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Correspondence

Data sharing: guard the privacy of donors

Shirley Y. Hill

I endorse Emma Kowal and colleagues' call for more-responsible sharing of people's research data (*Nature* **546**, 474; 2017). The reuse of data without participants' consent is a serious ethical problem and could discourage participation in future projects (see, for example, go.nature.com/2ub6qrq).

To the chagrin of privacy advocates, the US Department of Health and Human Services introduced reforms in January that allow sharing of medical-research data without re-consent by patients (see *Nature* **541**, 449; 2017). Researchers must now share their archived data, which were collected before the National Institutes of Health (NIH) data-sharing policy of 2003 and when consent forms did not let people opt out of having their data shared. Researchers who fail to comply can have their NIH funding withheld (see go.nature.com/2vzjthi).

This policy is particularly problematic for anonymous donors who have stigmatizing conditions such as alcohol or drug addiction. De-identified data in family collections can now be identified using genealogy databases (J. Bohannon *Science* **339**, 262; 2013). With the hacking of medical records for profit becoming more pervasive in the United States (see go.nature.com/2uytcpq), people who donated their private information could now be compromised.

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RAVICHANDRAN SUNDARAM • 7 months ago


Researchers generate lot of data by conducting experiments involving huge amount of money, labor and time. Once the data are generated, these data need to be preserved by creating huge databases which again involve all the three factors. The very purpose of preserving the data and use it for public sharing is to avoid duplication of research by other researchers involved in scientific research. Data generated out of public funding has to be preserved by public organizations carefully and in case these data are required by other researchers can be given on payment or by executing proper data sharing policies. Many of the public funded organizations keep the data in public domain and there exists data sharing policy by the individual public funded organizations. Interested clients can procure the data on payment after agreeing to the data sharing policy. Private funded organizations, however, keep their data in the custody and are not generally shared with anybody because of various issues. However, sharing of data by private organizations and any other donors need to guard their privacy.

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