
Sharing health data: developing country perspectives

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Not only is it difficult to change the “publish or perish” mindset among health researchers, there are other fundamental barriers in data sharing that Pisani & AbouZahr’s paper should have addressed.¹ Sharing data is not only about the technical dimension such as data management, repositories and libraries; developing countries are concerned about factors that impede data sharing, in particular, fairness. Pisani & AbouZahr provide clear analyses on barriers but their proposed solutions will not be effective unless they address the fundamental problems.

From the perspective of developing countries, the goal of data sharing is beyond national interests and is for the benefit of all mankind. Without this explicit goal, data sharing more often helps scientists in developed countries get published. While these scientists may have higher analytical capacities, they have neither shared the “legwork” in collecting routine administrative data nor made intellectual contributions to designing and solving problems in conducting field work with scientists in developing countries.

Developing countries need to strengthen capacities in survey design, data management and analysis and policy use. There is clearly an unlevel playing field that impedes data sharing. Scientists from developed countries often take the following approach with researchers in developing countries: “Share your data with me, you do not have analytical capacities. I will analyse and publish papers for global public good.” Instead, their approach should be: “We can analyse the data together and learn from each other for the benefit of all people.” This approach would gradually create equal partnerships, a level playing field, goodwill and trust for collaborations beyond simply sharing data.^{2–4} International data sharing cannot be achieved through forced marriage; as shown by the defeat of the policy proposed by the *Annals of Internal Medicine* of a publicly accessible database as a condition for journal publication.⁵

The recent sharing of avian flu virus specimens by developing countries through the World Health Organization resulted in the production of avian influenza vaccines at a price of US\$ 10–20 per dose. This is unaffordable in low-income countries where total health expenditure is less than US\$ 30 per person. Should an avian flu pandemic occur, there would be huge death tolls in countries without access to vaccines; while rich countries’ populations would be fully protected, literally from any moral obligations to countries that shared their specimens. Such unilateral benefit inhibits data sharing.

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It is important to have evidence on the benefits that populations receive directly as a result of sharing, beyond publications by secondary users. Success in international data sharing may start with efforts at country level or through multi-country research partnerships. Undeniably, multi-country studies provide huge benefit in supporting evidence-based policy. Collaborative partnerships among a number of developed and developing countries, such as for maternal and perinatal health, are foundations for building long-term trust.⁶ In research partnerships, there is equitable access to and use of data sets, beyond the conventional practice of passive data sharing without partnership.

In Thailand, rules and procedures for data sharing were developed through a research funding agency and the National Statistical Office. Primary users were granted a reasonable-use period of two years after complete data collection prior to access by secondary users. Good practices are emerging. With the aim of capacity building and mutual benefit, the National Statistical Office grants approval to international secondary users to access nationally representative household data sets, on the condition that they develop partnerships with local scientists. Such engagement gradually builds trust and longer-term partnerships between scientists from developed and developing countries. ■

Competing interests: None declared.

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