Research Data Alliance COVID-19 data sharing guidelines

Simon Parker - 11th June 2020

CANCER RESEARCH UK

Together we will beat cancer

Background

CANCER RESEARCH UK

The Research Data Alliance

- The Research Data Alliance (RDA) was launched as a community-driven initiative in 2013 by the European Commission, the United States Government's National Science Foundation and National Institute of Standards and Technology, and the Australian Government's Department of Innovation.

- The RDA has over 10k members from 145 countries (April 2020), and aims to provide a neutral space where members can come together to promote data-sharing and data-driven research, and develop a cohesive data community that integrates contributors across domain and national boundaries.

- Website: https://www.rd-alliance.org/
  Twitter: @resdatall

The Project

- At the end of March the Research Data Alliance (RDA) was asked by the EU Commission to produce guidelines on the sharing of COVID-19 data, recognising that access to data is vital to tackle and understand pandemics.

- As the guidelines were needed urgently, the RDA turned to its community to ask members to provide the required expertise.

- The guidelines are designed to be general principles and best practices that could be applied to any local legal context.

- The first draft was released on the 24th April, and the 5th version on the 28th May

The Guidelines

CANCER RESEARCH UK

The Sections

- The guidelines contain domain-specific advice for:
  - Clinical Data
  - Omics Data
  - Epidemiology Data
  - Social Science Data

- There are four cross-cutting sections which can be applicable across domains:
  - Community Participation
  - Indigenous Populations
  - Research Software
  - Legal and Ethical Considerations

Executive Summary

Sub-groups/cross cutting themes	Challenges	Guidelines for researchers	Recommendations for funders/policy makers
Clinical	Promotion of clinical data sharing is important due to many studies and trials being performed under enormous time pressure	Standardised clinical terminologies should be used and a fair balance achieved between timely data sharing and protecting privacy and confidentiality	Measures should be taken in order to organise the sharing of data and trial documents in a suitable, trustworthy and secure data repository

3.3.1 Trustworthy Sources of Clinical Data

1. Measures should be taken in order to organise the transferral of data and trial documents to a suitable and secure data repository to help ensure that the data are properly prepared, available in the longer term, stored securely and subject to rigorous governance. Repositories that explicitly support data sharing for COVID-19 trials should be announced.

2. Trustworthy repositories should be leveraged as a vital resource for providing access to and supporting the depositing of research data. However, as an emerging and evolving area in biomedical domains, trustworthiness assessment should not be limited to certification or accreditation (Consultative Committee for Space Data Systems, 2011; CoreTrustSeal Standards and Certification Board, 2019). A wide range of community-based standardised quality criteria, best practices, and principles (e.g. TRUST Principles (Lin et al., 2020)) should also be considered.

3.3.1 Trustworthy Sources of Clinical Data

3. If analysis environments that allow in situ analysis of data sets are available, but prevent downloads, they should be provided to the end-user researchers in a pandemic situation, without fees if possible.

4. Tools allowing different data sets from different repositories to be analysed together on a temporary basis should be provided.

5. Adequate tools should be implemented for collection and analysis of reliable real-world data on drugs approved for the treatment of COVID-19.

Other Resources

- Research Data Alliance COVID-19 Recommendations and Guidelines Executive Summary
- Research Data Alliance COVID-19 Complete Recommendations and Guidelines – 28 May 2020 Release
- Zotero Resource Library
- Decision Tree version of guidelines

What’s next?

CANCER RESEARCH UK

Future Plans

- The public consultation regarding the 5th draft version of the guidelines ended June 8th.
- The editors are beginning to address issues, respond to suggestions etc for the final version.
- The expected release for these is the end of June.
- The Decision Tree is expected to be available alongside the final release of the guidelines.

Questions

Thank you for listening

Email: Simon.Parker@cancer.org.uk