



RESEARCH DATA ALLIANCE

rd-alliance.org

Research Data Alliance Foundation

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The Global Research Data Alliance community response to the global COVID-19 pandemic

Data drives rapid response and informed decision making during public health emergencies. There is a need for timely and accurate collection, reporting and sharing of data with the research community, public health practitioners, clinicians and policy makers. Accurate and rapid availability of data will inform assessment of the severity, spread and impact of a pandemic to implement efficient and effective response strategies.

The Research Data Alliance (RDA) is a volunteer community of over 10,500 professionals from 145 countries across the globe. In less than two months, the community responded to an urgent call for action and defined much needed, comprehensive recommendations and guidelines for data sharing under the present COVID-19 circumstances.

Today, 28 May 2020, we publish the pre-final version of the RDA COVID-19 Recommendations and Guidelines covering four research areas – clinical data, omics practices, epidemiology and social sciences. This document is also complimented by overarching areas focusing on legal and ethical considerations, research software, community participation and indigenous data.

The detailed guidelines in this body of work aim to help stakeholders follow best practices to maximise the efficiency of their work and act as a blueprint for the current and future health emergencies. The recommendations aim to help policymakers and funders maximise timely, quality data sharing and appropriate responses to health emergencies, particularly COVID-19.

The report specifically emphasises the importance of the following during the COVID-19 emergency response:

- *Sharing clinical data in a timely and trustworthy manner to maximise the impact of healthcare measures and clinical research during the emergency response;*
- *encouraging people to Publish their data alongside a paper (particularly important in reference to omics data);*
- *underlining that epidemiology data underpin early response strategies and public health measures;*
- *providing general guidelines to collect or link important social and behavioral data in all pandemic studies;*
- *evidencing the importance of sharing research software alongside the research data it analyses, and providing guidelines and best practices for enabling this;*
- *offering general guidance to navigate the applicable rule of law and exploit relevant ethical frameworks relating to the collection, analysis and sharing of data in similar emergency situations;*
- *looking at data management and sharing issues related to the technical, social, legal and ethical considerations from the community participation perspective.*

research data
sharing without
barriers

Additional recommendations highlighted by the 200+ contributors involved in the generation of this output include:

- 1. Ensuring a fair balance between timely data sharing and protecting privacy and confidentiality;*
- 2. Publishing existing SARS-CoV, MERS-CoV or EBOV data now, as it can be a valuable reference;*
- 3. Encouraging the research community's ability to apply best practices for research software, including training in software development concepts;*
- 4. Ensuring various stakeholders (e.g., official statistical agencies, researchers) share social science data in a way that retains, stores, and protects relevant geographic and demographic information to link the data with other social science data and across domains;*
- 5. Sharing research, research data and research outcomes with all where possible, in particular thinking of vulnerable groups and the general focus on solidarity, engagement and trust;*
- 6. Sharing and making data from commercial organisations accessible to help engage with and understand the emergency situation;*
- 7. Developing an internationally harmonised specification to enable rapid reporting and integration of epidemiology and related data across domains and between jurisdictions;*
- 8. Taking an open, inclusive and active approach to bridge communities and ensure diverse perspectives are considered and actions are streamlined and widely communicated; this needs to be balanced with the requirement to establish appropriate and transparent governance mechanisms to have oversight of the data and its management.*

These guidelines and recommendations should be considered directly depending on the relevant area of COVID-19 research as well as the policy/decision-making area.

The RDA COVID-19 activities were conducted under the [RDA guiding principles](#) of Openness, Consensus, Balance, Harmonisation, Community-driven, Non-profit and Technology-neutral. The results and outputs are open to all.

For further information on this press release and the RDA COVID19 activities, please contact:

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Important Links:

- [Research Data Alliance COVID-19 Recommendations and Guidelines Executive Summary](#)
- [Research Data Alliance COVID-19 Complete Recommendations and Guidelines – 28 May 2020 Release](#)
- [RDA COVID-19 Working Group](#)
- [RDA COVID-19 All Working Group Outputs \(5 releases\)](#)