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# Research Data Alliance finalizes COVID-19 data sharing guidelines

The report offers best practices and advice – around software, data-governance, legal and ethical considerations and more – for four key research areas: clinical data, omics practices, epidemiology and social sciences.

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By **Mike Miliard (/author/mike-miliard)** | July 07, 2020 |

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As the coronavirus crisis gained steam this past March, the Research Data Alliance began compiling a new guide to data sharing during the global public health emergency.

This past week, alliance published the final version of its RDA COVID-19 Recommendations and Guidelines (<https://www.rd-alliance.org/group/rda-covid19-rda-covid19-omics-rda-covid19-epidemiology-rda-covid19->

clinical-rda-covid19-1). The report offers best practices and advice – around software, data governance, legal and ethical considerations and more – for four key research areas: clinical data, omics practices, epidemiology and social sciences.

## **WHY IT MATTERS**

RDA was convened in 2013 by the European Commission, the National Science Foundation and the National Institute of Standards and Technology, in the U.S., and the Australian Government's Department of Innovation.

The collaborative aims to build out the "social and technical infrastructure" to spur wider open sharing of healthcare research data.

"Under public health emergencies, and particularly the COVID19 pandemic, it is fundamental that data is shared in both a timely and an accurate manner," according to RDA. "This coupled with the harmonisation of the many diverse data infrastructures is, now more than ever, imperative to share preliminary data and results early and often. It is clear that open research data is a key component to pandemic preparedness and response."

More than 600 data professionals and domain experts worked to create the new report, which aims to help researchers maximize the value of their work, keep policymakers well-informed and "act as a blueprint for future emergencies," said RDA officials.

## **THE LARGER TREND**

The report shows how the worldwide spread of the novel coronavirus "has prompted a rapid and massive research response with a diversity of outputs that pose a challenge to interoperability."

As such, research findings and data need to be shared just as quickly, according to RDA, and in a way that's both useful and comprehensible. But researchers note the "trade-off between timeliness and precision."

Another big challenge is a dearth of pre-approved data-sharing agreements, along with "archaic information systems" that can hamstring real-time detection of emerging disease threats and slow the development of policies and treatments in response.

"While the research and data are abundant, multi-faceted, and globally produced, there is no universally adopted system or standard, for collecting, documenting, and disseminating COVID-19 research outputs," according to RDA. "Furthermore, many outputs are not reusable by, or useful to, different communities if they have not been sufficiently documented and contextualised, or appropriately licensed."

Meanwhile, the report authors point out, much research software is often developed and maintained in an ad hoc fashion.

The RDA study lists some key data-sharing imperatives in public health emergencies such as COVID-19:

- Sharing clinical data in a timely and trustworthy manner to maximize 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 analyzes, 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

## **ON THE RECORD**

"The Research Data Alliance COVID-19 Working Group members bring various, global expertise to develop a body of work that comprises how data from multiple disciplines inform response to a pandemic combined with guidelines and recommendations on data sharing under the present COVID-19 circumstances," the authors said. "The recommendations in the document are aimed at helping

policymakers and funders to maximize timely, quality data sharing and appropriate responses in such health emergencies."



## Actionable Intelligence

This month, we look at lessons from the COVID-19 pandemic on how data is put to work informing patient care decisions and population health.

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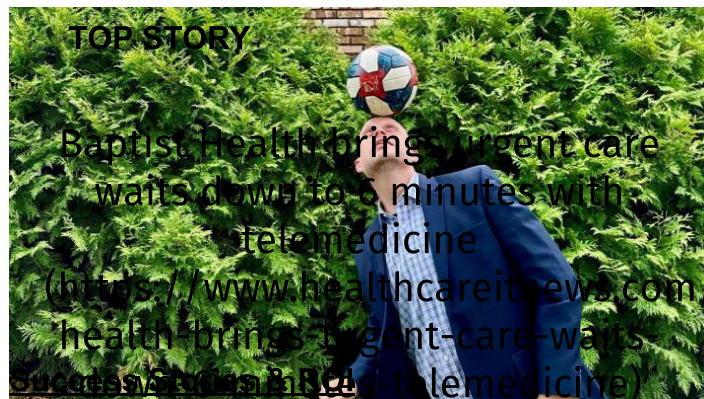
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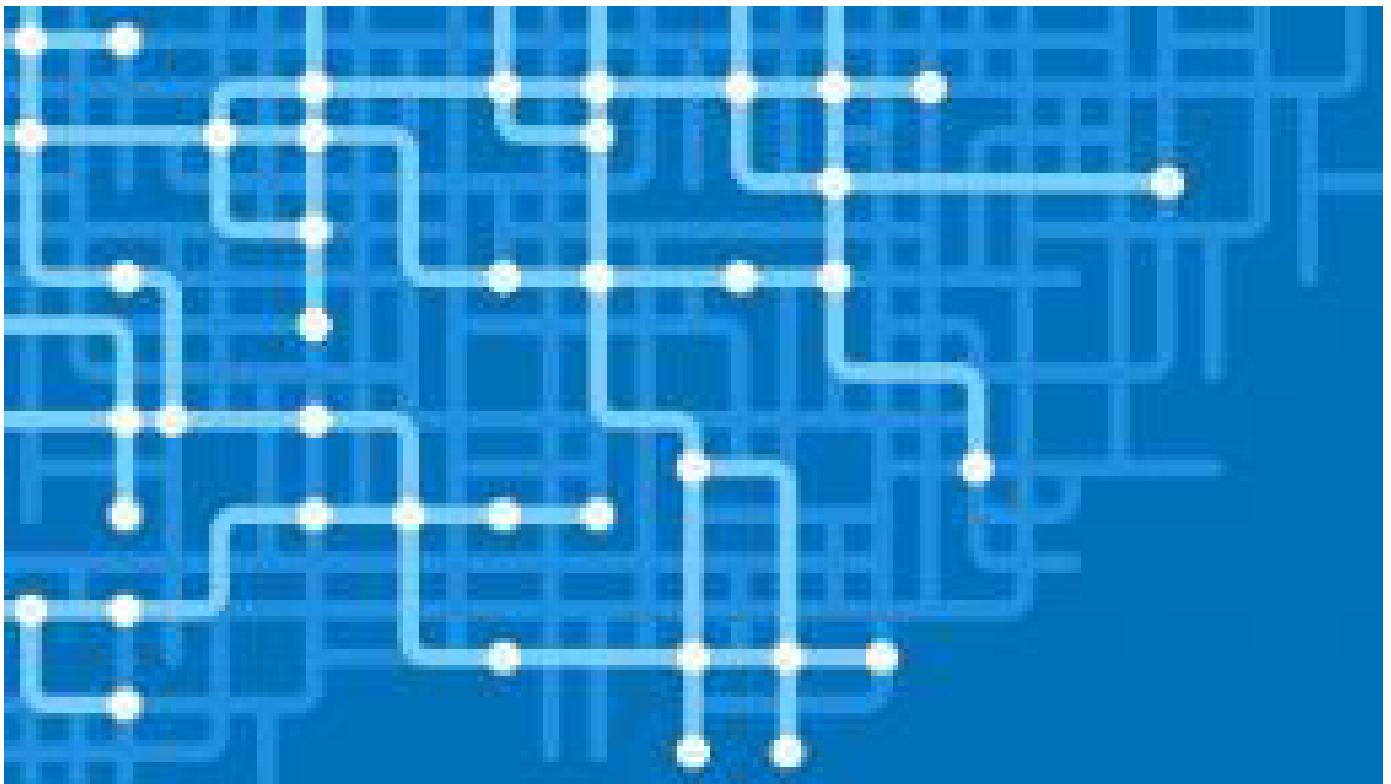
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