

11. Research data management at Queen Mary

11.1 Background

Data management, including planning for processing, long-term storage, sharing and integrity, is an increasingly important aspect of the UK Research environment. Most grant applications for research that will generate digital data sets require a data management plan that meets the UK Research Council (UKRC) policy; this states that: 'Publicly funded research data are a public good, produced in the public interest, which should be made openly available with as few restrictions as possible in a timely and responsible manner that does not harm intellectual property': <https://www.ukri.org/>.

As of May 2012, UKRI required all funded universities to have a data management policy and road map in place that will be fully implemented by 2015 to meet their expectations for data sharing, as follows:

- Publicly funded research data should be made openly available in a timely manner;
- Data with acknowledged long term value should be made accessible;
- UKRI recognises that there are legal, ethical and commercial constraints on the release of research data. To ensure that the research process is not damaged by the inappropriate release of data, research organisation policies and practices should ensure that these are considered at all stages in the research process; and
- Research Council funded work may be entitled to a limited period of privileged use of the data.

A summary of funder data management/sharing requirements can be found here: <http://www.dcc.ac.uk/resources/data-management-plans/funders-requirements>

Barts Health supports this stance and works with Queen Mary to manage its research data in ways that accord with the external policy recommendations and uphold data sharing expectations. Policy 16 on Barts Health Research Data Sharing outlines data transfer/sharing requirements and expectations from any organisation using Barts Health patient data.

11.2 Research Data Access and Management Policy

- (i) Queen Mary and Barts Health are committed to the general principle of Open Access to research, including to research data¹ within the necessary constraints of any funder, legal and ethical requirements, and following Queen Mary policies, guidelines and standards.
- (ii) Any Barts Health patient identifiable data can only be stored in in Faculty of Medicine and Dentistry's safe haven and not on any personal or shared Queen Mary drives.

¹ Queen Mary and Barts Health research data here refers to the final forms of information which are essential to the understanding of the published or otherwise publicly available final research output that represents the completion of a well-defined research project. This information is generated by QM and Barts Health researchers for the purposes of the research project, for example via experimentation, observation or interview. It may include samples and related material used or created in the course of the research. Published materials, bibliographies, and data acquired from third parties (generated outside QM and/ or Barts Health) are not included in this definition.

- (iii) Due to the particular concerns around access to medical-related data, access to data that is associated with medical research will be governed by the relevant funder's policies on data sharing. If a funder does not have such a policy, then the MRC's policy on data-sharing should be the default policy².
- (iv) Where reasonably practicable, publicly funded research data should be made available for access, subject to such conditions as are necessary to ensure compliance with legal, data protection, ethical, confidentiality, IP protection, and security or funder obligations.
- (v) Data identified for open access will be offered for deposit either in a Queen Mary or an appropriate external repository, following relevant standards and community best practices, which may be determined by the area of research activity.
- (vi) Data must be retained intact in an appropriate format and storage facility according to funder requirements and consonant with any data management plans approved as part of any funding.
- (vii) The rights of researchers to the exclusive use of research data that they generate as part of a well-defined research project will be protected up until the point of publication or public availability.
- (viii) Where data is made available on request rather than via straightforward open access the rationale for this must be made public and such availability should not be unreasonably withheld.
- (ix) Data arising from research involving human participants can only be made accessible if those participants give their informed consent in advance for the future public release of their data, with clear and study-specific explanations of how the data will be anonymised/de-identified so that it will not be possible for those in receipt of the data to identify any individuals. Where it has been determined that it would be inappropriate to make such data accessible, for example, because it might lead to the identification of research subjects or because seeking consent would make it unlikely that subjects would participate in the research, then the data will remain confidential.
- (x) For research collaborations, any open access arrangements can only take place with the agreement of all research partners.
- (xi) Where retention is not specified as a condition of funding, data storage and disposal will be determined by the nature of the research activity and would normally be retained for at least 5 years for non-clinical and at least 20 years for all clinically-based activities from the date of any publication which is based upon it, as specified in the Queen Mary and Barts Health Records Retention schedules.
- (xii) Protocols for research in which data will be generated or reused should include data management plans that explicitly address data capture, management, integrity, confidentiality, retention, sharing and publication. These plans will be retained by Queen Mary and Barts Health, as appropriate, to guide future management of the data.

² <https://mrc.ukri.org/funding/guidance-for-applicants/5-ethics-and-approvals/>

- (xiii) The Investigator, or most senior Queen Mary researcher, in a research project, has responsibility for ensuring that research data management requirements are observed during a research project or programme that they are undertaking.
- (xiv) Those responsible for research staff and students should ensure that researchers in their areas are aware of this policy and any associated guidelines and procedures. Supervisors should always have access to their student's data. No data should be stored outside the organisation (unless explicit consent from participants is in place).
- (xv) All researchers are expected to familiarise themselves with and act in accordance with this and other Queen Mary and Barts Health policies relating to research practice. This information will be made accessible from the Queen Mary and/ or Barts Health research webpages, both external and internal.
- (xvi) Queen Mary will provide their staff with advice, training and support regarding research data management.
- (xvii) Any queries on the application of this policy should be directed to the Records and Information Compliance officer or the JRMO Governance Section.
- (xviii) Appeals against the withholding of data may be made in writing to the JRMO Governance Section or the Records and Information Compliance Officer who will review the case from the researcher or their representative for withholding data. The case will then be submitted to the Vice Principal (Research) and on review will make a final decision.

11.3 Further information

For information about open access please see the Queen Mary Library research webpages <http://www.library.qmul.ac.uk/openaccess>

The *Queen Mary Guidelines on Open Access* are available at http://www.library.qmul.ac.uk/sites/www.library.qmul.ac.uk/files/users/user15/OA_Principles%20&%20Guidance.pdf

For information about IT Services support for IT resourcing and data management requirements please see the ITS webpages at <http://www.itstrategy.its.qmul.ac.uk/research/researchdatamanagement/>

This policy applies to Queen Mary.