

Sharing Research Data in Cardiology



Compartir datos de investigación en cardiología

To the Editor,

For more than a decade, the Open Access movement has made the complete text of numerous journals available to researchers, thus facilitating universal access to scientific advances. The *Revista Española de Cardiología* committed itself from the very beginning to this mode of publication, as well as to the bilingual edition of its online version in Spanish and English, a measure that has improved its international readership and impact.¹ One more step in this direction is to provide open access to the raw data that support the study, so they can be available and reused, a practice referred to as data-sharing. This movement is already well established in certain areas, such as genetics. For example, the two largest financial backers of the Human Genome Project, the Wellcome Trust in the United Kingdom² and the National Institutes of Health of the United States,³ have invested in the infrastructure necessary for large-scale, long-term data-sharing and have developed guidelines in this regard. There have also been appeals to this effect in the area of cardiovascular disease, especially stressing the need to share the data from controlled clinical trials, once the necessary measures have been taken to protect the privacy of the patients.^{4–6}

The advantages of sharing research data are well known. It provides investigators with greater opportunities to generate new knowledge; increases the number of blinded statistical analyses; stimulates further discoveries; avoids the repetition of costly projects that involve the same medical approaches or equipment used in previous studies; and could reduce scientific fraud if other researchers can verify the data. In short, it becomes possible to perform many studies at a minimum cost, taking advantage of existing data, which leads to a better use of the available resources.⁷

However, in the majority of the biomedical areas, with the exception of genetics, the data-sharing revolution moves very slowly, and researchers are usually reluctant to participate, meaning that research data are underutilized.⁸ Many investigators are wary of releasing their data in detail for fear that external analyses on the part of others might contradict the initial interpretations. The publication of flawed further studies would create a spiral of confusion that could disorient the international scientific community and distract it from other tasks. Others argue that they have devoted a great deal of time and effort to the design and collection of the data and, thus, want to be the ones to transmit the results, rather than others who have not participated in the process. On the other hand, they think that, in the future, they will be able to obtain new, additional observations from their data, and therefore offering them openly would impede their own further analysis if opportunistic investigators have already used the data. The solution in this case would be to protect the authorship of the original researchers for a certain period of time and to establish a policy of incentives such that those who share their data have certain advantages over those who do not.^{4–6}

Although many unresolved issues remain, the scientific community has initiated the process of developing guidelines and solutions to the most common problems as they arise. In Spain, the Working Group for the “Storage and Management of Data in Open Access” of the RECOLECTA project has prepared a report⁹ that reflects the relevant aspects of the management of research data in scientific repositories. On the other hand, the Spanish Ministry of Economy and Competitiveness funds the project entitled “OpenDataScience, resource center for the preservation and management of open research data”, the purpose of which is to promote the exchange and reutilization of primary research data in

a generalized and standardized way.¹⁰ Private foundations are also interested in research in this field; for example, the Spain-based *Fundación Mapfre* sponsors the project entitled “Strategies for the management and promotion of the shared use of scientific data on health”, with objectives similar to the aforementioned project but focused on the field of health sciences.¹¹

All in all, we feel that it is necessary to raise the consciousness of professionals so that they release their research data, but we must also create infrastructures that facilitate data storage and preservation and establish the rules of the game to clarify many of the implications of a strategy with these characteristics. Scientific journals with online versions have the appropriate technology to provide the storage of and access to these data, and this is the case of the *Revista Española de Cardiología*, which accepts the electronic transmission of additional material in several formats to support and improve the presentation of scientific research (although since April 2013, it has restricted open access to some of its web content). On the other hand, it is also necessary to create institutional and thematic repositories that enable researchers to store their data with the guarantee that the information will be safeguarded. Much remains to be done, but the process of achieving open and shared use of scientific data would appear to be unstoppable.

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REFERENCES

1. Bosch X, Villacastán JP, Alfonso F. Edición en inglés por Internet. Un nuevo gran paso adelante de Revista Española de Cardiología. *Rev Esp Cardiol*. 2002;55:1–3.
2. Wellcome Trust. Data sharing [accessed 12 Jul 2013]. Available at: <http://www.wellcome.ac.uk/About-us/Policy/Spotlight-issues/Data-sharing/>.
3. NIH Data Sharing Policy [accessed 10 Jun 2013]. Available at: http://grants.nih.gov/grants/policy/data_sharing/.
4. Gotzsche PC. Strengthening and opening up health research by sharing our raw data. *Circ Cardiovasc Qual Outcomes*. 2012;5:236–7.
5. Krumholz HM. Open Science and data sharing in clinical research: basing informed decisions on the totality of the evidence. *Circ Cardiovasc Qual Outcomes*. 2012;5:141–2.
6. Spertus JA. The double-edged sword of open access to research data. *Circ Cardiovasc Qual Outcomes*. 2012;5:143–4.
7. Ferrer Sapena A, Peset Mancebo F, Aleixandre-Benavent R. Acceso a los datos públicos y su reutilización: open data y open government. *Prof Inf*. 2011;20:260–9.
8. Pisani E, AbouZahr C. Sharing health data: good intentions are not enough. *Bull World Health Organ*. 2010;88:462–6.
9. Grupo de Trabajo de «Depósito y Gestión de datos en Acceso Abierto» del proyecto RECOLECTA. La conservación y reutilización de los datos científicos en España.

- Informe del grupo de trabajo de buenas prácticas. Madrid: Fundación Española para la Ciencia y la Tecnología, FECYT (2012) [accessed 14 Jan 2013]. Available at: http://www.recolecta.net/buscador/documentos/informe_datos_cientificos_en_esp.pdf.
10. Datasea - Datos Abiertos de Investigación/Open Research Data [citado 12 Jul 2013]. Disponible en: <http://www.datasea.es/>.
11. Healthdatasea. Estrategias para la gestión y la promoción del uso compartido de datos científicos sobre la salud [accessed 12 Jul 2013]. Available at: <http://www.healthdatasea.es/>.
<http://dx.doi.org/10.1016/j.rec.2013.08.005>