

RDA-COVID-19 Community participation sub-group

Initial considerations for building community participation recommendations

The context in which we work — data and community participation

Public health emergencies require profound and swift action at scale with limited resources, often on the basis of incomplete information and frequently under rapidly evolving circumstances. The current COVID-19 pandemic is one such emergency, and its scale is unprecedented in living history. Worldwide, many communities are coming together to address the emergency in a plethora of ways, many of which involve data in various fashions. For instance, they produce or mobilize data, add or refine metadata, assess data quality, merge, curate, preserve and combine datasets, analyze, visualize and use the data to develop maps, automated tools and dashboards, implement good practices, share workflows, or simply engage in a range of other activities that can or do leave data traces that can be leveraged by others.

While emergency-triggered sharing goes back millennia, data sharing is a relatively new aspect of emergency response, and the size, scale and complexity of the data relevant to the current pandemic are many orders of magnitude greater than even those of other recent epidemics, e.g. SARS, MERS, Zika or Ebola. This abundance of data, while in our favour in principle, can also be our Achilles heel if we - and our technology - are not able to openly share, understand and combine this data to gain the maximum insights it can provide, and to communicate those insights to the communities for which they are relevant and to the wider public.

The aims of the [RDA-COVID-19 Community Participation subgroup](#)

Our primary aim is to support the work of communities which are sharing data with the goal of improving research outputs and public knowledge. To achieve this, our objectives include highlighting the achievements and outputs of groups who practice sharing and to broaden access to the existing guidelines for sharing best practices. As described in “Principles of data sharing in public health emergencies” and similar publications, guidelines address issues of giving credit for contributions, legality in sharing data, technical considerations in making data Findable, Accessible, Interoperable and Reusable (FAIR), or other similar guidance for collaborating in research during a crisis.

With this objective in mind, the subgroup seeks to also take on an active role of bridging communities and ensuring inputs are streamlined, perspectives from communities are considered, and the collaborative outputs of all the RDA COVID-19 subgroups are widely communicated. The aim of linking communities and supporting communication is also designed to help coordination and avoid duplication of efforts since many communities are driving similar or complementary efforts to help the response to the current public health emergency.

These guidelines aim to facilitate the timely sharing of data relevant to the COVID-19 response and build much-needed capacity for similar events in the future. An effective and efficient response to a public health emergency, such as the current pandemic, demands

and holds immense value for both public and science communication, informing opinions and understanding, whilst supporting decision-making processes.

Although these principles have been developed with research data in mind, it is also desirable that data created directly by citizens (be that in a role as citizen scientists or not), patients, communities and other actors in a health emergency be produced, curated and shared in line with the spirit of these sharing principles. For example, community projects such as OpenStreetMap and Wikidata generate very valuable FAIR and open data, which can be analysed and used along with data from professional research and other sources.

Stakeholders

The intended audience for this subgroup's outputs includes

- **Researchers** undertaking activities along the entire life-cycle of pertinent data, especially those not covered by the other RDA COVID-19 WG subgroups and involving broad-scale community participation but also data stewardship of the community-generated data.
 - **Citizen scientists** undertaking research activities and in need of guidance (e.g. in terms of ethics) as well as means to seamlessly contribute to a common body of knowledge and collaborate with other actors involved.
- **Policymakers** are involved in setting the framework for community participation, funding innovation, working on research policy or focusing on integrating data in decision making.
- **Patients**, caregivers and the communities around them that are involved in leveraging data to improve prevention, diagnostics or treatment (this complements the work of the [RDA COVID-19 Clinical subgroup](#)).
- **Developers** involved in the creation or maintenance of applications targeted at community data collection that are specific to COVID-19 (e.g. contact tracing apps or exposure risk indicator apps) or more generic in nature (e.g. health or neighbourhood apps).
- **Sensor device makers** involved in developing sensors and data generating products for the community to use.
- **Communicators** involved in informing communities and societies at large about data-related aspects of the COVID-19 pandemic, translating data into meaningful and easy to grasp information, and circulating graphics or key messages in conventional or social media.
- **Citizens and the public at large**, i.e. members of any community wanting to contribute to the COVID-19 response in ways that involve data and who want to have a say in how to balance that with legal and ethical issues surrounding such data.
- **Other actors (individuals or organisations)** who are involved in community-based activities around COVID-19 related data.

Our approach going forward

Whenever possible, we aim to reuse and share applicable recommendations that already exist for specific communities and/ or types of data. To this end, we will adopt a standardised approach to identify existing guidance related to specific use cases in communication with relevant communities.

For existing guidance, the subgroup aims to collaborate with relevant communities to review and help refine it and support a broader distribution. If guidance is needed but not available yet, the subgroup will help identify issues and support drafting applicable recommendations. Beyond that, we encourage community members to help translate such recommendations (i) between languages; (ii) from prose into practice, including code and other formalized workflows; (iii) from one community or data type to similar ones.

Topics that we anticipate to be relevant in the context of the above-mentioned use cases include but are not limited to: collaborative data collection, collaborative service or software development initiatives, crowdsourcing of data curation services, data sovereignty when sharing across communities, citizen-led community responses, participatory disaster response strategies, digital platforms or apps to enable public participation and/or offer open data, digital tools to enable public participation.

Furthermore, the group plans to leverage the strengths of the RDA as an international community of data specialists and practitioners as well as reach out beyond to ensure expert input in addressing overarching topics such as ethics and social aspects, indigenous data, global open research commons, metadata standards, persistent identifiers and scientific annotation.

Important links

- [RDA-COVID-19](#)
- [RDA-COVID-19 Community Participation](#)
- [Initial scoping doc for Community participation recommendations](#)
- [Parent document of RDA COVID-19 WG](#)
- [Root folder](#)