



Research Data Sharing Policy

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| Sponsor | Wendy Bickmore, Director |
| Author | Helen Nickerson, Science and Strategy Manager |
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1. All publications arising from the MRC Human Genetics Unit (HGU) should be published as Open Access. The use of pre-print servers is encouraged.
2. We expect valuable data arising from MRC HGU research to be made available to the scientific community with as few restrictions as possible so as to maximise the value of the data for research and for eventual patient and public benefit. Such data must be shared in a timely and responsible manner.
3. We will support our researchers in maximising the long-term value of key datasets resulting from their research.
4. We expect that new research arising from data-sharing should be of high standard regarding scientific quality, ethical requirements and value for money. It should also add recognisable value to the original dataset.
5. We recommend that in all collaborations between new users and the original data creators or curators, that responsibilities and rights of all parties are agreed at the outset, including proper acknowledgement of original data source. We will support this process.
6. Data arising from the MRC HGU must be properly curated throughout its life-cycle and released with the appropriate high-quality metadata. This is the responsibility of the data owner.
7. Wherever possible, data will be stored in recognised public data repositories e.g. SRA, NCBI GEO etc., either independently and/or part of an agreement with the publishing journal. The assignment of unique identifiers e.g. Digital Object Identifiers (DOIs) to datasets are strongly encouraged.
8. A limited, defined, period of exclusive use of data for primary research is reasonable according to the nature and value of the data and how they are generated and used.
9. On-going research contributing to the completion of datasets must not be compromised by premature or opportunistic sharing and analysis. Sharing should always take account of enhancing the long-term value of the data.
10. We recognise that it may be necessary on occasion to delay publication for a short period to allow time for patent applications to be drafted.
11. For medical research involving personal data, the appropriate regulatory permissions – ethical, legal and institutional – must be in place before the data can be shared and a Data Protection Impact Assessment conducted.
12. All MRC HGU researchers, research participants and research regulators must ensure that, within the regulatory requirements of the law, opportunities for new uses are maximised. Potential research benefits to patients and the public should outweigh identified risks, which should be managed in a proportionate yet robust manner.
13. Access policies and practices for new and existing MRC-funded data collections must be transparent, equitable, practicable, and provide clear decisions consistent with MRC data sharing policy. Principal Investigators should consult the MRC policy and guidance on sharing of research data from population and patient studies for support on how to meet the MRC data-sharing principles.