

Dutch Kidney Foundation

Data Sharing Policy

27 January 2017

Program

BWO (Biomedisch Wetenschappelijk Onderzoek), Consortia Program.

Position on Data Sharing

- The Dutch Kidney Foundation (DKF) considers the wide and timely availability of the final data arising from DKF funded research to the renal research community an important condition to maximise public benefit from DKF research.
- The DKF expects researchers that it funds to strive for optimal access and availability of research data with as few restrictions as possible.
- The actual time from research to data release is dependent on the specific circumstances of the research, eg. regulatory requirements, best practice guidelines, privacy laws. Researchers should optimise availability within the limits of these conditions.
- This policy applies specifically to the DKF Consortia Program.

Research Data

- Final research data involves recorded factual material commonly accepted by the scientific community as necessary to validate research findings.
- All kinds of data are of interest. Examples are data from epidemiological studies, data from human subjects in clinical studies if identity and privacy are protected, data from basic studies like genomic sequences and protein databases.
- Especially relevant are research projects or programs
 - that have the specific goal of creating or developing a data resource that is useful for the entire renal research community;
 - that involve the generation of large quantities of research data that have a potential value for renal research.
- For small quantities of data, publication in a scientific journal is a sufficient form of data sharing. For instance the data resulting from an animal study with a very small number of animals.

Delayed and Restricted Availability

- The availability of research data may be delayed or temporarily restricted
 - as a consequence of procedures for protection of intellectual property rights (IPR);
 - to comply with conditions posed by scientific journals for publication of the research.
- Restrictions on and delay of data release should be limited and avoided as much as possible.

Data Sharing Plan

- The applicants of an awarded Consortium Grant shall provide a data sharing plan specifying (where applicable):
 - research data, materials and tools foreseen;
 - data formats and quality standards, use of public data repositories;
 - possible delays and restrictions in relation to IPR and publication strategies;
 - privacy protection of participants;
 - long-term preservation;
 - conditions and methods of Consortium and third party sharing.
- The DKF provides a template for the data sharing plan.

