Anne Cambon-Thomsen, MD, Emeritus Research director CNRS, RDA ambassador and member of the European Group on Ethics of science and new technologies. UMR 1027, Inserm, Université Toulouse III Paul Sabatier, Epidémiologie et analyses en santé publique; équipe BIOETHICS (team leader : Emmanuelle Rial-Sebbag)

**RDA-COVID19 Working Group**

https://www.rd-alliance.org/groups/rda-covid19

RDA France webinar, 9/7/2020

RDA = Research data alliance

An example regarding the organisation of international cooperation around COVID-19 data.
Outline of presentation

Basic elements on RDA
Context and characteristics of the RDA COVID-19 working group
Methods, organisation and steps
Outputs and other productions
Visualisation and help to use the document
How to foster impact?
Conclusion
Discussion
RDA in a Nutshell

Vision
Researchers and innovators openly share and re-use data across technologies, disciplines, and countries to address the grand challenges of society.

Mission
RDA builds the social and technical bridges that enable open sharing and re-use of data.

Some slides have been prepared by Hilary Hanahoe, Secretary general RDA
Working Groups
- develop and implement tools, policy, practices & products for data management that are adopted and used by projects, organisations, communities
- TIMING: 12-18 MONTHS
- TOTAL: 40 Working Groups

RECOMMENDATIONS: Concrete deliverables - “Running code”, tools, standards, etc.

Interest Groups
- focus on solving a specific data sharing problem and identifying what kind of infrastructure needs to be built.
- TIMING: as long as group is active
- TOTAL: 58 Interest Groups

OUTPUT: Possibly case statements for new WGs, guidelines, best practice, etc.
RDA Recommendations & Outputs

**RECOMMENDATIONS**
Equivalent of the “specifications” or “standards” that other organisations create and endorse.

25 Recommendations
of which 12 ICT Technical Specifications

**SUPPORTING OUTPUTS**
Outputs of RDA WGs and IGs that are fruit of RDA work, but are not necessarily adoptable bridges.

22 Supporting Outputs

**OTHER OUTPUTS**
Anything a WG or IG wants to register and report, e.g. workshop reports, articles, survey results, etc.
What is RDA’s impact?

- Global data agreements
- Standards
- Institutional change
- Discipline specific solutions
- Cross | multi | inter disciplinary solutions
- Education and Training
- Policy
- Professional career enhancement
Outline of presentation

- Basic elements on RDA
- Context and characteristics of the RDA COVID-19 working group
- Methods, organisation and steps
- Outputs and other productions
- Visualisation and help to use the document
- How to foster impact?
- Conclusion
- Discussion
RDA community response to COVID-19

RDA COVID-19 Recommendations and Guidelines on data sharing https://doi.org/10.15497/rda00052
Setting up an exceptional working group

- Internal discussions in RDA on how to contribute in the context of COVID-19 crisis
- Discussion with partners and institutions, in particular the European Commission
- Identification of needs for guidelines and recommendations towards data sharing good practices in context of pandemic, for researchers and for policymakers: fall in RDA worldwide mission, spirit and know how
- A few TC between mid- and end of March to define the objectives, mandate and first steps of process
The Research Data Alliance COVID-19 Data Sharing Recommendations and Guidelines by the community for the community

How is it both classical and exceptional?

9 July 2020
Objectives

Recommendations and guidelines:

- **Detailed guidelines** to help **researchers** and **data stewards** follow best practices to maximise the efficiency of their work, and to act as a blueprint for future emergencies;

- **Recommendations** to help **policymakers** and **funders** to maximise timely, quality data sharing and appropriate responses in such health emergencies.

- **Address interests** of researchers, policymakers, funders, publishers, and providers of data sharing infrastructures.
RDA Community response

Call to action to create a **fast track Working Group** aimed at developing a system for **data sharing in public health emergencies, specifically COVID-19**

- Around 600 RDA members and newcomers registered for the different groups
- 165 active contributors to the documents
- Experts in different fields as group moderators
- Regular calls and iterations
- Weekly webinars, requests for comments
- 5 releases produced (April – June 2020)
- Final release – 30 June 2020

**RDA’s guiding principles:**

- Openness
- Consensus
- Balance
- Harmonization
- Community-driven
- Non-profit and technology-neutral
Working group co-chairs

Juan Bicarregui  
STFC

Anne Cambon-Thomsen  
CNRS

Ingrid Dillo  
DANS

Natalie Harrower  
DRI

Sarah Jones  
DCC

Mark Leggott  
Research Data Canada

Priyanka Pillai  
University of Melbourne

https://www.rd-alliance.org/groups/rda-covid19
RDA COVID-19 Guidelines and Recommendations

Clinical
Oomics
Epidemiology
Social Sciences

Community Participation for Data Sharing under COVID-19
Indigenous Data under COVID-19
Legal and Ethical Considerations under COVID-19
Research Software for Data Sharing under COVID-19
# RDA-COVID19 Clinical sub-group

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## Clinical Sub-group Moderators

### Clinical Sub-group Co-chair
Anne Cambon-Thomsen, CNRS

### Clinical
- Andrea Jackson-Dipina, NIH
- Sergio Bonini, CNR
- Dawei Lin, NIH
- Christian Ohmann, ECRIN

09/07/2020
# RDA-COVID19 Clinical sub-group

## Members

<table>
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<tr>
<th>Andrea Jackson Dipina</th>
<th>Angel Alberich-Bayarri</th>
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### RDA COVID19 Omics sub-group

**RDA COVID19 UMBRELLA GROUP WEB PAGES**

https://www.rd-alliance.org/groups/rda-covid19

**RDA COVID19 CASE STATEMENT**

https://www.rd-alliance.org/node/68704/case-statement

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**RDA COVID19 OMICS SUBGROUP WEB PAGES**

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**RDA COVID19 OMICS SUBGROUP GOOGLE FOLDER**

https://drive.google.com/open?id=1bHzfxQLIMdsJtrbl_ZeoSeNZUnY0r2o1

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**Omens Sub-group Co-chair**

Juan Bicarregui  
STFC

---

**Omics Sub-group Moderators**

Rob Hooft: rob.hooft@dtls.nl | @rwwh  
Natalie Meyers: natalie.meyers@nd.edu | @nkmeyers

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09/07/2020
### Members

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RDA-COVID19 Epidemiology sub-group

Epidemiology Sub-group Co-chair

Priyanka Pillai
University of Melbourne

Epidemiology Sub-group Moderators

Claire Austin, Environment and Climate Change Canada
Gabriel Turinici, University Paris Dauphine

09/07/2020
# RDA-COVID19 Social Science sub-group

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### Social Sub-group Co-chair

- **Ingrid Dillo**
  - DANS

### Social Sub-group Moderators

- **Social**
  - Iryna Kuchma, EIFL
  - Amy Pienta, University of Michigan

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**Community participation Sub-group Moderators**

- **Sarah Jones**
  - DCC
  - Co-chair

- **Joanne Stocks**, University of Nottingham

- **Kheeran Dharmawardena**, Cytrax Consulting

- **Daniel Mietchen**, School of Data Science, UVA

- **Eva Mendez**, Uni Carlos III Madrid

- **Susanna-Assunta Sansone**, Oxford e-Research Centre

- **Timea Biro**, DRI

**09/07/2020**
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*09/07/2020*
Indigenous Populations and Data Sharing

Contributors: Stephanie Carroll, Pyrou Chung, Donna Cormack, Maui Hudson, Tahu Kukutai, Robyn Rowe, Michele Suina, Waggie Walter

International Indigenous Data Sovereignty Interest Group
Cross-cutting Legal and Ethical Issues

https://www.rd-alliance.org/groups/rda-covid19-legal-ethical

Chair: Anne Cambon-Thomsen
Moderator: Alexander Bernier
Moderator: Brian Pickering
RDA-COVID19 Legal/Ethical sub-group

Members

Alexander Bernier
Claire Austin
Diana Navarro-Llobet
Gustav Nilsonne
Katharina O Cathaoir
Mary O'Brien Uhlmansiek
Paula Andrea Martinez
Sa-kwang Song
Timea Biro
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Carlos Luis Parra-Calderon
Diana Dimitrova
Gauthier Chassang
John Brian Pickering
Mark Taylor
Paul Uhlfir
Rodrigo Sara
Stéphanie Rennes
# RDA-COVID19 Software sub-group

<table>
<thead>
<tr>
<th>RDA COVID19 UMBRELLA GROUP WEB PAGES</th>
<th><a href="https://www.rd-alliance.org/groups/rda-covid19">https://www.rd-alliance.org/groups/rda-covid19</a></th>
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<tbody>
<tr>
<td>RDA COVID19 EVENTS (WEBINAR DETAILS)</td>
<td><a href="https://www.rd-alliance.org/node/68704/events">https://www.rd-alliance.org/node/68704/events</a></td>
</tr>
<tr>
<td>RDA COVID19 WORKING &amp; SUB-GROUP ORGANIZATION</td>
<td><a href="https://www.rd-alliance.org/group/rda-covid19/wiki/working-sub-group-organization">https://www.rd-alliance.org/group/rda-covid19/wiki/working-sub-group-organization</a></td>
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<td>RDA COVID19 SLACK CHANNEL (SELECT #SOFTWARE)</td>
<td><a href="https://app.slack.com/client/T0121RE9LAC/C012V7DT34L">https://app.slack.com/client/T0121RE9LAC/C012V7DT34L</a></td>
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<td>RDA COVID19 SOFTWARE SUBGROUP WEB PAGES</td>
<td><a href="https://www.rd-alliance.org/groups/rda-covid19-software">https://www.rd-alliance.org/groups/rda-covid19-software</a></td>
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<td>RDA COVID19 SOFTWARE SUBGROUP GOOGLE FOLDER</td>
<td><a href="https://drive.google.com/drive/folders/103hFPuNPwwEB8kTUopegaFyjNSkObPRI?usp=sharing">https://drive.google.com/drive/folders/103hFPuNPwwEB8kTUopegaFyjNSkObPRI?usp=sharing</a></td>
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  - DANS

- Michelle Barker, Research Software Alliance, Fotis Psomopoulos, Institute of Applied Biosciences (INAB/CERTH), Hugh Shanahan, Royal Holloway, University of London

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- Leyla Jael Garcia Castro, ZB Med
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09/07/2020
## RDA-COVID19 Software sub-group

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<td>Hugh Shanahan</td>
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Collaboration with Research Software Alliance (ReSA)

09/07/2020
Overarching Guidelines Editorial Team

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Megan Underwood  
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Mary O’Brien  
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Bridget Walker  
RDA Foundation
Working methods and coordination

• A general feature: intense!
• Meetings and co-ordination:
  o Co-Chairs weekly meetings
  o Weekly webinar for updating on the work
  o Weekly Co-Chairs plus Co-Moderators plus RDA secretariat team (coordination)
  o 1 to 3 weekly meetings in each sub-group, plus some moderators
  o A specific group to take care of the zotero file of resources
  o A specific group to design « visualisation tools » to help navigating the document produced

• Momentum in production and consultation: 1st release 24 April, 5th release 31 May (for community input), Final adoption 30 June
Basic elements on RDA
Context and characteristics of the RDA COVID-19 working group
Methods, organisation and steps
Outputs and other productions
Visualisation and help to use the document
How to foster impact?
Conclusion
Discussion
WG outputs

• Best practice guidelines per sub-group and overall
• Recommendations for researchers and policymakers to help maximise data sharing
• Catalogue of key resources to inform guidelines (e.g. key datasets, standards, tools, repositories etc)
• A visualisation tool to facilitate navigation to specific resources by different stakeholders
A 145 page document with context, general guidelines and recommendations, specific (per sub-group)

An executive summary

Supporting output: RDA-COVID19-WG Zotero Library
  - https://doi.org/10.15497/rda00051
  - The RDA-COVID19-WG Zotero Library was created to support development of the RDA-COVID19 Data Sharing Recommendations and Guidelines. It is an extensive, but not a comprehensive bibliography. The Library is publicly available on the Web at:
    - https://www.zotero.org/groups/2485086/rda-covid19_wg

Other outputs: Epidemiology document (endorsed), articles in preparation
Research Areas & Cross-cutting themes

CLINICAL
OMICS
EPIDEMIOLOGY
SOCIAL SCIENCES

COMMUNITY

INDIGENOUS DATA GUIDELINES

RESEARCH SOFTWARE

LEGAL AND ETHICAL CONSIDERATIONS
Overarching Challenges

- Rapid sharing of research efforts, findings, and data
- Timeliness vs. precision
- Lack of “pre-approved” data sharing agreements
- No universal standard / system for COVID-19 research outputs
- Cross-disciplinary reusability
- Contextualisation, licensing, documentation
- Ad-hoc Research software
# What are the key recommendations?

The RDA COVID-19 Recommendations and Guidelines are aimed at developing a systematic approach for data sharing in public health emergencies that supports scientific research and policymaking, including an overarching framework, common tools and processes, and principles that can be embedded in research practice.

1. Coordinate cross-jurisdictional efforts to foster global Open Science through policy and investment.
2. Incentivise early publication and release of data and software outputs.
3. Invest in state-of-the-art IT, data management systems infrastructure, economies of scale, and people.
4. Data, software and models should be **timely and FAIR:** Findable, Accessible, Interoperable, Reusable.
5. Require the use of Data Management Plans.
6. Use common domain-specific metadata standards, and persistent identifiers.
7. Provide documentation of context, methodologies used to define, construct, and compile data, data cleaning and quality checks, data imputation, and data provenance.
8. Use **Trustworthy Data Repositories** committed to the long-term preservation and sustained access to their data holdings.
9. Use common generic as well as domain-specific metadata standards, and persistent identifiers.
10. **Balance ethics and privacy,** taking into account public interests and benefits while addressing the health crisis.
11. Access should be as open as possible and as closed as necessary.
12. Seek technical solutions that ensure anonymisation, encryption, privacy protection, and de-identification to increase trust in data sharing.
13. Provide legal frameworks that promote sharing of surveillance data across jurisdictions and sectors.
## Cross cutting theme highlights

<table>
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<tr>
<th>Cross cutting themes</th>
<th>Challenges</th>
<th>Guidelines for researchers</th>
<th>Recommendations for funders/policy makers</th>
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<td><strong>Clinical</strong></td>
<td>Promotion of clinical data sharing is important due to many studies and trials being performed under enormous time pressure</td>
<td>Standardised clinical terminologies should be used and a fair balance achieved between timely data sharing and protecting privacy and confidentiality</td>
<td>Measures should be taken in order to organise the sharing of data and trial documents in a suitable, trustworthy and secure data repository</td>
</tr>
<tr>
<td><strong>Omics</strong></td>
<td>An increased need of rapid openness for omics data to gain early insights into molecular biology of the processes at cellular level</td>
<td>Omics research should be a collaborative effort to learn the genetic determinants of COVID-19 susceptibility, severity and outcomes</td>
<td>Promote use of domain-specific repositories to enable standardisation of terms and enforce metadata standards</td>
</tr>
<tr>
<td><strong>Epidemiology</strong></td>
<td>Data and models are frequently incomplete, provisional, and subject to correction under changing conditions</td>
<td>Data models must include clinical data, disease milestones, indicators and reporting data, contact tracing and personal risk factors</td>
<td>Incentivise the publication of situational data, analytical models, scientific findings, and reports used in decision-making</td>
</tr>
<tr>
<td><strong>Social Sciences</strong></td>
<td>Require equal inclusion of social and economic context with health-related information to enable evidence-based decision-making</td>
<td>Enable interoperable cross-disciplinary and cross-cultural data collection, data use and collaboration for managing social sciences data during pandemics</td>
<td>Ensure robust funding streams for social sciences research for understanding and managing the human aspects of pandemics</td>
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</tbody>
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### Cross cutting theme highlights

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<td>Community</td>
<td>Need specific guidelines for enabling citizen scientists undertaking research to contribute to a common body of knowledge</td>
<td>Encourage public and patient involvement (PPI) throughout the data management lifecycle from research question to final data sharing and usage</td>
<td>Balance between timely testing and contact tracing, emergency response, community safety and individual privacy concerns</td>
</tr>
<tr>
<td>Indigenous Data Guidelines</td>
<td>Indigenous data rights, priorities and interests must be recognised in all COVID-19 research and surveillance activities</td>
<td>Indigenous governance of data collection, ownership, sharing and use priorities is the central principle of Indigenous data sovereignty</td>
<td>CARE Principles of Indigenous Data Governance set minimum standards for collectors, users and stewards of data</td>
</tr>
<tr>
<td>Legal and Ethical Considerations</td>
<td>Achieve a balance between rights of people and interests of researchers and policymakers</td>
<td>Ethical instruments should be interpreted with the law, and can guide the interpretation of the law if the law does not address a particular issue</td>
<td>During a pandemic, ethical review and approval for legally sharing data should be expedited</td>
</tr>
<tr>
<td>Research Software</td>
<td>Need systems in place for sharing of research software and accelerated and reproducible research during a pandemic</td>
<td>It is critical for software that is used in data analysis to produce results that can, if necessary, be reproduced</td>
<td>Funders must allocate financial resources to support the development and maintenance of new research software</td>
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Example of content

Regarding software.
Require that software citations be included in publication

- It is essential that the role of software in achieving research outcomes is supported. **Treating research software as a first class research object in a scholarly publication** is a very effective mechanism for implementing this, as it increases the visibility and credit to the research software developers (for example by enabling academic and commercial citation services and/or databases, such as Google Scholar, Scopus and Microsoft Academic) *(Smith et al., 2016)*.

- **Examples:** The FORCE11 Software Citation Implementation Working Group *(Chue Hong et al., 2017)* has been leading work in this area for 3+ years, and currently has a journals task force that is developing sample language for journals to use. The American Astronomical Society (AAS) Journals encourage software citation in several ways (explicit software policy, added the LaTeX `\software{}` tag to emphasise code used, etc.) *(AAS Journals, 2020)*.
Require that software developed for a publication is deposited in a repository that supports Persistent Identifiers

- For publishers to ensure that the research they publish is reproducible, software developed as part of the work reported in a submission must also be findable. Publishers should require such software to be deposited in an archival repository that supports PIDs such as Zenodo (CERN, 2020) and Figshare (FigShare, 2020). These repositories provide PIDs that can be directly included in the citation and referenced in a publication, supporting research integrity (Di Cosmo et al., 2018). If the software is deposited along with data (DataCite, 2020), as recommended in certain communities of practice, the selected data repository should provide a PID for the collection. Several versions of the software can be tagged with PIDs and, thus, if multiple versions are used for research, having different PIDs ensures reproducibility.

- Example: The Journal of Open Source Software (JOSS, 2020) review process requires authors to make a tagged release of the software after acceptance, and deposit a copy of the repository with a data-archiving service such as Zenodo or Figshare. This is part of the guidance from the FORCE11 Software Citation Implementation Working Group (Chue Hong et al., 2017). The GigaScience journal is another example of publication requiring the availability of software (GigaScience, 2020).
Outline of presentation

- Basic elements on RDA
- Context and characteristics of the RDA COVID-19 working group
- Methods, organisation and steps
- Outputs and other productions
- Visualisation and help to use the document
- How to foster impact?
- Conclusion
- Discussion
How to use the document?

- No one will generally need to explore the full document.
- The need will be for a rather specific question or domain.
- How to quickly find what you need?
- A « visualisation group » is working on 3 tools:
  - An infographics (most recent version here) (https://drive.google.com/file/d/1sUGJrdqmA2R2ZpSf_oPkdx2uy4ufwWP4/view)
  - A mindmap
  - A wizard
How to foster impact?

- Recommendations and guidelines that are not implemented are useless!
- Dissemination to communities and institutions is essential
- These recommendations are broad enough to be of interest for numerous stakeholders across the world
Outline of presentation

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Highlights of general policies

1. Promote FAIR sharing of COVID-19 related Data
2. Encourage expedited review processes for pandemic related research
3. Encourage researchers to apply generic metadata for COVID-19 related data
4. Request authors to add available contextual documentation
5. Promote the use of trustworthy repositories
6. Respect the ground rules for Ethics, Privacy and sound Legal Frameworks in COVID-19 data sharing

Take home messages

• Data availability in time of a pandemic is a priority
• A variety of well documented data is needed, not just numbers of cases and deaths, with good metadata (interdisciplinary oriented)
• The Research data alliance (RDA) has issued guidelines and recommendations to increase data sharing, especially regarding standards and trustworthy data sources, as well as policy oriented
• These recommendations are in principle applicable in a broad geographical coverage, (not specific to a given jurisdiction)
• As interdisciplinarity is needed, referring to community accepted standards was chosen, even if already well known within a specific community.
The Research Data Alliance
COVID-19 Data Sharing
Recommendations and
Guidelines
by the community for the
community

9 July 2020

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