

Sharing data, credits and privacy

Agnes van der Heide MD, PhD

Erasmus MC Rotterdam

Data sharing will become the norm

ZonMw general terms and conditions governing grants:

20.2. The grant recipient must draw up a data management plan in which it indicates how data will be shared, when the data will be made available to third parties and the manner in which the data will be made accessible. That plan must be submitted to ZonMw for approval.

20.3. Databases, together with the related explanatory notes, will in any event be made available in the manner indicated by ZonMw for use for the benefit of further scientific and/or academic research. Therefore, the data that are collective within a project must be documented and saved in an accessible manner that is in accordance with the applicable standards.

US National Institutes of Health:

“Timely release and sharing” is defined as no later than the acceptance for publication of the main findings from the final data set.

Lancet:

Authors may be required to provide the raw data for research papers when they are under review and up to 10 years after publication in The Lancet.

PLOS One:

PLOS journals require authors to make all data underlying the findings described in their manuscript fully available without restriction, with rare exception.

When submitting a manuscript online, authors must provide a Data Availability Statement describing compliance with PLOS's policy.

Data sharing is good for:

- progress in health science
- generating scientific hypotheses
- costeffectiveness of health science
- less burden for patients / study participants
- transparency / integrity

Barriers for data sharing:

- competition
- effort
- costs
- lack of credits
- concerns about privacy / informed consent of patients / participants

Data sharing developments

Guiding principles for scientific data management and stewardship

F = findability; unique and persistent identifier, description of metadata

A = accessibility; retrievable in open formats, license and access conditions

I = interoperability; ready to be combined with other datasets by computer systems

R = Reusability; documentation needed to understand the data and analysis

Legal situation

Important legal regulations: WMO and WBP

- Informed consent is needed for all personal data collection
- Re-use of data only if in accordance with original informed consent
- Personal data should be adequately secured

Data storing

Unclear (legal) situation

- Maximum term because of privacy
- Minimum term because of reproducibility and re-use

- 15 years?

Open Data/ Open Access

- Open Access
 - results (publications)
 - data: full open access vs. restricted open access
- 'Open if possible, restricted if necessary



Data sharing in Dutch research

5 research organisations:

Interviews with junior researchers, senior researchers

Interviews with data managers

Evaluation ZonMW checklist data
management:

Usability?

Support of open access?

VERMENIGVULDIGEN DOOR DELEN

*Data delen in gezondheidsonderzoek,
van ambitie naar praktijk*

Een rapport van COREON/Federa, in opdracht van ZonMw

Auteurs: Danielle van den Brink
Alex Burdorf
Ernst de Graag
René Melis

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Data sharing in Dutch research

- * wide support for the idea of data sharing (for science, society and researcher)
- * knowledge about data management is available but not shared
- * adequate data management saves time, increases quality, supports transparency
- * little support for full open access (concerns about credits, quality, privacy)
- * more support for restricted open access
- * little organizational support in terms of protocols, guidance, infrastructure
- * structured data management plan provides guidance, creates awareness, increases quality
- * time needed for appropriate data stewardship
- * lots of work...for whom ? Will data ever be used ?

Data sharing in Dutch research

Important unresolved issues in data stewardship:

- * full versus restricted access
- * privacy and informed consent, storage of identifiers for future linkage
- * timing of open access, fixed datasets versus ongoing data collection
- * linked, enriched data, ownership
- * sustainable storage
- * scientific recognition, data citation

Data sharing in Dutch research

Facilities and support in organisations:

- * provision of data protocols and practical support for data stewardship
- * agreement on informed consent
- * retention period of data (15 years?)
- * provision of infrastructure for data sharing (technical, legal)
- * parameters of acknowledgements for data collection (credits)
- * evaluation of scientific and societal benefits of data sharing (data graveyards)

Data sharing recommendations

Funding agencies:

1. Differentiate in requirements for open data access
2. Facilitate open access to research data (infrastructure, protocols, instruments)
3. Facilitate research with reuse of data (grants)
4. Lobby for data protection regulations that support appropriate research

Researchers and their organizations:

1. Provide training and support for researchers and departments
2. Provide adequate infrastructure (IT, software, legal)
3. Design and implement local policies