

The two authors challenge institutions, in particular research funders, to take charge of the agenda to make these changes happen. They call for leadership but, while funding agencies are clearly influential and can certainly facilitate changes in scientific behaviour and culture, they are unlikely to be able to effect all the changes called for by Pisani & AbouZahr. While funders might support and encourage, we are not in a position to dictate changes to professional structures, to create career paths for scientific disciplines at academic institutions, nor to determine scientific reward mechanisms.

What is required as a first step is the facilitation of dialogue and the building of consensus between all interested parties, including funders, researchers, institutions, journal editors, ethics committees, multilateral agencies and governments. No one agency has the mandate or the legitimacy to take this whole agenda forward unilaterally. A more sustainable and palatable pathway will be to build consensus and to create a broad coalition.

It is worth reflecting on why data sharing is not more commonly practiced among epidemiologists and public health researchers. Pisani & AbouZahr point out many of the constraints, such as the lack of appropriate incentives from employers such as research councils, foundations and universities, the short supply of data managers especially in low- and middle-income countries, and concerns over the control and ownership of data. There are also technical issues, data sets for cohort studies are more complicated than standard genetic data sets because of their longitudinal nature, and there are no off-the-shelf tools available for managing and curating standardized and interoperable longitudinal data sets.

Overcoming these constraints requires a broad consensus among stakeholders. Indeed Pisani & AbouZahr seem to acknowledge this. When they write that “we” need to develop a search portal, invest in training in data management, develop reliable citation standards, develop methods to track the value of data sharing, and so on, these are clearly tasks for the wider scientific community.

Of course, individual institutions – and funders – can take the initiative over certain aspects of the agenda and form alliances with those agencies that can help in other domains. Indeed, the Wellcome Trust has already led various initiatives in this field, including convening international meetings of public health researchers and funding agencies, and has raised these issues at meetings of public health policy-makers and international journal editors. The Trust is currently revising its grant conditions about data sharing, which will be strengthened and, importantly, will provide more guidance about the technicalities of *how* to share data more effectively. We are ready to take the lead in those areas, where it is appropriate for us to do so, and we are open to the formation of alliances with other agencies that can help to facilitate progress in other areas. ■

**Competing interests:** Jimmy Whitworth is employed by the Wellcome Trust, which commissioned Elizabeth Pisani to work on its data-sharing project.

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## 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.<sup>1</sup> 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.<sup>2–4</sup> 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.<sup>5</sup>

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.<sup>6</sup> 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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