

A service for Danish health research in Danish Data Archives (DDA)

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DDA Health (DDA Sundhed) is part of the Danish Data Archives (DDA) under the Danish State Archives.

DDA Health collects, preserves and disseminates health-related research data. The unit offers Danish health science researchers seven key services: 1) Safe and optimal storage of data, 2) methodological processing of data and documentation in connection with archival storage, 3) data archiving in standardised format, 4) re-access to original research data in case of later research continuation, 5) recycled use of

data from other studies, 6) support to researchers in documenting data (the DDI3 standard), and 7) benefits from Nordic networking activities with Swedish National Data Service (SND)

The services offered by DDA Health are focused on original, digital data collected by interviews or registration as part of human-based health research. The DDA Health initiative has been in many respects a first mover in the field of providing preservation and infrastructure for health-related research data.

Depositing data with DDA Health requires

copies of research data and documentation. The Danish Data Protection Agency (Datatilsynet) has granted permission for the material to contain person-identifiers. This allows researchers, upon application, to re-possess variables with personal identification for the purpose of continuing or extending original research projects. The Danish Data Protection Authority considers archival storage at DDA Health as deletion or depersonalisation. At DDA Health personal data are stored separately and in accordance with the security regulations of the Danish State Archives.

DEPOSITING DATA

Why?

- For safe-keeping of health related research data in a secure environment independently of software versions and hardware failure
- For long term preservation of a standardised version of data and documentation
- To enable research documentation to meet increasing demands for archiving and re-use by international journals
- To preserve research data containing personal identifiers beyond time limit for deletion
- To have well-preserved data and documentation for research continuation

RECYCLING DATA

Why?

- Research including many respondents/patients is expensive and work intensive. By using data from DDA Health work load and costs may be kept down
- To pay tribute to respondents/patients who have made the effort to take part in epidemiological research
- Most often only a small part of the research potential of a data set is exploited by the primary researcher. New analysis may be performed by other researchers, lecturers or students
- In Denmark, contrary to many other countries, the population willingly engages in health related research interviews and other research. Obviously, it is preferable to keep it that way, by not disturbing the population unnecessarily

INTERNATIONAL

In 2008 The Danish Ministry of Sciences, Technology and Innovation implemented a Nordic evaluation of DDA Health from 2005-2007.

The evaluation group summarized „...by promoting good archiving practices and hence good data management through teaching, opinion-making, counselling and concrete involvement the general research environment in Denmark is enhanced in a way that fills researchers in most other countries with envy“.

As a first mover DDA Health has for more than 10 years gathered important Danish health research data.

We want to share experiences on archiving and documenting data with:

- Nordic researchers/epidemiologists
- Data archives and data services in other Nordic countries
- Research funding organisations

At the moment DDA Health collaborate with The Swedish National Data Service (SND) especially on accounting for similarities and differences in Nordic health research. Our initial efforts show great potential for further collaboration reaching out to interested parties in other Nordic countries.



STATENS ARKIVER

DANSK DATA ARKIV

COVERAGE

DDA Health receives and disseminates qualitative and quantitative research data. Data deposited in DDA Health are humanly related and in electronic form.

DDA Health collects and disseminates research data from:

- Cross-sectional studies
- Cohort studies
- Intervention studies
- Case/control studies
- Combined studies
- Cross-national studies

Based on:

- Questionnaires
- Personal interviews
- Registration
- Clinical investigations

RESULTS

Important results are:

- More than 500 studies have been archived in DDA Health
- DDA Health receives approximately 60 studies per year
- The studies are searchable on the web
- Recycling of data and metadata increases remarkably
- Visibility of our services in the Danish research environment has increased

DDA Health is supported by:

- The Danish Ministry of Sciences, Technology and Innovation
- The Danish Research Councils
- The Danish Protection Agency