

Solutions to COVID-19 data sharing

We read with interest *The Lancet Digital Health* Editorial regarding transparency during global health emergencies, and we wanted to bring to your readers' attention our work on data sharing.¹

After WHO's declaration of COVID-19 as a global pandemic, the COVID-19 Clinical Research Coalition was established on April 2, 2020.² The Coalition is made up of global health researchers working in, or allied with, resource-limited settings across multiple continents. This umbrella group has grown, with working groups now spanning nearly a dozen interest areas including ethics, clinical pharmacology, and data sharing. Here, we outline the rationale and aims of the Data Sharing Working Group, which comprises researchers working on ethics, regulatory, and operational aspects of data sharing.

As the Editorial highlighted, the importance of promoting effective, ethical, and equitable data sharing has increased in the time of COVID-19. International funders such as the Wellcome Trust³ and the Bill & Melinda Gates Foundation have mandated that funding recipients share data from research related to COVID-19 as soon as the study is completed, regardless of publication status. However, the challenges of data sharing persist. These include complexities of broad consent,

lack of data management capacity, and the potential for exacerbating existing inequalities between researchers in low-resource and high-resource settings.^{4,5} Based on our observations, although many journals require a data sharing statement, mechanisms for accessing individual participant data are seldom provided by the authors of published COVID-19 trials, and data sharing defaults to interested investigators contacting authors to inquire about data acquisition.

Given the public health imperative to share data to accelerate effective COVID-19 responses, the Data Sharing Working Group was convened to facilitate and promote effective, ethical, and equitable data sharing across geographies and disciplines. Specifically, the Data Sharing Working Group synthesises existing policies, guidance, and good practice on data sharing by funders, journals, and practitioners; and provides practical advice to researchers and data management teams on data sharing, including recommended language for broad consent for secondary use of data, recommendations for selecting repositories or platforms for data sharing, guidance on governance for data sharing, and recommendations for developing data access agreements. We aim to promote the greatest use possible of the data generated to help with the management of the pandemic,

while protecting the interests of study participants, their communities, and the researchers who generated the data.

We encourage researchers who are seeking practical solutions to data sharing to contact us (WorkingGroups@covid19crc.org).

We declare no competing interests.

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- 1 The Lancet Digital Health. Transparency during global health emergencies. *Lancet Digit Health* 2020; 2: e441.
- 2 COVID-19 Clinical Research Coalition. Global coalition to accelerate COVID-19 clinical research in resource-limited settings. *Lancet* 2020; 395: 1322–25.
- 3 Wellcome Trust. Sharing research data and findings relevant to the novel coronavirus (COVID-19) outbreak. 2020. <https://wellcome.org/coronavirus-covid-19/open-data> (accessed Nov 15, 2020).
- 4 Bull S, Cheah PY, Denny S, et al. Best practices for ethical sharing of individual-level health research data from low- and middle-income settings. *J Empir Res Hum Res Ethics* 2015; 10: 302–13.
- 5 Cheah PY, Jatupornpimol N, Hanboonkunupakarn B, et al. Challenges arising when seeking broad consent for health research data sharing: a qualitative study of perspectives in Thailand. *BMC Med Ethics* 2018; 19: 86.



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For the **COVID-19 Clinical Research Coalition** see <https://covid19crc.org/>

See Online for appendix

For the **Data Sharing Working Group** see <https://covid19crc.org/research-areas/data-sharing/>