

# WIPM Data Sharing Policy

September 2020

The purpose of this policy is to provide appropriate guidance for Wolfson Institute for Preventive Medicine (WIPM) staff in order to share WIPM datasets (where WIPM is the data owner or data controller, or has agreement from the data controller to share data) appropriately in line with regulatory requirements to protect patient confidentiality and funding organisations' requirements to share data.

## Controlled access

WIPM has adopted a controlled access model for requesting access to its data assets. This model requires data requesters to provide information to support their request. This information is then reviewed by the Principal Investigator, or custodian in the event that the PI has left QMUL, in order to decide whether or not to approve or reject the request.

## Dataset request process

1. Dataset Requester submits request
  - 1.1. Request is logged by the Research Manager (see Appendix 1 for log template)
2. Principal Investigator (or custodian<sup>1</sup>) reviews request<sup>2</sup>
  - 2.1. Outcome is logged by Research Manager
3. Principal Investigator approves request
  - 3.1. Dataset Requester is informed by Research Manager
  - 3.2. Data Sharing Use Agreement is signed
  - 3.3. Data is Released by Research Manager
4. Principal Investigator rejects request
  - 4.1. Dataset Requester is informed by Research Manager

Since the data access request process is intended to be transparent, the log of all approved and rejected requests will be made available for public reference on the WIPM website.

## Example Assessment Criteria

1. The value of the research proposal to medical science and or patient care
2. The ability of the proposed statistical analysis plan to meet the scientific objectives of the research proposal
3. The publication plan
4. Potential conflicts of interest that may impact on the research proposal and measures to manage these conflicts.
5. The qualifications and expertise of the research team to conduct the proposed research

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<sup>1</sup> If the PI no longer works at QMUL, an executive group will handle the request

<sup>2</sup> Whoever owns the data will be approached for the final decision, e.g. Steering Committee for Clinical Trials

6. The WIPM staff resources required to process the request
7. Risk of patients being re-identified or their privacy and confidentiality being breached
8. Failure of the data requester to demonstrate data can be kept secure
9. For data requesters who have successfully applied for other WIPM datasets; failure to abide by the terms of a previous data sharing use agreement
10. Risk of datasets being used to misrepresent WIPM research or bring WIPM's scientific credibility into disrepute

### **Preparation of the Data Pack**

If the data pack has been previously created, for example as stated in the data sharing plan for a study, then the data pack need only be checked against the dataset manifest before release.

For custom data packs, WIPM must ensure it has adequate data manager and statistician resources to prepare the Data Pack and validate the dataset. WIPM may request the data requester funds the cost of preparing the data pack. In line with the Freedom of Information Act Regulation 7(5), WIPM staff time is to be charged at the flat rate of £25 per hour, irrespective of whether a high actual rate is incurred. Charging is discretionary for the budget holder of the staff responsible for preparing the dataset.

### **When data will not be shared**

1. Ongoing studies: Data from ongoing studies will not be released by WIPM unless otherwise stated in that study's data sharing plan.
2. Uncontrolled risk of patient re-identification: Data sharing should not be considered if WIPM is unable to effectively anonymise a dataset or there remains a risk that individual participants could be re-identified. This may occur for example when the study population is small.
3. Inadequate detail: If the documentation and metadata necessary to describe a dataset is inadequate then it may not be possible to share the data. A reasonable attempt should always be made to improve the dataset documentation.

### **Development of Data Sharing Plans for Funding Bodies**

Some funding bodies, including MRC, CR-UK and Wellcome Trust, require data sharing included as part of the data management plan submitted for grant applications and is maintained for successful bids. These funding bodies will provide template forms outlining their data management and sharing expectations; however, staff writing applications are advised to make use of the DCC Data Management Plan Online (DMPOnline) tool <https://dmponline.dcc.ac.uk/>

**Appendix 1 – Log template**

<b>Date of request</b>	<b>Requester affiliation</b>	<b>Dataset Requested</b>	<b>Outcome of Request</b>	<b>Date of Data pack release</b>