

How can we improve data sharing of biomedical research across the globe?

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With the globalization of biomedical research and growing concerns about possible pandemics of diseases such as HIV, SARS, and Ebola, international data-sharing practices are of growing interest to the biomedical science community. But what are the advantages and disadvantages of sharing data in low and middle-income settings? What challenges stand in the way for researchers in countries such as India, Kenya, and Vietnam? A new special issue of SAGE's *Journal of Empirical Research on Human Research Ethics (JERHRE)* presents guidelines, protocols, models, and new resources to improve data sharing across the globe.

"Gatekeepers of data in these studies, although positive about the general concept, were skeptical about sharing their own data, not unlike the responses of persons in Western countries who have not shared data," wrote *JERHRE* Editor-in-Chief Joan E. Sieber. "However, in this issue, we see the emergence of exciting next steps in human [data sharing](#)."

A special issue of *JERHRE*, edited by Susan Bull and Michael Parker from the University of Oxford, publishes research funded by the Wellcome Trust, on behalf of the Public Health Research Data Forum. It outlines the views of researchers and gatekeepers of biomedical research in five developing countries - India, Kenya, South Africa, Thailand, and Vietnam - on the possibility of expanding the sharing of their individual-level biomedical research data.

Through interviews, small group discussions, focus groups, and literature

reviews, authors of the articles in the special issue found the following:

- Among researchers in Mumbai, India, concerns for data sharing were centered on three themes: acknowledgment of data producers, skepticism about the process of sharing, and the fact that the terrain of data sharing was essentially uncharted and confusing (Hate et al.)
- In Vietnam, it was recognized that there is a need to ensure that the rights and interests of participants, communities, and primary researchers are respected through transparent and accountable data-sharing processes (Merson et al.)
- In Kenya, trust-building practices such as prior awareness and consent are crucial to promoting data sharing (Jao et al.)
- In Thailand, data sharing was generally seen as something positive: a means to contribute to scientific progress, to higher-quality analysis, better use of resources, greater accountability, and more outputs (Cheah et al.)
- Commitment to promote access to data is evident within South Africa's public research sector, despite the absence of national guidance and regulation. However, disparate views emerged among researchers about the possible harms and benefits of data sharing (Denny et al.)
- Challenges raised by sharing individual-level data from low and middle-income settings can differ in important and morally significant ways from those arising in high-income settings (Parker and Bull)

The concluding paper from the study found that the majority of researchers studied had very limited experience sharing individual-level health research data and that even senior researchers had little experience sharing data with secondary researchers not known to them (Bull et al.). In an effort to support data sharing, the study authors developed an open access online resource, including a free online course,

focusing on ethics and best practices in sharing individual-level data in low and middle-income settings. More information on this new resource can be found [here](#).

Five commentaries from independent experts accompany the study results and discuss funders' perspectives (Carr and Littler), global data sharing challenges (Alter and Vardigan), human rights (Harris and Wyndham) and experiences of establishing data sharing repositories in low and middle income settings (Herbst et al., Lotter and van Zyl).

"Data sharing enables researchers worldwide to build on the efforts of others in a cost-effective way. Base-line data will be in place when epidemics strike. The political, scientific, and economic problems of understanding and stopping new diseases will be vastly reduced when an infrastructure and baseline data are readily available to scientists," Sieber wrote. "Each discipline raises its own set of challenges, risks, and benefits of [data](#) sharing, but with ingenuity, the risks can be overcome."

More information: Find out more by reading the full special issue of the Journal of Empirical Research on Human Research Ethics titled "Ethics and sharing individual-level health research data from low and middle income settings." us.sagepub.com/en-us/nam/journal-ethics/journal202321

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