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Editorials

Improving access to research data in Europe

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The European Commission needs to promote access to the data whose collection it has financed

The year 2007 marks the beginning of the European Commission's seventh framework programme for research and technological development, its main vehicle for funding research over the next seven years. It is more ambitious than its antecedent—the sixth framework programme—with a large increase in funding (63%) and the creation of a European Research Council. Health research has been boosted, having been allocated €6bn (£4.3bn; \$9bn) of the overall budget of €50.5bn. Yet the seventh framework programme has done little to promote access to the data whose collection it will finance.

This lack of concrete policies on access to data in Europe contrasts with the proliferation of wider international initiatives over recent years. Such initiatives have been particularly successful in genomics and proteomics,¹ and more recently in the field of chemistry,² but they have also shown promise in health. Examples in the United Kingdom include the policies of the Medical Research Council and Wellcome Trust, which both require grantees to share data. In the United States, the National Institutes of Health have a similar policy—the “data sharing initiative.”

The responsible sharing of health research data through open access should be encouraged for several reasons. Firstly, as a matter of principle, publicly funded research should benefit everyone, and easy access to research data represents sound stewardship of public resources.³ Secondly, access to data facilitates the generation of new knowledge, in the form of developing alternative conceptual frameworks, testing new hypotheses, undertaking meta-analyses, and applying enhanced econometric models. Thirdly, it fosters a more critical approach to interpretation of results, which is currently perceived to be lacking in some clinical trials funded by the drug industry.^{4 5} Lastly, it confronts the selective reporting of favourable results, although this problem is solved to some extent by the increasing requirement for advance registration of clinical trial protocols.

However, problems also need to be overcome. Sharing data from health research is more complex than for other types of research because of ethical and regulatory problems. For data to be meaningful, individual records should ideally be available. This would require data to be anonymised, and provision

should be made to prevent reverse processing. Linking anonymised individual records to other data sets would require a complex approval system. It is unclear whether the benefits of creating a Europe wide system to facilitate this would be outweighed by the costs, given the diversity in national regulatory and data protection systems. Other legal considerations include concerns about national security, patents, royalties, embargoes on use, and ownership or intellectual property rights.^{1 6 7 8 9}

A second challenge in sharing data relates to technical barriers to interoperability of computing systems and the use of different storage formats.^{1 3} Thirdly, cultural, institutional, and administrative problems, such as linguistic or managerial barriers, may exist. Furthermore, practical concerns exist for the transference of data, as exemplified by the recent loss of discs containing personal details of more than 25 million British people. Financial constraints, such as allocating costs of data management between disparate agencies, may also be a problem. Fourthly, other researchers may not be willing to use data unless their quality can be assured.¹ Finally, questions exist about the allocation of responsibility for ensuring the quality of secondary research.¹⁰

The many problems related to improving access to research data need not be insurmountable. Despite the absence of explicit requirements on data sharing, two important health related initiatives that are funded by the sixth framework programme and academically led—the European social survey and the survey of health, ageing and retirement in Europe—provide open access to data, free of charge. Surveys coordinated by the European Commission—specifically the survey on income and living conditions, the European core health information survey (administered by Eurostat), and Eurobarometer—also provide access to data, but users may be charged, even though these surveys are funded by European taxpayers.

The European Commission's Directorate General for Research is taking steps to improve access, with exploratory workshops on data access and earmarked funding to develop and link digital repositories and create mechanisms to preserve data.¹¹ Yet much more needs to be done. As major public funders of research, the framework programmes should develop policies to facilitate access to data generated by grant recipients. If framework programme 7 cannot be amended, frustratingly, the next opportunity will be framework programme 8, which is not due to begin until 2014. In the meantime, steps that the European Commission could take include developing a framework within which clear policies on access to research data can be agreed; funding and developing European data repositories; encouraging national and international public funders to develop data access policies; and supporting initiatives aimed at understanding and overcoming regulatory, technical, legal, cultural, and institutional barriers to increasing access to research data. Academically led initiatives that have made progress in sharing health related data at the European level provide examples of best practice.

Footnotes

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