

DDA Health

Vision, Coverage, Results and the need for DDI

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

DDA Health preserves machine-readable data about the health of men, women and children based on health research. Depositing data in

DDA Health requires copies of research data and documentation and is free of charge.

The Danish Data Protection Authority has permitted that the material may contain personal 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 preservation at DDA Health as deletion or de-personalisation. At DDA Health personal data are stored separately and according to the security regulations of the Danish State Archives.

The Danish Council for Independent Research (Medical Sciences) requires that research data collected on researchers' own initiatives and funded by the council is archived in The DDA Health.

DDA Health has since 2005 been an integrated part of the Danish Data Archive (DDA) under the Danish State Archives. DDA has since 1996 collected data on health issues. The Danish Ministry of Sciences, Technology and Innovation has financially supported the entity since 2005.

RESULTS

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

The evaluation report from the appointed evaluation group summarize the results like this "*...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 researches in most other countries with envy*".

Important results are:

- More than 400 studies have been archived in DDA Health
- We receive approximately 50 studies per year
- All the received studies are searchable on the web
- Recycling of data and meta data increase
- Presentations on various kinds of scientific gatherings
- Contributions to undergraduate courses and research training
- Articles in scientific journals

DDA Health is supported by

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

VISION

The vision of DDA Health is to become the natural choice in Danish research communities for the preservation and dissemination of Danish health-related research data for secondary research purposes.

COVERAGE

DDA Health receives and distributes qualitative and quantitative research data on health related issues. Data deposited in DDA Health are commonly interview-based, humanly related and in electronic form.

DDA Health collects and distributes research data from:

- Cross sectional studies
- Cohort studies
- Intervention studies
- Case/control studies
- Combined studies
- Studies based on open databases
- Cross national studies

Based on:

- Questionnaires
- Personal interview
- Registration
- Clinical investigations
- Patient journals

THE NEED FOR DDI

The Data Documentation Initiative (DDI) is an XML specification for social science metadata that is being developed by an international group called the DDI Alliance and it is based on a life cycle model. DDI supports the life cycle of a study from conception to archiving to reuse and re-archiving. DDA Health has chosen DDI as our new archiving standard because DDI offers better opportunities to protect data and meta data through the whole life cycle.

We need a life cycle model because:

- It will ease the implementation of our vision
- We will get the opportunity to group studies
- DDA Health has several large cohorts and complex intervention studies. DDI offers a better overview of the cohorts and enables us to keep the original structure of the intervention studies
- We need a model which can handle studies with a very large number of variables 15.000+
- Health studies are increasing in size in terms of variables and concepts. The growing number of variables and concepts challenge our old archiving format



STATENS ARKIVER

DANSK DATA ARKIV

DDA Health homepage: sundhed.dda.dk