

Ethics of data sharing in health research: 2 November, 1pm-2.30pm GMT (London)

Data sharing has the potential to increase scientific efficiency by maximising the availability and utility of data, and can be critical to generating knowledge during a public health emergency. Research funders and journals are increasingly promoting open sharing to improve the transparency and utility of research, with the ultimate aim of improving health. However, the research community are also concerned about the harms of data sharing, such as the potential to exacerbate existing inequalities, particularly if data sharing benefits only researchers from well-resourced institutions, leaving researchers in low-resourced settings worse off.

The 2018 [Global Forum on Bioethics in Research](#) (GFBR) meeting focused on this important topic. This [PHEPREN](#) and GFBR seminar will examine the GFBR meeting conclusions in the context of the current COVID-19 research response, where the pandemic has created more tension to the issues. We will explore how research practice and policy has progressed since this topic was discussed at GFBR, and what has changed – and should change – in light of the COVID-19 pandemic.

Chair: Robert Terry, TDR, Switzerland

Panel: Phaik Yeong Cheah, University of Oxford, Thailand
Gloria Mason, National Research Ethics Board, Liberia
Oommen John, The George Institute for Global Health, India

The following questions were discussed at GFBR and will form the basis of the seminar's panel discussion. The full GFBR meeting report is available [at this link](#). Seminar attendees are invited to submit questions in advance of the seminar when they [register](#) or by [email](#), or during the live discussion. The seminar is not presentation based, but is discussion based.

What are the possible benefits and harms associated with data sharing?

Why is the sharing of data being promoted and what is 'good' about such sharing? What are the perverse effects of data sharing policies e.g. if researchers in low resource settings are compelled under funding agreements to immediately share their data, is this equitable? How do we share for maximum benefit and least harm?

What do we need to do to ensure that data sharing policies and processes are respectful of participants and communities and what are the limits and tensions?

How should policies and processes to promote respectful sharing be developed, and who should contribute to their development? How should we respond to differing (cultural) views about what is required? Are there circumstances – such as the current COVID-19 pandemic – where procedures that have been proposed as necessary to promote respect (e.g. ensuring consent), are arguably inappropriate, unfeasible or burdensome?

What are the key features of a governance framework for sharing patient data for health research? Are some features distinct for research during public health emergencies?

How can we create a governance mechanism that means patient data can be shared – especially where there is no individual consent for research use? What is appropriate and required (e.g. data access committees, security systems etc).

What policy changes are needed to underpin a governance framework that enables responsible sharing of health data?

What are the ethics/regulatory reviews and/or training programmes that need to be put in place? What expertise and resource commitments are required e.g. from funders and governments? What role does the public or other stakeholders have (if any)? What does capacity building mean in this context? How should (and could) international forums and networks facilitate these changes?