LifeGene | LifeGene Project | Cohort | 100,000 | Sweden | 4,266 |
| MA | Mammary Screening Cohort | | | | - |
| MDC | Malmö Diet and Cancer study | | | | - |
| MISS | MISS-cohort, Melanoma in Southern Sweden | | | | - |
| MONICA-Gbg | MONICA survey in Gothenburg | | | | - |
| MONICA-Northern Sweden | Northern Sweden MONITORing of trends and determinants in Cardiovascular disease (MONICA) | Cohort | 12,000 | Sweden | - |

<https://www.maelstrom-research.org/mica/network/cohorts.se>

Norway: CONOR

- CONOR: 10 different health surveys during 1994–2003

All surveys comprised:

- a common set of questions
- standardized anthropometric measures
- blood pressure measurements
- non-fasting blood samples

The image shows a sample questionnaire form titled "QUESTIONNAIRE". It includes fields for "Date of completion" (Day, Month, Year), "Sex" (Male, Female), and "Height in cm". The form is divided into several sections:

- Known diseases:** Questions about heart attack, stroke, and diabetes mellitus, with checkboxes for "Yes" and "No".
- Year of diagnosis:** Fields for "Year of diagnosis" and "Number of years on insulin".
- Smoking:** Questions about current and former smoking status, with checkboxes for "Yes" and "No".
- Age when you started smoking:** A field for "Age when you started smoking" and "Age in years".
- Number of years as a smoker:** A field for "Number of years as a smoker" and "Years".
- Number of cigarettes (or equivalent) per day:** A field for "Number of cigarettes (or equivalent) per day" and "Number".
- Family medical history:** Questions about family history of diabetes, cancer, and other conditions, with checkboxes for "Yes" and "No".
- How tall are you:** A field for "How tall are you" and "Height in cm".
- What is your weight:** A field for "What is your weight" and "To the nearest kg".

Finland

- Tradition of health surveys from 1966
- The National FINRISK Study was carried out every fifth year between 1972 and 2012.
- Three national surveys between 1978 and 2011 (the Mini-Finland Survey, the Health 2000 and the Health 2011 Surveys).
- FinHealth Study since 2017

The screenshot shows the website of the Finnish Institute for Health and Welfare (THL). The header includes the logo and name of the institute, a search bar, and navigation links for CONTACT / FOR MEDIA. A main navigation menu contains links for WHAT'S NEW, TOPICS, SERVICES, RESEARCH AND EXPERT WORK (highlighted), STATISTICS, PUBLICATIONS, and ABOUT US. The breadcrumb trail reads: THL.FI > RESEARCH AND EXPERT WORK > POPULATION STUDIES > NATIONAL FINHEALTH STUDY. The main content area features a sidebar with a menu for RESEARCH AND EXPERT WORK, including Population studies, National FinHealth Study (selected), Background information on the FinHealth Study, Notice to study subject, The FinHealth Study schedule and localities, and Contact details. The main heading is 'National FinHealth Study' in green. Below it is a large image of hands holding blueberries with the text 'FinHealth' overlaid. To the right of the image are two boxes: 'FINHEALTH IN OTHER LANGUAGES' with links for 'FinTerveys-tutkimus' and 'Undersökningen FinHälsa', and 'ON OTHER WEBSITES' with links for 'The National FINRISK Study' and 'Chronic diseases topic pages'. At the bottom, there are three columns: 'Duration: 2017-', 'Unit at THL: Health Monitoring', and 'On other websites:'.

Denmark

DATA PRESENTATION

The Danish National Health Survey

DATABASE

Primary variables

Introduction

In 2010, 2013 and 2017, the five regions, the Danish Health Authority and the National Institute of Public Health at the University of Southern Denmark investigated the health and illnesses of the adult population - Danes' Health - The National Health Profile.

The survey covers the presence and distribution of health and health-related quality of life, health behaviour, illness, contact with GP and social relations, meaning data that is not available in the part of the national Danish information systems that covers illness, mortality and social events in treating institutions.

The aim of the survey is to provide an overview of adult Danes' health, illness and wellbeing and to elucidate trends in this field in recent years.

Data collection is based on questionnaires circulated to a whole range of Danes throughout the country. The response rate has been between 54-59%. The plan is for Danes' health to be surveyed again in 2021.

<https://www.danishhealthdata.com/find-health-data/Danskernes-sundhed>

Health survey data- Challenges

- Exposure status may change over time
- Limited amount of confounders available
- Surveys at different time points
- Consider immortal time bias

2. Other cohorts

Examples

- Military recruits
- Special occupational cohorts
- Mandatory tuberculosis screening
- Cross Nordic cohorts

Cohort profile: a nationwide cohort of Finnish military recruits born in 1958 to study the impact of lifestyle factors in early adulthood on disease outcomes

Box List of the variables collected at study entry for each member of the cohort

- ▶ Personal identity code of the individual
- ▶ Professional group
- ▶ Marital status
- ▶ Beginning of military service (date)
- ▶ End of military service (date)
- ▶ Reason for preliminary discontinuation of military service (diagnosis)
- ▶ Duration of military service
- ▶ Military service classifications at different stages of the service
- ▶ Classification diagnoses at different stages of the military service
- ▶ Self-perceived health status at the beginning and at the end of the service
- ▶ Height and weight at different stages of the service
- ▶ Blood pressure at different stages of the service
- ▶ Physical condition test results at different stages of the service
 - Twelve-minute running test results
 - Muscle strength test results
- ▶ Smoking status and amount smoked at different stages of the service
- ▶ Use of alcohol and the amount drunken at different stages of the service

Purpose The cohort was set up to study the impact of lifestyle factors in early adulthood on disease outcomes, with a focus on assessing the influence of body composition and physical performance in early adulthood on subsequent cancer risk.



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Data Resource Profile

Data Resource Profile

Data Resource Profile: Danish Conscription Registry Data (DCRD)

**Gunhild Tidemann Christensen,^{1,2,3*} Sissel Skogstad,^{2,3}
Lars Ravnborg Nissen⁴ and Merete Osler^{1,2,3}**

BMJ Open Copenhagen Airport Cohort: air pollution, manual baggage handling and health

Karina Lauenborg Møller,¹ Charlotte Brauer,² Sigurd Mikkelsen,² Steffen Loft,³ Erik B Simonsen,⁴ Henrik Koblauch,⁴ Stine Hvid Bern,² Tine Alkjær,⁴ Ole Hertel,⁵ Thomas Becker,⁶ Karin Helweg Larsen,¹ Jens Peter Bonde,² Lau Caspar Thygesen¹

Tuberculosis screening programme

- From 1948 to 1975, Norway had a mandatory tuberculosis screening programme
- Miniature chest X-ray
- Tuberculin test
- BCG-vaccination status
- Measurement of height and weight

Epidemiology
Cohort profile



Cohort profile: cerebral palsy in the Norwegian and Danish birth cohorts (MOBAND-CP)

Mette C Tollånes^{1, 2}, Katrine Strandberg-Larsen³, Ingeborg Forthun^{1, 2, 4}, Tanja Gram Petersen³, Dag Moster^{1, 2, 4}, Anne-Marie Nybo Andersen³, Camilla Stoltenberg^{1, 5}, Jørn Olsen^{6, 7}, Allen J Wilcox⁸

[Author affiliations +](#)

Abstract

Purpose The purpose of *MOthers* and *BABies* in Norway and Denmark cerebral palsy (MOBAND-CP) was to study CP aetiology in a prospective design.

Participants MOBAND-CP is a cohort of more than 210 000 children, created as a collaboration between the world's two largest pregnancy cohorts—the Norwegian Mother and Child Cohort study (MoBa) and the Danish National Birth Cohort. MOBAND-CP includes maternal interview/questionnaire data collected during pregnancy and follow-up, plus linked information from national health registries.

Findings to date Initial harmonisation of data from the 2 cohorts has created 140 variables for children and their mothers. In the MOBAND-CP cohort, 438 children with CP have been identified through record linkage with validated national registries, providing by far the largest such sample with prospectively collected detailed pregnancy data. Several studies investigating various hypotheses regarding CP aetiology are currently on-going.

Future plans Additional data can be harmonised as necessary to meet requirements of new projects. Biological specimens collected during pregnancy and at delivery are potentially available for assay, as are results from assays conducted on these specimens for other projects. The study size allows consideration of CP subtypes, which is rare in aetiological studies of CP. In addition, MOBAND-CP provides a platform within the context of a merged birth cohort of exceptional size that could, after appropriate permissions have been sought, be used for cohort and case-cohort studies of other relatively rare health conditions of infants and children.

3. Biobanks

Types of biobanks

- Diagnostic biobanks
- Treatment biobanks
- Research biobanks



Informed consent

- Biobanks are based on informed consent from participants
- GDPR: Classical informed consent
- No international consensus on the consent issue -differences between legal system of countries
- Dynamic consent?

Consent issues after GDPR

- Can stored biological material be used for research on topics that the participants were not informed about?
- Should new, written, informed consent be obtained?
- What to do when participants in the meantime have died or are unable to give consent?

Biobank registers

- Norway: <https://biobankregisteret.no/#/home>
- Denmark: <https://www.danishnationalbiobank.com/danish-biobank-register>
- Finland: <https://www.biopankki.fi/en/finnish-biobanks/>
- Sweden: <https://biobanksverige.se/english/research/#>
- Iceland: <https://www.decode.com/research/>

Biobanks

- Both samples and results from laboratory measurements are defined as biobank data

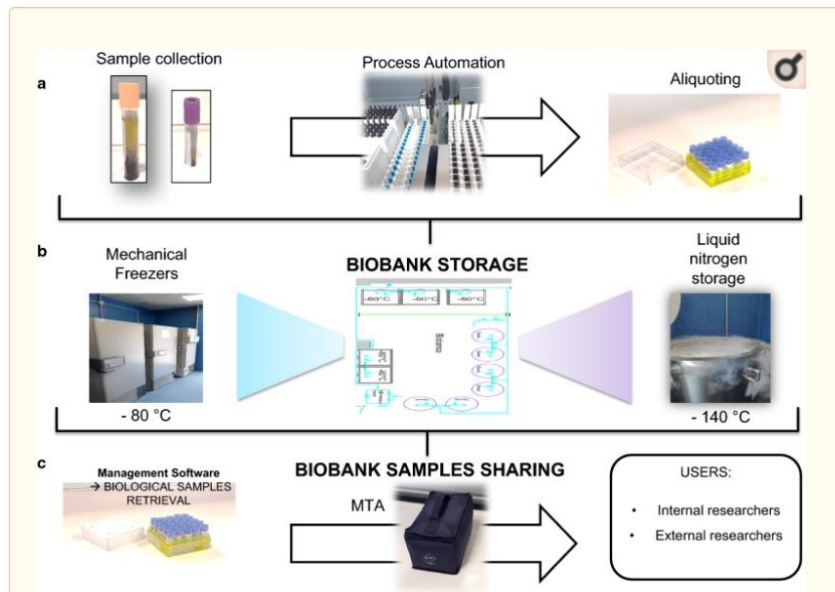


Fig. 2

Hypothetical workflow model for collection, storage and distribution of samples in biobanking. **a** displays an example of automation of biological sample aliquoting. **b** shows a storage unit where biosamples can be stored in mechanical freezers or liquid nitrogen storage device. **c** displays the phases needed for samples sharing. A management software is needed for samples retrieval and an approved material transfer agreement (MTA) in case of both internal and external users before samples transferring

- Information about freezing thawing cycles
- Transportation

Challenges – bio bank samples

- Different stability for molecules
OBS; number freezing, thawing cycles..
- Storage temperature, tube type
- Volume required?
- Samples can become empty or volume can be too small

4. Clinical data

- Specific project
- Clinical databases

Medical journal information from primary health care

- The physicians get a little box linked to their computer
- Selected data will be transferred to the box
- By connecting the Snow Box server to the electronic medical record (EMR) all personal data remain within the practice
- The program Medrave is installed in the box, and enables searches, including validity studies



Foto: Colourbox

SSI-afgørelse: DAMD høster ulovligt oplysninger om patienter hos læger

NYHEDER



Den omstridte database DAMD har ikke fået tilladelse af Statens Serum Institut til at indsamle generelle patientoplysninger, viser et udkast til udredning. Minister i samråd om sagen om en uge.

Dato

21. Nov 2014

Forfattere

Anders Heissel, ah@dadl.dk

1

Region Syddanmark og DAK-E har aldrig fået tilladelse til den omfattende indsamling af helbredsoplysninger om alle patienter, som har fundet sted.

Ifølge et udkast til den redegørelse, som Statens Serum Institut (SSI) er blevet bedt om lave og

5. Historic population data

- Extend before the start of population registers

| 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 fyldte Aar). | Af hvilken Præst Begravelsen er forrettet. | Anmær- kelser |
|-----------|---|--|--|---|--|--|------------------|
| 0 | 1906 - 22 November. Limbstrup, Rallemandsogn, Vester Flakkebjerg Herred. | 29 November 1906. | Karen Mikaelsdatter | Opholdt sig indtil sidst i Limbstrup, Vestergaards Sogn, Vester Flakkebjerg Herred, født i Ejlskovsmagle. Enke efter Poul Hans Jensen, Nimbstrup. | 86 Aar | Pastor Petri | |
| 1907 1 | 1907 - 19 januar. Allerhus, Holsteinborg Sogn, Vester Flakkebjerg Herred. | Holsteinborg Kirke- gaard d. 24 januar 1907. | Anna Margrethe Brodtbagen. | Enke efter afdøde Nylstrøm, Albrecht Danischer Ingeniør og Siger af Allerhus ved Holsteinborg, Holstein- borg Sogn, Vester Flakkebjerg Herred. født i Nyrup, Suisendal Sogn. Datter af Gymnasistlærer Lars Brodtbagen af Nyrup. | 89 Aar | Pastor Petri | |
| 2 | 1907 - 29 Marts Bisserup, Holsteinborg Sogn, Vester Flakkebjerg Herred. | Holsteinborg Sogns Kirkegaard. 1907 - 4 April | Karen Marie Jørgensen. | Enke efter afdøde Knudmann Peter Larsen i Bissrup, Holsteinborg Sogn, Vester Flakkebjerg Herred, født i Nyrup, Suisendal Sogn. Datter af registe Karen Hansdatter af Nyrup. | 75 Aar | Pastor Petri | |
| 7 | 1907 - 15 Juni. Bisserup, Holsteinborg Sogn, Vester Flakkebjerg Herred | Holsteinborg Sogns Kirkegaard 21 Juni 1907. | Karen Jensen datter. | Enke efter afdøde Knudmann og Sigerkar d. Christian Jensen Bisserup, Holsteinborg Sogn, Vester Flakkebjerg Herred, født i Bissrup, Datter af Knudmann Jørg Jørgensen og Karlstrøm Anne Olddatter, Bissrup. | 81 Aar | Pastor Petri | |
| 8 | 1907 - 13 April Bisserup, Holstein- borg Sogn, Vester Flakke- bjerg Herred | | Karoline Sophie Nielsen. | Gift med Badermand Peter Jørgensen i Bissrup | 35 Aar | | |

HOVED LISTE

| Byråes eller Stedernes Navne med Angivelse af Gaardenes, Husenes osv. Matr.-Nr. | Familie- og Løbe-Numre Søn "Familie" tages ogsaa med, boms, men ikke Logerende. — Person Logerende (indret Stalkpersoner samt Indlo-gerede Famil-iers Medlemmer) sættes 2. Foran midlertidigt tilværende sættes F.v. (F. S. 14) | 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. Færøerne, Grønland, Island eller vedkommende fremmede Lands Navn. | Statsborgerforhold Personer, der har dansk Indfødsret, skriver: „dansk“; andre anføres her Navnet paa det Land, hvori de har Statsborgerret (Island, Sverige, Tyskland, Forenede Stater o. s. v.) | Ægte- skabelig Silling Ugift (U) Gift (G) Enkem. eller Enke (E) Separeret (S) Fraakilt (F) | Silling i Familien Husfader, Husmoder; Barn, Slægtning o. l.; Husassistent, Tjenestekar, - pige, Pensioner, Logerende. Hvor en Familie er indlojeret hos en anden Familie, angives dette særskilt ved Betegnelsen „Indlojeret Familie“. For den indlojerede Familias 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 Børnene særlige Erhverv, anføres disse. Man angiver udtrykkelig det Paa, man arbejder i, og Ens Silling i Faget. Lever man hovedsagelig af Formue, privat Understøttelse, Alderdomsunderstøttelse, Fattighjælp, anføres dette, men tillige Erhvervet. Forhenværende Næringsdrivende o. l. sættes „f.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 | | |
|---|--|-------------------------|---|---------------------------------|-------------|---------------------|--|--|--|---|---|---|----------------------------|---|---|
| | | 1 | 2 | | | | | | | | | | 3 | 4 | 5 |
| 5 | | Jenssen Hans Sten | M | 17/1 | 1888 | Torshavn Island | J. | J. | Husf. | Husmoder | | | | | |
| | | Jenssen Helene | K | 23/1 | 1883 | Torshavn Island | J. | J. | Husm. | | | | | | |
| | | Jenssen Lars Sørensen | M | 3/6 | 1911 | Torshavn Island | J. | J. | Barn | | | | | | |
| | | Sørensen Hans Sørensen | M | 2/6 | 1879 | Torshavn Island | J. | J. | Husf. | Husmoder | | | | | |
| 6 | | Karstensen Christian | M | 28/1 | 1862 | Mallingen Island | J. | J. | Husf. | Husmoder | | | | | |
| | | Karstensen Christian | K | 2/1 | 1865 | Torshavn Island | J. | J. | Husm. | | | | | | |
| 7 | | Jensen Johannes | M | 20/5 | 1900 | Torshavn Island | J. | J. | Husf. | Husmoder | | | | | |
| | | Jensen Elise | K | 29/6 | 1900 | Torshavn Island | J. | J. | Husm. | | | | | | |
| 8 | | Jensen Hans Ole | M | 11/6 | 1888 | Older Island | J. | J. | Husf. | Husmoder | | | | | |
| | | Jensen Johannes Marie | K | 17/6 | 1889 | Torshavn Island | J. | J. | Husm. | | | | | | |
| 9 | | Kjær Hans | M | 17/1 | 1877 | Torshavn Island | J. | J. | Husf. | Husmoder | | | | | |
| | | Kjær Signe | K | 1/6 | 1880 | Korsvænngård Island | J. | J. | Husm. | | | | | | |
| | | Kjær Hans Esabetsd. | K | 8/4 | 1920 | Torshavn Island | J. | J. | Barn | | | | | | |
| | | Kjær Ejvind | M | 23/6 | 1919 | Torshavn Island | J. | J. | Barn | | | | | | |
| 10 | | Kristiansen Niels Søren | M | 3/6 | 1878 | Skanderborg | J. | J. | Husf. | Husmoder | | | | | |
| | | Kristiansen Hans Marie | K | 3/6 | 1882 | | J. | J. | Husm. | | | | | | |
| | | Kjær Hans | M | 29/1 | 1880 | Torshavn Island | J. | J. | Husf. | Husmoder | | | | | |
| | | Kjær Hans Kirstine | K | 15/1 | 1865 | Older Island | J. | J. | Husm. | | | | | | |
| | | Kjær Hans Sørensen | K | 2/6 | 1860 | København | J. | J. | | | | | | | |

10-9

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

5. Historic population data

- Norwegian Historical Population Register
- Extend backwards in time before 1964
- The parts older than 1920 open to the public
- The goal data since 1800
- Parts already built
- Concentrated on building the register for the first two decades of the 19th century (17/5 1814)
- 9.7 million people lived in Norway, and for them 37.5 million events (such as birth, death, or migration) have been recorded



Hvidbog for et dansk
multigenerationsregister

*– en infrastruktur for
fremtidens forskning*



RIGSARKIVET

Brug arkivet

Hjælp og vejledning

Undervisning

Offentlig forvaltning

Hele folketællingen 1940 er nu online

Syv måneder efter de tyske tropper havde besat Danmark, blev der holdt folketælling i hele landet. Nu er Rigsarkivets arbejde med at digitalisere de ca. 2,5 millioner spørgeskemaer afsluttet, og hele folketællingen 1940 er dermed online og offentlig tilgængelig. Her får du film og fakta om 1940 folketællingen og den omfattende digitaliseringsproces.

Hidtil har det udelukkende været muligt at se Folketællingen 1940 med særlig tilladelse og kun på Rigsarkivets læsesal i København. Men nu er den fyldt 75 år og er "almindeligt tilgængelig" efter arkivloven. Derfor har Rigsarkivet digitaliseret de 2,5 millioner spørgeskemaer fra folketællingen, så alle nu kan se dem gratis på [Arkivalieronline](#).

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