Beyond open data: realising the health benefits of sharing data

Accessible data are not enough. We need to invest in systems that make the information useful, say Elizabeth Pisani and colleagues

Elizabeth Pisani visiting senior research fellow, Peter Aaby professor, J Gabrielle Breugelmans networking manager, David Carr programme manager, Trish Groves director of academic outreach, Michelle Helinski project officer, Dorcas Kamuya researcher, Steven Kern deputy director, quantitative sciences, Katherine Littler senior policy adviser, Vicki Marsh associate professor, Souleymane Mboup professor, Laura Merson researcher, Osman Sankoh executive director, Micaela Serafini medical director, Martin Schneider PhD candidate, Vreni Schoenenberger manager, policy, ethics and compliance, Philippe J Guerin director

As little as a decade ago, many researchers working in global health recoiled at the idea that they should openly share individual patient data with one another. Now, data sharing is being herded into the mainstream by pioneering researchers, with added pressure from funders, medicine regulatory authorities, public health agencies, and medical journals. But even those researchers most willing to share data are given little guidance on how that should happen, and the practice is still unusual, especially in low and middle income countries.

Concerns continue to be raised that data sharing will lead to data being analysed by rich institutions in industrialised countries while researchers in poorer countries with the highest burdens of infectious disease will lose control of their data and get little in return. Some fear that data sharing might harm patients and communities by breaching confidentiality, that the infrastructure is not up to it, and there is nowhere safe to put shared data.

Our group includes researchers working for academic and humanitarian organisations, as well as public, charitable, and industry funders of data sharing efforts. Although we have raised concerns in the past, we are now involved in sharing information collected in low and middle income settings, including demographic surveillance data and the records of individual patients in clinical trials. We examine the extent to which the fears about data sharing have been realised in our work and what is needed to get the most value out of shared data.

Getting more health out of the same data

Data sharing is often asserted to be good for health and to generate new information that can save lives. We found many examples where this was demonstrably true, with analyses of data pooled from different studies in different locations providing new information relevant to appropriate dosing, improved treatment of subgroups, and the development of new treatments.

Box 1 lists some of the better known data sharing models. One example is a meta-analysis of individual patient data from a large and diverse population of patients shared through the WorldWide Antimalarial Resistance Network (WWARN). This provided the power to determine the efficacy of antimalarial drug dihydroartemisinin-piperaquine across a wide range of age groups and settings. The meta-analysis revealed that treatment failure associated with a lower dose of piperaquine was particularly dangerous in young children, suggesting potential for further dose optimisation. The results contributed to a revision of the World Health Organization’s guidelines for treating malaria.

We also identified areas where the failure to share data has disrupted efforts to respond rapidly to outbreaks or foreclosed more detailed evaluation of interventions that may be harmful. In these cases, not sharing data has been bad for science and almost certainly bad for health. In the 2014 Ebola outbreak in west Africa some researchers made genomic data immediately available for further study, confirming that the virus had spread from Guinea to Sierra Leone, that it was...
Datasets and even data repositories have multiplied so rapidly and chaotically that one of our group likened them to an asteroid field. Better technology and metadata standards—especially common search portals, improved discoverability, and tools for reliable anonymisation and standardisation of heterogeneous data—could begin to reshape the asteroid field into an organised solar system.

Developing that solar system and keeping the planets in orbit will require substantial long term investment. In recent years, the pharmaceutical industry has expanded efforts in data transparency through platforms such as clinicalstudydatarequest.com and has begun the process of transforming useable data into something more useful through data standardisation and curation in fields such as oncology. In some cases it is outsourcing this work to academic institutions—for example, the YODA platform held at Yale. There is scope to expand these public-private partnerships using fees from well resourced diseases to subsidise curation of data for conditions with less commercial appeal.

Realistically, however, grants from development institutions are likely to remain a key source of funding for data platforms for neglected diseases. Currently, few such institutions provide long term funding for data infrastructure and curation. In addition, the groups best connected to those funding sources tend to be academic, and academic researchers may not be best placed to design or build the data solar system. Initiatives such as the Clinical Data Interchange Standards Consortium are crowdsourcing metadata standards from scientists, but we need to draw on data management expertise from the vast data industry outside academia to develop data sharing platforms most efficiently, not least in order to reduce unnecessary reinvention and duplication.
Do no harm

Concerns that patient confidentiality and consent may be breached are often cited by researchers as a reason for not sharing data. Several of us have been sharing data for a decade or more, including around illicit behaviours and stigmatised diseases. Between us we could find few examples of harm—certainly far fewer than examples of benefits—partly because we have worked hard to develop strong governance structures. We have also consulted with patients and communities about sharing the information they provide to us, because we believe that efforts to expand data sharing can succeed only with broad social support. While governance structures for secondary analysis should be simplified so that they are proportionate to the often more limited risks of data reuse, they must remain robust. These governance protocols should be shared more widely as we gain experience in how to maximise useful sharing while minimising risks. Collaboration around governance also reduces the hurdles to contributing data to repositories for pooled analyses.

Equity in research: the threat of data parasites

A common generalisation in discussions of data sharing is that it undermines the career prospects for researchers, especially in low and middle income countries, exposing them to “research parasites” who will ingest their data into far-off computers and beget papers for high impact journals. We could find no evidence for this. It is difficult to pick poorly documented data out of scattered repositories and make coherent, publishable sense of it. When well documented data are shared usefully in professional networks, our experience is that sharing has increased our work’s visibility and expanded our collaborations. Investigator led networks in which secondary users work collaboratively with the researchers collecting the data to define and answer questions are an important start in moving towards a “fair trade” culture in health research, though it is still only a start. In journal publications of secondary analyses, first and last authors are still most often from wealthier countries.

Conducting clinical trials and other health research in low and middle income countries is time consuming, challenging, and often financially insecure. It leaves investigators with little time to build up, let alone exercise the skills needed for large scale secondary analysis of pooled datasets. Data sharing collaborations have the potential to introduce greater equity in global health research, but that will require long term investments in both skills and career pathways for researchers from countries with high disease burden. Changing the incentive system to reward the publication of quality assured datasets with standardised metadata in the same way that we reward the publication of research papers in high impact journals would go a long way to damping down the panic about data parasites.

Towards a data sharing solar system

In our experience sharing data from demographic surveillance and health research, including clinical trial data at the individual patient level, can lead to advances in knowledge that wouldn’t have been possible without bringing those data together. To that extent, data sharing is good for health. But knowledge improves health only if it leads to changes in policy and practice; one of the most important determinants of the translation of research results into health policy in low and middle income settings is collaboration between local researchers and policy makers in shaping research questions and interpreting results. Most examples of policy change based on analysis of shared data in low and middle income settings involve compendia of datasets that are quality controlled, standardised, and otherwise highly curated. In general, the analyses are performed in collaborations between global disease experts and local researchers who know their contexts well and who help formulate questions and answer them. These researchers can also act as a bridge to national policy makers, ultimately delivering changes that benefit the populations from which data were collected.

This sort of sharing requires far more effort than simply uploading a dataset to an online repository. Useful scientific collaborations are expensive to develop and require a shift in attitudes, incentives, and investment patterns. A degree of technical and economic efficiency may have to be sacrificed in the interests of fostering collaboration and equity—for example, by investing in building skills in high disease burden countries rather than simply using skills already available in universities in industrialised countries. The peer reviewed research results paper must lose its supremacy as the major metric of scientific productivity; and funders must commit to long term investments in both technical and human infrastructure if they want to promote data sharing that is useful, used, and likely to change policies for the greater benefit of patients.

This cannot happen for all diseases or all types of data at once—it is just too expensive. The alternative is not, however, to downgrade to a useable (but not used) or accessible (and not useable) model of data sharing. Rather, we must think in fresh ways about how existing structures can be made more useful to maximise health gains. We need to figure out which platforms and technological structures can be shared across diseases and which diseases would most benefit from the sort of pooled analysis that has already proved useful. Obvious candidates include neglected tropical diseases and other infectious diseases in poor regions with only sparse data and small sample sizes; emerging infections about which little is known; and diseases such as tuberculosis and malaria that face changes in disease burden and spreading drug resistance. The value of investing in a platform is also likely to be affected by many other factors, including the potential for data standardisation, the institutional politics in which the disease is embedded, and the degree to which research is financed by public or charitable bodies.

We need to stop thinking of data sharing as an afterword to the scientific enterprise: it is relevant to every stage of the research cycle. Depositing decontextualised results into a growing asteroid field may tick a transparency box, but it is otherwise wasteful. To be useful in the low and middle income settings which should high burdens of disease and a legacy of under-investment in research infrastructure, data sharing must be treated as an integral part of the larger scientific solar system. We favour sharing data, certainly, but only as one part of a research collaboration that also fairly shares models of governance and the tools, technology, and analytical skills that turn shared data into better health.

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Table 1 | Benefits and costs of different levels of data sharing

<table>
<thead>
<tr>
<th>Benefits and costs</th>
<th>Research becomes transparent</th>
<th>Potential health benefit</th>
<th>Upfront curation costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accessible—online repository</td>
<td>Yes</td>
<td>Uncertain</td>
<td>Cheap</td>
</tr>
<tr>
<td>Useable—repository with discoverable, well documented metadata</td>
<td>Yes</td>
<td>Possible with extensive user effort</td>
<td>Moderate</td>
</tr>
<tr>
<td>Useful—data are curated, standardised, and comparable across time and place</td>
<td>Sometimes</td>
<td>Great</td>
<td>Expensive</td>
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