

Health Archives and Records Group: Response to the Review of UK Health Research

The Health Archives and Records Group (HARG) was founded in the 1980s as a group for the discussion of issues common to archivists working with medical records. Membership has since expanded, and it currently has around 85 members, including archivists and records managers working in the NHS, the Medical Royal Colleges, professional associations such as the British Medical Association, and in higher education, voluntary sector and local authority repositories that have responsibility for health archives. The National Archives is also represented. The Group has been affiliated to the Society of Archivists since 2001. In addition to acting as a support group for its members, HARG exists to raise the profile of health archives and, in liaison with the Department of Health, to improve awareness within the NHS about record-keeping issues. It has published best-practice guidance on a number of issues relating to the management of medical records.

Key recommendations

Medical research generates huge quantities of raw data. In order to maximise the public and economic benefit from this massive investment in resource creation, as well as for the dynamic and creative development of the UK's research base, it is essential that this data be available for sharing and re-use by the medical research community, both now and in the future. In order for research data to be re-used effectively, it is also essential that the administrative records and other background material that surround research projects are preserved and made available for future researchers. Without responsible data curation, records and archive management, the UK is failing to reap the full rewards of investment in medical research.

The Health Archives and Records Group recommends that any future arrangements for medical research funding should:

- Adopt and promote a standards-based approach for data collection, management, preservation, access and re-use
- Promote the importance and value of good record-keeping and ensure that responsible records management is undertaken by all funding recipients
- Require that all funding proposals include a strategy for the long-term preservation and re-use of research data and related records
- Provide authoritative advice and guidance to creators and custodians of research records
- Support technical infrastructure for the long-term preservation of, and access to, digital research records
- Ensure that institutions providing record-keeping and archival services to the medical research sector are adequately supported and funded
- Ensure that a full archival record of the UK's medical research activity is preserved for future generations.

Records management and preservation

Both paper and digital records require active and informed custodianship from the point of creation onwards in order to ensure their long-term preservation and access. Digital records are a particular cause for concern.¹

Funders in other discipline areas have taken steps to ensure that investment in the creation of research data is maximised by providing support for data sharing, dissemination and preservation. The Arts and Humanities Data Service, funded jointly by the Joint Information Systems Committee (JISC) and the Arts and Humanities Research Council, hosts a substantial collection of electronic research resources, acts as a clearing house about the location of further resources, and provides expert guidance to data creators, depositors and custodians about archival management. The Economic and Social Data Service (ESDS) is another national data archiving and dissemination service. It is a jointly-funded initiative sponsored by the Economic and Social Research Council and the JISC. The ESDS is a distributed service, based on a collaboration between four key centres of expertise which work collaboratively to provide preservation, dissemination, user support and training for an extensive range of key economic and social data, both quantitative and qualitative. The Digital Curation Centre (DCC), funded by the JISC and e-Science programmes, provides a national focus for research and development into curation issues and promotes expertise and good practice for the management of research outputs in digital format.

Existing medical research bodies do provide some general advice on data curation, and the MRC has a data sharing and preservation initiative, but this is still in its infancy.² General awareness in the medical research community about records management and the importance of long-term preservation of research material remains low. Very little practical support is available to the individual researcher in order to enable them to put the advice into practice. Moreover, there is no central repository for the preservation of medical research data. Individual researchers and their institutions, some of them relatively small, are therefore left struggling with highly technical issues surrounding long-term digital curation and/or the storage of large quantities of paper records for which they do not have adequate resources. This places important medical research data at risk.

Any new funding body should, as a matter of urgency, build on and develop the work begun by the MRC. It should adopt a collaborative approach, working closely with funders in other discipline areas, and with existing providers of record-keeping and archival services.

¹ National Council on Archives, *Your Data at Risk: Why you should be worried about preserving electronic records*. Retrieved 21/07/2006 <http://www.ncaonline.org.uk/materials/yourdataatrisk.pdf>
For an example of the particular problems of this in relation to a long-term health study, see Michael Wadsworth, 'Data curation in the MRC National Survey of Health and Development'. Retrieved 25/07/2006 <http://www.slais.ucl.ac.uk/c21/Wadsworth/>.

² MRC, *Good Research Practice*, Chapter 5. Retrieved 20/07/2006 http://www.mrc.ac.uk/pdf/good_research_practice.pdf; MRC *Data sharing and preservation initiative*. Retrieved 25/07/06 http://www.mrc.ac.uk/index/strategy-strategy/strategy-science_strategy/strategy-strategy_implementation/strategy-other_initiatives/strategy-data_sharing.htm

Access to medical research records

As the long-term custodians of data sets generated by medical research, archivists and records managers are often the first point of contact for those seeking to re-use research data. Members of HARG have extensive experience in negotiating the ethical issues surrounding the provision of such access. They are very aware that there are significant uncertainties over the interpretation of current legal and ethical frameworks for research using personally identifiable information, and that considerable variation between governance structures and oversight bodies adds to this confusion.

Research data that cannot be made accessible or re-used within a reasonable time-scale is not only failing to contribute to further research activity, but is also put at risk of accidental loss or destruction. Moreover, it acts as a drain on resources without providing any benefit to the public's health.

Whilst fully supporting the need for the protection of personal information and the importance of respecting confidentiality, HARG is convinced that responsible information sharing is essential for an open and flourishing research environment, and that publicly-funded research data should be exploited to the maximum extent possible for the public good.

Any regulatory framework that surrounds the provision of research funding should ensure that this balance is negotiated in such a way that access to important research resources is not denied to future researchers. It is key that any decisions are sensitive to public opinion. Some existing studies have already highlighted that, provided sufficient safeguards are in place, the public supports the re-use of research data in order to advance medical science.³ Much more research is required in order to develop an evidence-base for these judgements. Moreover, there is a need for advocacy work with the public in order to increase their confidence in, and support for, the responsible sharing and re-use of medical information.

Conclusion

Any modification in structures for health research funding provides an ideal opportunity to embed responsible and standards-based data curation, records and archive management within UK research practice, to establish the necessary technical infrastructure for digital preservation, and to tackle ethical issues around the re-use of research data, thus ensuring that the country reaps the full benefits from investment in medical research, both now and in the future.

³ Barrett et al, 'National survey of British public's views on use of identifiable medical data by the National Cancer Registry', *BMJ*, 332: 6 May 2006, 1068-1070.