Sharing research data to improve public health: a perspective from the global south

Osman Sankoh a, Carel Ijsselmaiden b, 25 others

Mark Walport and Paul Brest (Feb 12, p 537) wrote on behalf of several research funders about a statement of purpose on sharing research data to improve public health. INDEPTH, a southern-based research network, the Council on Health Research for Development (COHRED), an organisation enabling research and innovation systems for health in low-income and middle-income countries, and many other people are pleased with this demonstration of leadership and commitment. We wish to comment on three areas and suggest a way forward.

First, Walport and Brest state that they are committed to “fair trade, not free trade” when it comes to data sharing. The question is how to achieve fair trade. Fair trade is usually governed by mutually binding agreements and measures. This implies achieving a balance between the rights and responsibilities of those who generate data and those who analyse and publish results using those data. Such a balance lies in ensuring that the means and capacity to share and actively participate in the analysis of those data are in the hands of those who generate the data and not only in those who want to analyse it.

Second, there is a need to clarify what is meant by “population data collected for health research”; this is not a homogeneous entity. Some data will be substantially more straightforward than others. For example, in the INDEPTH/WHO SAGE multicentre study on ageing, health, and wellbeing in eight countries in Africa and Asia, it was not too difficult to put a single cross-sectional survey datafile into the public domain within a few months of completion of data analysis and publication. Addition of individually linked mortality data from the same contributing longitudinal health and demographic surveillance systems would be much more difficult. Longitudinal surveillance data are more complex and dynamic. We are, however, making good progress in understanding how to deal with such data.

Third, in addition to data analysis capacity, southern-based research institutions typically do not have the legal capacity to ensure that the contracts they sign with international research partners give them a fair share of the benefits from collaborative research. Without this, even contracts negotiated in good faith can lead to inequitable agreements that might not deal with, for example, fair data ownership, technology transfer, capacity building, intellectual property rights, and future benefit sharing.

Walport and Brest state that, “As funders of public health research, we need to ensure that research outputs are used to maximise knowledge and potential health benefits”. However, such health benefits seem to be limited to technical solutions to address specific diseases or health conditions, which ignores the fact that most health benefits, particularly in low-income and middle-income countries, result from creating environments, capacities, and systems in which what is already known can be applied.

Further, to be effective, discussions around data sharing must not be limited to individual research projects. The Demographic and Health Surveys programme has a technical Data Processing and Development team that deals with data processing, cleaning, analyses, storage, sharing, and ICT systems. Although it is unlikely that such a system could be easily replicated in every country, funders could identify and invest in specific data systems in the global south, and in stronger academic institutions with regional partnerships, that hold the greatest promise for maximising public health knowledge.

We declare that we have no conflicts of interest.
References


a. INDEPTH Network, PO Box KD 213, Kanda, Accra, Ghana

b. COHRED, Geneva, Switzerland