



# Foundation for Healthcare Innovation and Development (FHIND) - Research Data Management Policy

## **Purpose and overview**

FHIND considers research data to be a valuable asset that forms the basis for rigorous scientific enquiry, serves as evidence of research conduct, and has the potential to enable new and innovative research in public health. To protect the intellectual investment made into its creation and ensure it is handled in compliance with ethical, contractual, legal, and regulatory requirements, research data should be managed in accordance with good research practice. This Research Data Management Policy (henceforth RDM Policy) sets out expectations that FHIND researchers should meet to ensure the research data with which they work are managed in accordance with good research practice and relevant ethical, contractual, and legal obligations. The RDM Policy establishes FHIND's commitment to complying with frameworks for best practice with respect to research data management. It forms part of FHIND's research governance framework

## **Policy**

Research projects working with research data must possess a Data Management Plan. Projects working with research data are expected to prepare a Data Management Plan before the commencement of research, even if not required by their research funder. This should outline the requirements (ethical, legal, contractual, etc.) to be met, actions to be performed to achieve them, and any resources necessary (staff time, hardware/software, finances). A Data Management Plan should be written prior to submission of a funding application (if required by the funder).

All members of a research project must be made aware of and abide by the Data Management Plan covering their research. This document should be reviewed annually during the project life to ensure adherence and continued relevance to the research. Funder-specific templates and guidance for writing a Data Management Plan should be followed, where applicable.

## **Data management Costs**

Data management costs should be recovered from the research funder, where permitted. Research data management costs incurred during the project lifetime and following its completion should be considered at the earliest opportunity, preferably when preparing the research application so that suitable arrangements can be made. Researchers should review research funder guidelines on allowed costs and, where permitted, write these into the justification of resources and budget of the research application. Common examples of data management costs include:

1. Hardware and software purchases
2. Data-related training course attendance
3. Staff time needed to prepare data for analysis and sharing
4. Use of third party web services.

## **Data Rights**

Data rights should be recognised and agreed at the earliest opportunity. Research data are produced with input from multiple groups, including research participants, consortium collaborators, host

institutions, and country governments. To ensure the Data Management Plan can be implemented, it is essential that the contribution provided by each rights holder are recognised and appropriate permission obtained at the earliest opportunity. Research participants must be provided with information sufficient to understand and influence how their information will be stored and used during the study lifetime and following its completion, so that they can provide explicit consent.

Research partners should agree on a collaboration agreement that clearly describes the rights they possess and permissions they provide to enable research data to be used for current and future research. Exclusive rights to ownership or use of research data should not be handed over to a third party, unless it is a condition imposed by contractual or other obligations, without first consulting the Research Data Manager. Instead, Researchers are encouraged to apply a non-exclusive license that enables research data to be accessed and used by many parties.

### **Research Data Storage**

Research data must be stored in a managed environment throughout the period it is kept. Research data must be kept for a minimum of 10 years following project completion with the recognition that a longer retention period may be specified by third parties. Data provided by third parties on condition that they are held for a shorter time period are exempt from this requirement. During this time, research data must be stored in a managed environment that is backed-up on a regular basis and offers security functionality sufficient to comply with legal, regulatory, contractual, or other obligations during the time period that it must be retained. The managed environment may be operated by FHIND and/or a trusted third party. In circumstances where institutional storage is not available (e.g. when working in the field), the researcher must take all reasonable steps to ensure adequate measures are in place to ensure research data are stored safely and securely. The research data must be transferred into a managed storage environment at the earliest opportunity.

### **Research Data Access**

Researchers working on consultancy work are encouraged to register details of their research data within the FHIND catalogue. The Principal Investigator may request that data is withheld for a designated time period. E.g. to allow time to obtain a patent, publish research findings, or comply with contractual obligations. Decisions on whether to approve requests will be made based on criteria specified by the Research Governance Committee. Research data that underpins findings should be made available at the earliest opportunity using appropriate access methods. Research data that underpins findings should be made available within 12 months of the grant closure or at the point when research findings based on the data are published, where feasible. Funder policies and community practices that stipulate more rapid data sharing supersede this requirement.

Access mechanisms should be appropriate to the research data being made available. Prior to release, an impact assessment should be performed to identify and assess the risks associated with data release (e.g. research participants being re-identified) and steps taken to minimize risks. This may include: de-identification and redaction of content, use of access controls, and use of a data transfer agreement.

### **Research Data Documentation**

Documentation should be sufficient to understand and analyze the research data. Research data must be accompanied by documentation sufficient to access, understand and use it to verify findings and develop them further. Documentation may take the form of survey questionnaires, codebooks, Standard Operating Procedures, informed consent forms, processing scripts, software code, workflows and other resources.

To ensure research data remains accessible and usable over time, particularly across changing technological environments, researchers are encouraged to adopt open file formats and well-documented standards applicable to their research field to store their data, where these exist.

Good research practice is built upon the recognition of all source material used in the research process, including research instruments, data, software code, scripts, and other resources. Good citation practice should be followed, where appropriate standards exist. For instance, by citing the Digital Object Identifier (DOI) of research outputs in a Data Access Statement or reference list.

### **Contacts**

Questions related to the Research Data Management Policy and its implementation should be directed to the Research Data Manager of FHIND

### **Definitions**

- Research Funder: An agency responsible for the financial support of research activities.
- Non-Exclusive License: A license that grants the same rights to an intellectual property to several licensees. This differs from an exclusive license, which assigns rights to a specific licensee, to the exclusion of others.
- Principal Investigator: The lead researcher or scientist for a project.
- Researcher: Any person conducting research or involved in the creation, collection, or generation of Research Data, for or on behalf of FHIND.
- Research Project: A unit of work performed by one or more researchers that has been established for the purpose of addressing specific aims and objectives.
- Retention Period: The time period for which the research data must be kept.