OECD's data sets can now be discovered more easily and they can be cited as simply and as easily as a research article using the downloadable citation provided. Later in 2010, librarians will be supplied with MARC records and the bibliographic records for OECD data sets will be shared with discovery platforms like RePEc (Research Papers in Economics)[4] – the world's largest collection of economics grey literature – enabling visitors to find data objects alongside working papers and journal articles. Imagine being able to discover and cite data sets as easily and as simply as journal articles. Imagine no more. ■

Competing interests: None declared.

References

1. Pisani E, AbouZahr C. Sharing health data: good intentions are not enough. *Bull World Health Organ* 2010;88:462–6.
2. Green T. *We need publishing standards for datasets and data tables.* Paris: Organisation for Economic Co-operation and Development; 2010. Available from: http://dx.doi.org/10.1787/603233448430 [accessed 1 March 2010].
3. OECD iLibrary [Internet site]. Paris: Organisation for Economic Co-operation and Development; 2009. Available from: www.oecd-ilibrary.org [accessed 19 May 2010].
4. RePEc (Research Papers in Economics) [Internet site]. Available from: www.repec.org [accessed 1 March 2010].

Sharing data for public health: where is the vision?

Alan D Lopez[a]

"By refusing to share data, researchers are slowing progress towards reducing illness and death." Pisani & AbouZahr are making a big claim in this round table.[1] Is this claim sensationalist or does it have some basis? Can we argue that data from public health research really affect the ways prevention and control programmes are designed? Lives have become longer and healthier in the past 50 years, despite an arguably poor evidence base for health and an even poorer appreciation by policy-makers of the value of reliable health information.[2,3] Pisani & AbouZahr are arguing that such gains would have been bigger, faster and more equitable had the world had better information about what works and does not work in public health; lost ground is partly due to widespread hoarding of research findings, particularly primary data.

They have a point. Restricting access to data to only those scientists directly engaged in a research project limits the scope of legitimate scientific enquiry and the potential for research to influence policy and practice. No individual scientist who collects or collates data has all the possible analytic methods, expertise and time to extract key public health messages from research or routine data sets.[4–7] Lost opportunity for analysis is the main consequence of poor data sharing practices.

Yet, as Pisani & AbouZahr argue, it is unreasonable to expect data collectors to share without adequate incentives. Incentives could include professional recognition for well collected and documented data, appropriately disseminated using good data management practices. Data collectors too need assurance that their efforts will be respected and that errors in data are inevitable and rarely disastrous. Experienced researchers are aware of these risks and can use a range of quality assessment techniques to deal with errors.

Mentoring is one incentive that is missing from the otherwise excellent set proposed by Pisani & AbouZahr. Partnerships between researchers and data collectors, including intensive methodological workshops, are feasible and can help ensure that those who collect data realize the public health potential and value of their efforts. Such an approach could rapidly increase analytical capacity and diversify the analysis of rich, but underutilized, data sets. Funding such collaborations would be an innovative and constructive use of research funds. Competent analysts should be able to resolve potential challenges in interpreting data because of specific local conditions surrounding their collection. Restricting access on this basis reflects a lack of confidence, imagination or trust by those who collect data and should be questioned when used to preclude further analysis.

The authors propose an urgent agenda for action to improve data sharing practices that will benefit all stakeholders – data collectors, analysts, the policy community and, ultimately, the public. This is admirable but, for such a plan to succeed, funders, researchers and data collectors alike need to understand its benefits. That will only happen with effective and committed leadership. What better role for the World Health Organization? ■

Competing interests: None declared.

References

1. Pisani E, AbouZahr C. Sharing health data: good intentions are not enough. *Bull World Health Organ* 2010;88:462–6.
2. Setel PW, Macfarlane SB, Szreter S, Mikkelsen L, Jha P, Stout S et al.; Monitoring of Vital Events. A scandal of invisibility: making everyone count by counting everyone. *Lancet* 2007;370:1569–77. doi:10.1016/S0140-6736(07)61307-5 PMID:17992727
3. Horton R. Counting for health. *Lancet* 2007;370:1526. doi:10.1016/S0140-6736(07)61418-4 PMID:17992726
4. Murray CJL, Lopez AD. The utility of DALYs for public health policy and research: a reply. *Bull World Health Organ* 1997;75:377–81. PMID:9342897
5. Rajaratnam JK, Tran LN, Lopez AD, Murray CJL. Measuring under-five mortality: validation of new low-cost methods. *PLoS Med* 2010;7:e1000253. doi:10.1371/journal.pmed.1000253 PMID:20405055
6. Obermeyer Z, Rajaratnam JK, Park CH, Gakidou E, Hogan MC, Lopez AD et al. Measuring adult mortality using sibling survival: a new analytical method and new results for 44 countries, 1974–2006. *PLoS Med* 2010;7:e1000260. doi:10.1371/journal.pmed.1000260 PMID:20405004
7. Murray CJL, Rajaratnam JK, Marcus J, Laakso T, Lopez AD. What can we conclude from death registration? Improved methods for evaluating completeness. *PLoS Med* 2010;7:e1000262. doi:10.1371/journal.pmed.1000262 PMID:20405002

Data sharing: reaching consensus

Jimmy Whitworth[b]

Pisani & AbouZahr write passionately about the need to change the culture of data sharing in public health research.[1] They explain why this is in everybody's best interests and outline ways in which the main obstacles can be overcome. This is laudable and much appreciated; it is time for a change, the current situation is unacceptably inefficient in terms of scientific progress and value for money from research.

---

[a] School of Population Health, University of Queensland, Herston Road, Herston, Qld., 4006, Australia (e-mail: a.lopez@sph.uq.edu.au).
[b] Wellcome Trust, Gibbs Building, 215 Euston Road, London, NW1 2BE, England (e-mail: j.whitworth@wellcome.ac.uk).

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 be will 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.

References

1. Pisani E, AbouZahr C. Sharing health data: good intentions are not enough. *Bull World Health Organ* 2010;88:462–6.

Sharing health data: developing country perspectives

Viroj Tangcharoensathien,[a] Jirawan Boonperm[b] & Pongpisut Jongudomsuk[c]

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.

---

[a] International Health Policy Program, Ministry of Public Health, 376 Mooban Panya, Patanakan Road, Bangkok, 10250, Thailand.
[b] National Statistical Office, Laksi, Thailand.
[c] Health Systems Research Institute, Bangkok, Thailand.
Correspondence to Viroj Tangcharoensathien (e-mail: viroj@ihpp.thaigov.net).