Sharing data for public health: where is the vision?
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“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. 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. 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. 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?

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References

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