

# RDA COVID-19 Guidelines and Recommendations on Data Sharing

## Part 2: Navigational Tools and Other Outputs

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# Agenda

- > Summary of the *RDA COVID-19 Recommendations and Guidelines on Data Sharing* (Rs&Gs)
- > Additional “navigational tools”
  - Infographic
  - Outputs Card
  - Zotero Library
  - Data Stewardship Wizard
  - Mindmap
- > Supplementary Outputs/Journal Articles

<https://doi.org/10.15497/rda00052>



## Slide Decks

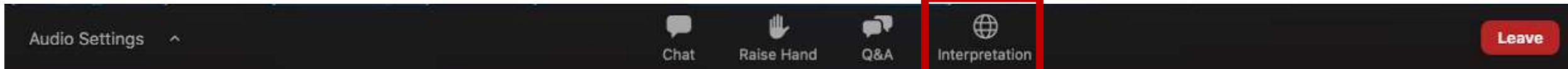
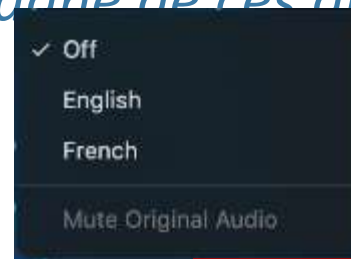
**English:** [http://bit.ly/RDC Webinar Sep-16 EN](http://bit.ly/RDC_Webinar_Sep-16_EN)

**French:** [http://bit.ly/DRC Webinaire Sep-16 FR](http://bit.ly/DRC_Webinaire_Sep-16_FR)



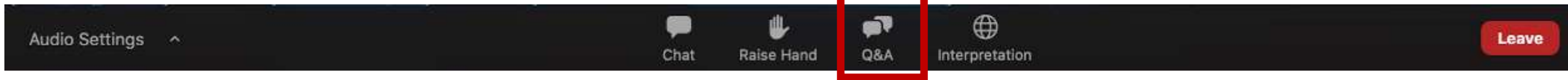
# Simultaneous Interpretation in French

- > This session features both English and French language audio channels.
- > *Cette session propose des canaux audio en anglais et en français.*
- > Select the Interpretation option from your menu to select preferred language.
- > *Sélectionnez l'option Interprétation dans votre menu pour sélectionner la langue préférée.*
- > A recording of this session, along with these slides, will also be made available in French.
- > *Un enregistrement de cette session, accompagné de ces diapositives, sera également disponible en français.*



# Questions & Answers

- > Please use the Q&A option to ask questions of the presenters. Questions will be monitored throughout the session and addressed at the end.
- > The Q&A option can be found at the bottom of your Zoom screen:



- > Please note that this **event is being recorded**, including questions and answers.

# The Recommendations & Guidelines





# Background and Why

- > Request from the European Commission to the Research Data Alliance (RDA)
- > Working Group setup within weeks
  - 4 Research Areas, 4 Cross-cutting themes, each with Co-Moderators
- > Structured through a series of teams
  - Co-Chairs, Co-Chairs + Moderators, 8 Themes, Editorial, Visualization, Zotero
- > April 1 - 30 June continual sprints, webinars, etc.
  - 6 releases over 3 months
- > Exhausting and exhilarating!



# What are the Challenges Being Faced?



## Critical Need for Rapid Data Sharing

Rapid massive research response with diverse outputs challenges **interoperability of data**.

A trade off between...



Timeliness

Precision



## Lack of Harmonised Universal Standards and Context

**Lack of pre-approved sharing agreements and archaic information systems** hinder rapid threat detection and evidence-based response.

### No universally adopted system or standard for



COVID-19 research outputs.



Lack of documentation, context, and appropriate licensing challenges **reusability**.



# What are the Objectives?



**1.0**  
Clearly define detailed guidelines on data and software sharing for COVID-19 research.



**1.1**  
Help stakeholders follow best practices to **maximise efficiency**.



**1.2**  
Act as a **blueprint** for future emergencies to maximise the efficiency of their work.



**2**  
Develop **recommendations** for funders and policymakers to maximise timely, quality data and software sharing and appropriate responses in health emergencies.



**3**  
**Address interests** of researchers, policymakers, funders, publishers, and providers of data sharing infrastructures.

## Global Effort to Raise the Bar for Data Sharing



- 117 cross-sectoral signatories to the [Wellcome Trust statement](#) in January 2020.
- Agreement by 30 leading publishers on [immediate open access](#) to COVID-19 publications and underlying data.

# 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 generic as well as 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** **Expedite** article and data review processes, **prioritising and fast-tracking data** at all stages.
- 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.



# A Collaborative Cross-Disciplinary Effort



## CLINICAL

- i** Standardise terminologies, and find balance between timely data sharing and protecting privacy, confidentiality
- ★** Organise data sharing and trial documents in trustworthy repositories



## OMICS

- i** Select the best data formats and standards to fit the sub-discipline
- ★** Promote use of domain-specific repositories to enable standardisation



## EPIDEMIOLOGY

- i** Data models must include clinical data, disease milestones, indicators, reporting data, contact tracing and personal risk factors
- ★** Incentivise publication of situational data, analytical models, scientific findings and reports



## SOCIAL SCIENCES

- i** Enable interoperable cross-disciplinary, cross-cultural data use and collaboration
- ★** Ensure robust funding streams for research aimed at understanding and managing the human aspects of the pandemic



## COMMUNITY

- i** Encourage public and patient involvement throughout data management lifecycle
- ★** Balance between timely testing and contact tracing, emergency response, community safety, and individual privacy concerns



## RESEARCH SOFTWARE

- i** Software used in data analysis must be able to reproduce results, if necessary
- ★** Allocate financial resources to support development and maintenance of new research software



## INDIGENOUS DATA GUIDELINES

- i** Indigenous governance of data collection, ownership, and sharing and use priorities is the central principle of Indigenous data sovereignty
- ★** CARE Principles set minimum standards for collectors, users, and stewards of Indigenous data.



## LEGAL AND ETHICAL CONSIDERATIONS

- i** Although the law provides the foundation for data handling, ethical frameworks should also inform expedited approval to maximise data use and sharing
- ★** Expedite ethical review and approval for legal data sharing during a pandemic

# Omics Example: 4.4.2 Guidelines for Host Genomics Data

Several different types of host genomics data are being collected for COVID-19 research. Some suitable repositories for these are:

1. **Gene expression data** should in general be retrieved from or deposited in the repositories listed below ([Blaxter et al., 2016](#)). To achieve load balancing, it is recommended to choose the respective regional repository. It should be noted that [INSDC](#) resources (i.e., [DDBJ](#), [ENA](#) and [NCBI](#)) synchronise most of their datasets daily<sup>2</sup>.
  - 1.1. Transcriptomics of human subjects (requiring authorised access):
    - 1.1.1. [Database of Genotypes and Phenotypes](#) (dbGaP) ([Mailman et al., 2007](#))
    - 1.1.2. [European Genome-Phenome Archive](#) (EGA) ([Lappalainen et al., 2015](#)); the corresponding non-sensitive metadata will be available through EBI [ArrayExpress](#) ([Athar et al., 2019](#))
    - 1.1.3. [Japanese Genotype-phenotype Archive](#) (JGA) ([Kodama et al., 2015](#))
  - 1.2. Transcriptomics (from cell lines/animals):
    - 1.2.1. [ArrayExpress](#) ([Athar et al., 2019](#))
    - 1.2.2. [Gene Expression Omnibus](#) ([Barrett et al., 2013](#))
    - 1.2.3. [Genomic Expression Archive](#)
  - 1.3. Underlying reads can be retrieved from/will automatically be deposited to the corresponding read archive:
    - 1.3.1. [DDBJ Sequence Read Archive](#) (DRA) ([Kodama et al., 2012](#)), for submission documentation see [here](#)
    - 1.3.2. [European Nucleotide Archive](#) for submission documentation see [here](#)
    - 1.3.3. [NCBI Sequence Read Archive](#) (SRA) for submission documentation see [here](#)
  - 1.4. Microarray-based gene expression data:
    - 1.4.1. [ArrayExpress](#) ([Athar et al., 2019](#))
    - 1.4.2. [Gene Expression Omnibus](#) ([Barrett et al., 2013](#))



# Legal/Ethics Example: 10.4.5 Consent Guidelines

## 10.4.5 Consent

*Consent* is the act by which a participant, patient or data subject indicates that they permit something to happen to them, or to their data, which would otherwise not be able to happen. It covers a number of different specific contexts:

1. **Clinical:** a patient agrees to undergoing a procedure, including taking part in a trial;
2. **Data Protection:** a data subject agrees to personal data being processed for specified purposes;
3. **Research:** a participant agrees to take part in a research study or experiment.

In both cases, the informed consent sheets for clinical or research purposes would explicitly set out how data protection will be handled, as well as samples or biobanking, rights to self- images and others.

Giving consent should be informed (e.g. the individual knows what is going to happen and why), freely given (there is no coercion or similar motivation), given by somebody with capacity, unambiguous and auditable (the consent is recorded somewhere) (See also [Parra-Calderón, 2018](#)). Depending on the jurisdiction and the research domain, there may be an additional requirement to seek consent. This may include a representative community board as well as participants themselves.

Ideally, consent should be sought for collecting, processing, sharing and publishing data. However, there are other legal bases for processing personal data. Some specific examples from the European General Data Protection Regulation ([GDPR, 2016](#)) are described below. Our recommendation would therefore be as follows:

1. Where possible, use data where the data subject has provided a valid consent that includes or is compatible with intended use of the data and complies with the requirements on consent in the specific country or region.

Where these are not possible, there are other reasons why data may be used (see [Hallinan, 2020, Ó](#)



# Additional Navigational Tools



# Infographics



## Research Data Alliance COVID-19 Recommendations and Guidelines on Data Sharing



### The Research Data Alliance (RDA) COVID-19 Working Group

was created as a response to the challenges posed by data sharing in the midst of the pandemic.



June 2020  
440+ members  
from across disciplines  
and across the globe.



## Lignes directrices et recommandations de la Research Data Alliance concernant le partage des données durant la pandémie



### Le groupe de travail sur la COVID-19 de la Research Data Alliance (RDA)

a été mis sur pied à la suite des difficultés que  
posait le partage des données en pleine pandémie.



Juin 2020  
plus de 440 membres  
du monde entier dans  
diverses disciplines.

## What are the Challenges Being Faced?



### Critical Need for Rapid Data Sharing

Rapid massive research response  
with diverse outputs challenges  
**interoperability of data.**



### Lack of Harmonised Universal Standards and Context

Lack of pre-approved sharing agreements  
and archaic information systems hinder rapid  
threat detection and evidence-based response.

## Les enjeux



### Besoin crucial que l'on partage les données sans attendre

Les recherches accélérées et massives ont  
débouché sur des résultats variés qui  
mettent en danger **l'interopérabilité des  
données.**



### Absence de normes universelles uniformes et de contexte

L'absence d'ententes sur le partage des  
données et les systèmes d'information  
**archaïques** nuisent à la détection rapide des  
menaces et aux interventions s'appuyant sur des  
données factuelles.





# RDA Outputs Card




**RDA**

## COVID-19 Recommendations and Guidelines for Data Sharing

**The Challenge:**

Under public health emergencies, particularly the COVID-19 pandemic, where the rapid pace of a disease and the immense and rapid mobilisation of resources could create an environment for inaccurate or low-quality data, sharing preliminary data and results in both a timely and accurate manner and harmonising the many diverse data infrastructures is crucial. The availability of research data is a key component of pandemic preparedness and response; the timeliness of accessing data and the harmonisation across information systems are currently major roadblocks.



Produced by: **RDA COVID-19 Working Group**  
<https://www.rd-alliance.org/groups/rda-covid19>



**What is the solution?**

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 COVID-19 circumstances. This extends to research software sharing, in recognition of the key role in software in analysing data. The work is divided into four research areas (Clinical, Omics, Epidemiology, Social Sciences) with four cross-cutting themes (Community Participation, Indigenous Data, Legal and Ethical Considerations, Research Software). The guidelines aim to help stakeholders follow best practices to maximise the efficiency of their work and to act as a blueprint for future emergencies. The recommendations aim to help policymakers and funders maximise timely, quality data sharing and appropriate responses in such health emergencies.

**What is the impact?**

A system 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. Guidelines that address general aspects of data practice, for example the FAIR principles, or the adoption of research-domain community standards.



Find out More about the RDA COVID-19 Recommendations and Guidelines for Data Sharing

August 2020

# Zotero Library

- > Over 1,100 bibliographic entries
- > All citations in the Rs&Gs are in the Zotero library, facilitating access to the resources, as well as formatting for inclusion in other bibliographies
- > Includes separate folders for Sub-Group outputs
- > Some additional resources not cited in the Guidelines are also included
- > Zotero Library will be maintained/updated going forward
- > Citations can be exported/imported to most reference manager tools
- > Main contact is [Claire Austin](#)

<https://www.rd-alliance.org/group/rda-covid19/outcomes/rda-covid19-wg-zotero-library>

# Zotero Web Interface

The screenshot displays the Zotero Web Interface. At the top, there are navigation links for Groups, Documentation, Forums, Get Involved, and Log In. A search bar contains the text 'Title, Creator, Year' and an 'Upgrade Storage' button is visible on the right.

The main content area shows a list of items under the group 'RDA-COVID19-WG'. The list includes columns for Title, Creator, Date, and Item Type. The first item is highlighted:

Title	Creator	Date	Item Type
10 Tips for Making Sense of COVID-19 Models for Decision-Making	Stuart et al.	2020	Web Page
2019-novel Coronavirus (2019-nCoV): estimating the case fatality r...	Battagay et al.	2020-02-07	Journal Article
2019-nCoV - China National Center for Biotechnology Information	National Genomics Data Center	2020	Web Page
2014 Identifiers for Digital Objects: The case of software source c...	[B] Coakley et al.	2018-08-21	Journal Article
3DCellNotes: Automated biochemical and biomedical animations on...	DNB and Segura	2020	Web Page
4 Tips for Keeping on Top of Project Dependencies   OSS Watch Ins...	Wilson	2013	Blog Post
6-SAFES-WHITE-PAPER_FINAL_ELECTRONIC.pdf	Emami and Arbuckle	2018	Web Page
A Better Toolbox	Quinn	2017-11-27	Blog Post
A call for a new generation of COVID-19 models	Engler	2020-04-23	Blog Post
A chronicle of SARS-CoV-2: Part-I - Epidemiology, diagnosis, progr...	Kumar et al.	2020	Journal Article
A comparison of bats and rodents as reservoirs of zoonotic viruses:	Lus et al.	2013-04-07	Journal Article
A comparison of observational studies and randomized, controlled tr...	Benson and Hartz	2003-06-22	Journal Article
A COVID-19 specific instance for ROSC: Life's Workflows	University of Manchester and HITS g0bel	2020-04-05	Web Page
A data tea for a digital economy	Avetis	2018-10-22	Web Page
A database of geospatial Middle East Respiratory Syndrome Coro...	Ramshaw et al.	2019	Journal Article
A Delphi Survey and Analysis of Expert Perspectives on One Health ...	Degele et al.	2017	Journal Article
A Dictionary of Epidemiology	Forna	2018-07-21	Book
A European standardization framework for data integration and dat...	O' Cathain et al.	2020-03	Report
A framework for identifying regional outbreak and spread of COVID...	Bosman et al.	2020-05	Journal Article
A Full Spectrum View of the COVID-19 data domain: An Epidemiolo...	Greenfield et al.	2020	Book Section
A Global Ethics Code to fight 'ethics dumping' in research	Schroeder	2020	Report
A Guide to Benchmarking COVID-19 Performance Data	George et al.	2020	Journal Article
A Multi-Methodology Approach to Creating a Causal Loop Diagram	Dhrazzani and Sahin	2019-09	Journal Article
A new emerging zoonotic virus of concern: The 2019 novel Coronavi...	Milan-Dražić et al.	2020	Journal Article
A pneumonia outbreak associated with a new coronavirus of probab...	Zhou et al.	2020-03	Journal Article
A Quantitative Approach to the Prioritization of Zoonotic Diseases ...	Ng and Saigont	2013-08-21	Journal Article
A review of data quality assessment methods for public health inform...	Chen et al.	2014	Journal Article
A Review of Zoonotic Disease Surveillance Supported by the Armed...	Burke et al.	2012	Journal Article
A simplified machine approach to predict ICU beds and mortality rate in...	Mansoor et al.	2020	Journal Article
A simulation of a COVID-19 epidemic based on a deterministic SER ...	Cerdone et al.	2020-05-10	Journal Article
A Spatiotemporal Epidemiological Prediction Model to Inform Cou...	Zhou et al.	2020	Journal Article
A study on the quality of novel coronavirus (COVID-19) official datasets	Ashtorah and Bravo	2020	Journal Article
A survey of approaches and trends in person re-identification	Bodagiar, Gale and Shan	2014-04	Journal Article
A Systematic Review of COVID-19 Epidemiology Based on Current Evi...	Falk et al.	2020	Journal Article
A systems approach to preventing and responding to COVID-19	Bradley et al.	2020-04-01	Journal Article

On the right side of the interface, there are tabs for 'Info', 'Notes', 'Tags', 'Attachments', and 'Related'. The 'Info' tab is active, showing details for the selected item:

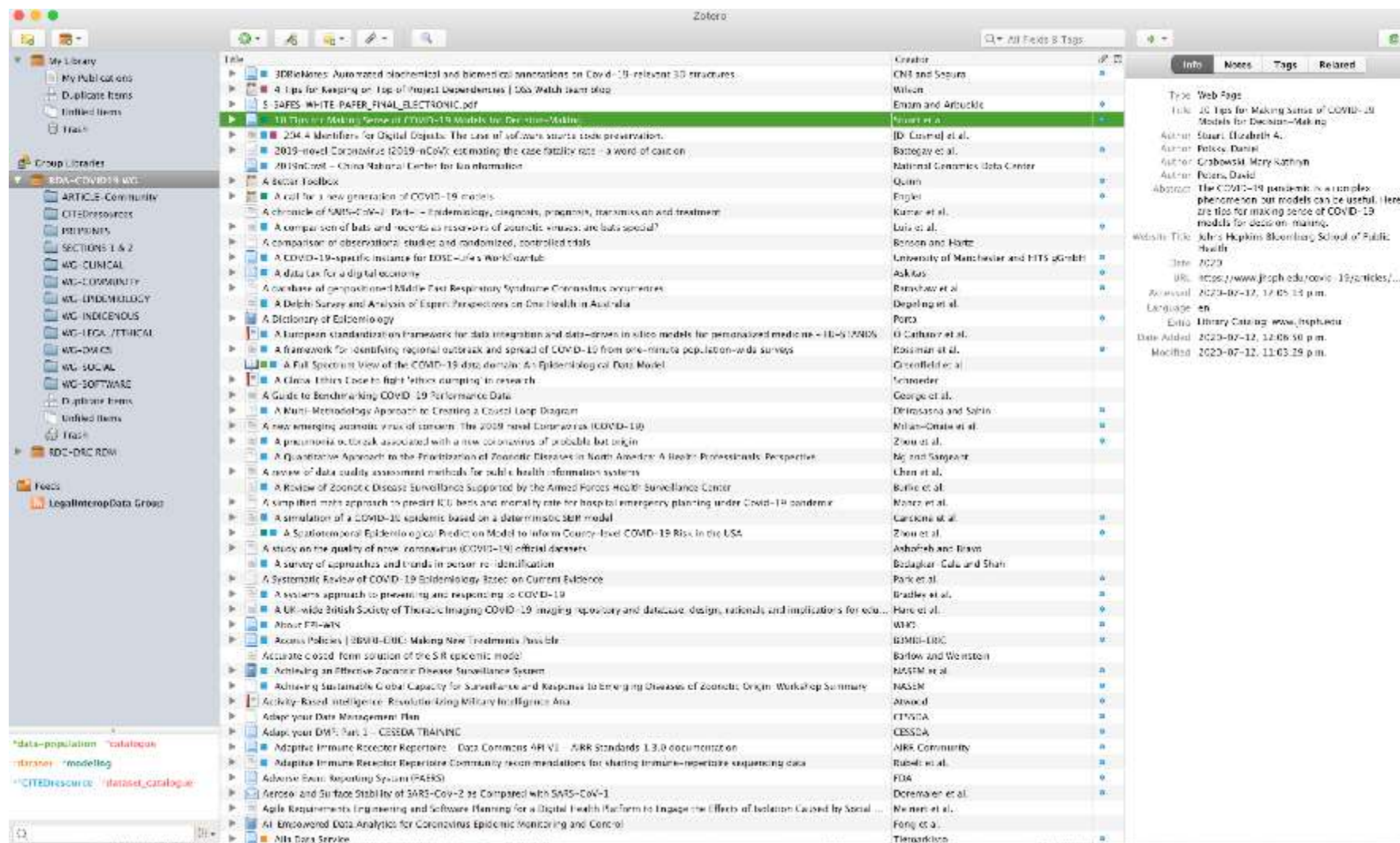
- Original URL: <https://www.bhsph.edu/ccc/covid-19/>
- Filename: 10-tips-for-making-sense-of-covid...
- Access Time: 7/12/2020, 12:05:17 PM
- Modify Time: 7/12/2020, 12:06:50 PM

At the bottom left, there is a legend for tags, including categories like 'data-coalition', 'catalogue', 'dataset', 'modeling', etc.

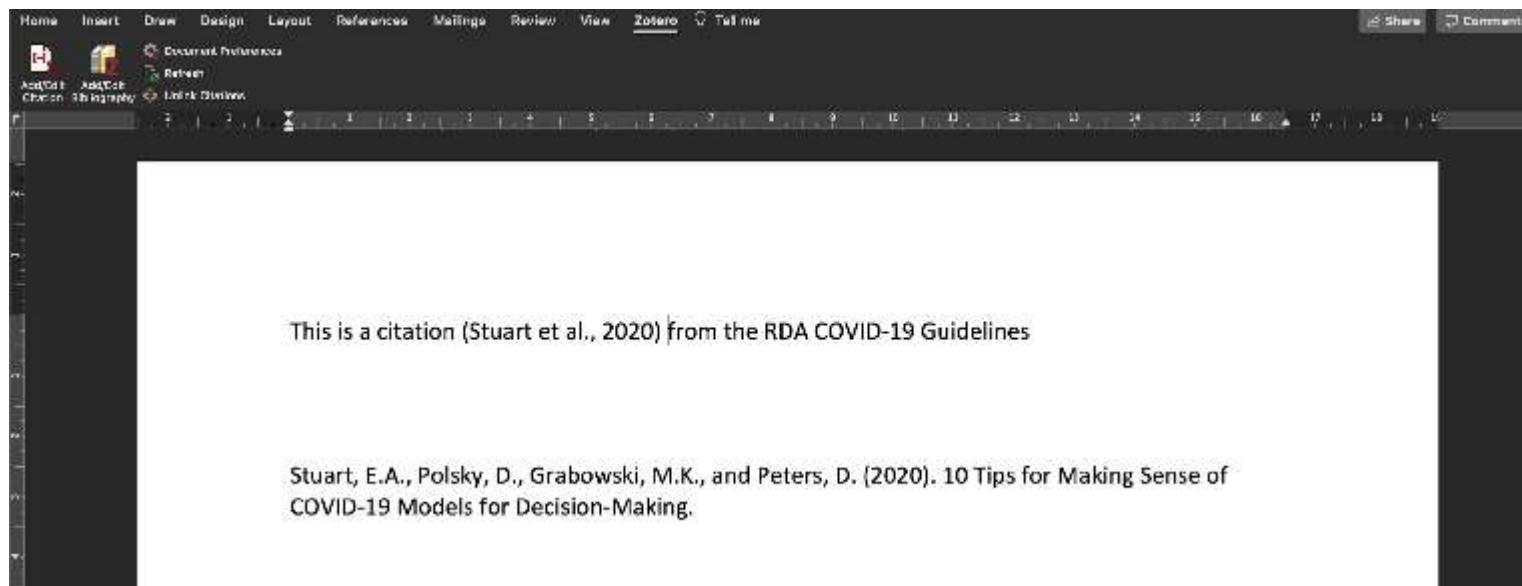
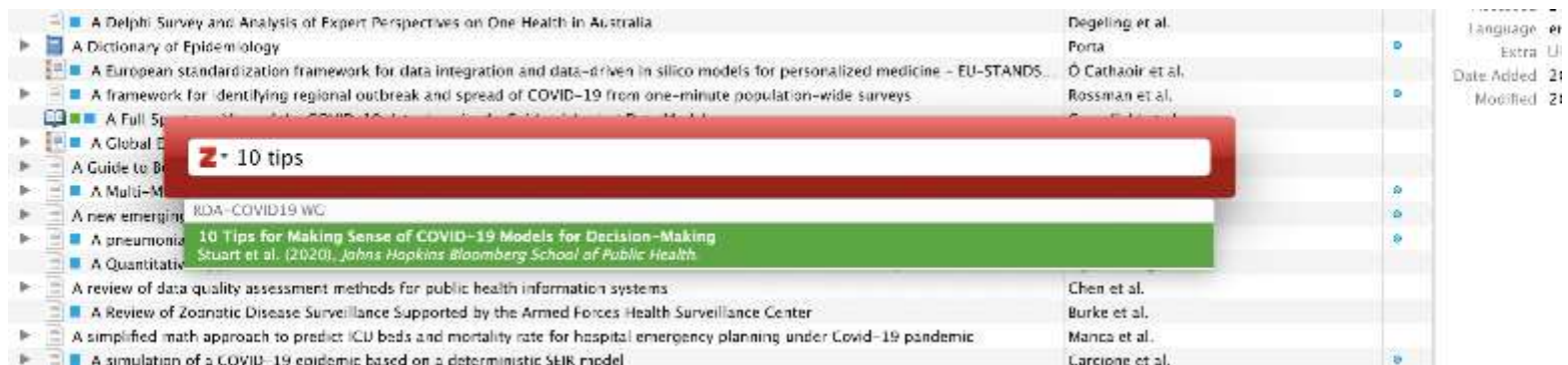




# Zotero Desktop Client



# Zotero Word Plugin



# COVID-19 “Wizard”

- > Select the parts of the complete 150 page document that are applicable to your own situation
- > Quickly select those sections through answering a few questions
- > Download a PDF with exactly that content

<https://covid-19.ds-wizard.org/>



covid-19.ds-wizard.org

**DS Wizard**

- Users
- Knowledge Model Editor
- Knowledge Models
- Questionnaires
- Documents
- Templates
- Create a project

Settings

Help >

Rob Hooft >


<< Collapse sidebar

This is a navigation tool for the RDA Covid-19 Recommendations. It can help you to quickly select those parts of the extensive document that are applicable to your situation.

To use this tool, click on "Questionnaires", "Create" a new questionnaire, name it any way you want, base it on the "RDA Covid-19" knowledge model, and fill in questions to get to applicable recommendations.

When you're done, you can save your result and use the "three vertical dots" menu (on the right in the "Questionnaires" screen) to create a document with all guidance you selected. In the same menu you can also select "Fill questionnaire" to go back and change your answers.

Please contact [Rob Hooft](#) if you have any questions.



Welcome to the DS Wizard!



# Create Questionnaire

To get here, click "Questionnaires" and then "Create"

Name

Give it a recognizable name

Knowledge Model

Select the "Covid recommendations"

Visible by other logged users

Public link

Tags

- Clinical
- Collecting Data
- Community Participation
- Covid-19 specific guidance
- Data Sharing Guidance
- Epidemiology
- Generic guidance
- Indigenous Peoples
- Legal and Ethical
- Omics
- Pandemic-specific guidance
- Planning Research
- Preserving Data
- Processing and Analysis
- Publishing and Sharing
- Research Software
- Reusing Data
- Social Sciences

Ignore the rest of the options for now

You can filter questions in the questionnaire by tags. If no tags are selected



Rob's test ✓ Create Document More ▾

**Current Phase**  
Before Submitting the Proposal

**Chapters**

- I. Objectives and Foundational Elements 8
- II. Guidelines for Researchers 5**
- III. Recommendations for Policymakers 1
- IV. Recommendations for Funders 1
- V. Recommendations for Publishers 1
- VI. Recommendations for Providers of Data Sharing Infrastructures 3
- VII. Recommendations for Community Participation 3

More

**1.b.1 Will you be re-using existing data?** +

Desirable: *Before Submitting the Proposal*

a. No

b. Yes ☰

**(2.2.5)**  
Persistent identifiers for primary data sources should be included as a rule in secondary analyses to recognise primary data providers.

**(2.2.6)**  
Reusability of data requires documented provenance: when sharing any secondary data, the generation of which involves comparison against other resources, both the public availability of these used resources and unambiguous referencing of the used resources, including version numbers, should be ensured.

**1.b.1.b.1 Are you looking for primary source of epidemiological data?** +

Desirable: *Before Submitting the Proposal*

a. No

Chapters for each target audience show how many open questions are left

Rob's test ✓ Create Document More ▾

**Current Phase**  
Before Submitting the Proposal

**Chapters**

- I. Objectives and Foundational Elements 8
- II. Guidelines for Researchers 5**
- III. Recommendations for Policymakers 1
- IV. Recommendations for Funders 1
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- VII. Recommendations for Community Participation 3

**1.b.1 Will you be re-using existing data?** +

Desirable: *Before Submitting the Proposal*

a. No

b. Yes ☰

↺ Clear answer

**(2.2.5)**  
Persistent identifiers for primary data sources should be included as a rule in secondary analyses to recognise primary data providers.

**(2.2.6)**  
Reusability of data requires documented provenance: when sharing any secondary data, the generation of which involves comparison against other resources, both the public availability of these used resources and unambiguous referencing of the used resources, including version numbers, should be ensured.

**1.b.1.b.1 Are you looking for primary source of epidemiological data?** +

Desirable: *Before Submitting the Proposal*

a. No

Answer all open questions; new questions may appear when you select an answer.

Rob's test ✓ Create Document More ▾

**Current Phase**  
Before Submitting the Proposal

**Chapters**

- I. Objectives and Foundational Elements 8
- II. Guidelines for Researchers 5**
- III. Recommendations for Policymakers 1
- IV. Recommendations for Funders 1
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- VI. Recommendations for Providers of Data Sharing Infrastructures 3
- VII. Recommendations for Community Participation 3

**1.b.1 Will you be re-using existing data?** +

Desirable: *Before Submitting the Proposal*

a. No

b. Yes ☰

↻ Clear answer

**(2.2.5)**  
Persistent identifiers for primary data sources should be included as a rule in secondary analyses to recognise primary data providers.

**(2.2.6)**  
Reusability of data requires documented provenance: when sharing any secondary data, the generation of which involves comparison against other resources, both the public availability of these used resources and unambiguous referencing of the used resources, including version numbers, should be ensured.

**1.b.1.b.1 Are you looking for primary source of epidemiological data?** +

Desirable: *Before Submitting the Proposal*

a. No

Applicable sections from the guidance will appear in shaded text boxes

Use “+” to give us feedback



Browser window: covid-19.ds-wizard.org

Page title: Rob's test

Navigation: Create Document (circled in red), More

**Current Phase**

Before Submitting the Proposal

**Chapters**

- I. Objectives and Foundational Elements ✓
- II. Guidelines for Researchers ✓
- III. Recommendations for Policymakers ✓
- IV. Recommendations for Funders ✓
- V. Recommendations for Publishers ✓
- VI. Recommendations for Providers of Data Sharing Infrastructures ✓
- VII. Recommendations for Community Participation ✓**

**More**

TODOs

Indigenous data, in general, comprise data, knowledge, and information that relate to Indigenous Peoples at both the individual and collective level, including data about lands and environment, people, and cultures. In the context of COVID-19, Indigenous data include data about COVID-19 testing (individual and community, e.g., wastewater), cases, hospitalisations, health service access, deaths, and comorbidities, as well as related Indigenous Knowledges about COVID-19, and data on the socioeconomic and environmental correlates and impacts of COVID-19.

For more information, see [Rainie et al., 2017](#), and [Nickerson, 2017](#).

Desirable: *Before Submitting the Proposal*

a. No

b. Yes

**3 Are you looking into different types of community participation, roles and data challenges?**

Desirable: *Before Submitting the Proposal*

a. No

b. Yes

When you are done, use “Create document” to assemble all guidance into a PDF tailored for you.

# Create document

## Name

Rob's test

## Questionnaire

Rob's test

Answered (current phase): 41/41



Answered: 41/41



## Template

Questionnaire Report

## Format

JSON Data

HTML Document

PDF Document

LaTeX Document

MS Word Document

OpenDocument Text

Markdown Document

Cancel

Create

Select the "Questionnaire report"

Select "PDF Document"

Click "Create"



# DS Wizard Editing Mode - Structure

The screenshot displays the DS Wizard interface in editing mode. On the left is a blue sidebar with navigation options: Knowledge Model Editor, Knowledge Models, Questionnaires, Documents, Create a project, Help, and Mark Leggott. The main area is titled 'KNOWLEDGE MODEL' and shows a tree structure for 'RDA Covid-19 Data Sharing Recommendations: Omics'. The selected item is 'Objectives and Foundational Elements'. The right panel shows the editing details for this element, including a title field containing 'Objectives and Foundational Elements', a text editor with a preview tab, and a questions section.

**DS Wizard**

KNOWLEDGE MODEL TAGS PREVIEW Close

RDA Covid-19 Data Sharing Recom... > Objectives and Foundational EL...

Expand all Collapse all

- RDA Covid-19 Data Sharing Recommendations: Omics
  - Objectives and Foundational Elements
  - Guidelines for Researchers
  - Recommendations for Policymakers
  - Recommendations for Funders
  - Recommendations for Publishers
  - Recommendations for Providers of Data Sharing Infrastructures
  - Recommendations for Community Participation
    - Planning Research
    - Collecting Data
    - Processing and Analysis
    - Publishing and Sharing
    - Preserving Data
    - Reusing Data
    - Clinical
    - Omics
    - Epidemiology
    - Social Sciences
    - Community Participation
    - Legal and Ethical
    - Indigenous Peoples
    - Research Software
    - Generic guidance
    - Data Sharing Guidance
    - Pandemic-specific guidance
    - Covid-19 specific guidance

Help >

Mark Leggott >

Collapse sidebar

**Title**

Objectives and Foundational Elements

**Text**

Editor Preview

The RDA COVID-19 WG was initiated after a conversation between the RDA and the European Commission. The first meeting of the CWG to determine the work was held in March 2020. As of June 2020, the CWG counted over 440 members spread across the different sub-groups. This effort also reflects the work of a host of other RDA Working Groups, as well as external stakeholder organisations, including the Global Indigenous Data Alliance and the Research Software Alliance.

The CWG and the sub-groups operate according to the RDA guiding principles of Openness, Consensus, Balance, Harmonisation, Community-driven, Non-profit, and Technology-neutral, and are open to all.

The objectives of the RDA COVID-19 Working Group (CWG) are:

- to clearly define detailed guidelines on data and software sharing under the present COVID-19 circumstances to help stakeholders follow best practices to maximise the efficiency of their work, and to act as a blueprint for future emergencies;
- to develop recommendations for policymakers to maximise timely, quality data and software sharing and appropriate responses in such health emergencies;
- to address the interests of researchers, policymakers, funders, publishers, and providers of data sharing infrastructures.

You can use Markdown and see the result in the Preview tab.

**Questions**

Would you need guidance on the main challenges?

Do you need guidance on the coordinated, cross-jurisdictional efforts to foster global Open Science?

# DS Wizard Editing Mode – Questions & Text

The screenshot displays the DS Wizard Knowledge Model Editor interface. The left sidebar contains navigation options: Knowledge Model Editor, Knowledge Models, Questionnaires, Documents, Create a project, Help, and Mark Leggett. The main area shows a breadcrumb trail: RDA Covid-19 Data Sharing Rec... > Objectives and Foundational El... > Would you need guidance on th... > Yes. A tree view on the left shows the selected question: "Would you need guidance on the main challenges?" with "Yes" selected. The right panel shows the "Answer" section with a label "Yes" and an "Advice" section containing text about data availability and sharing. Below the advice is a "Follow-up Questions" section with an "Add follow-up question" button.

DS Wizard

KNOWLEDGE MODEL TAGS PREVIEW

Close

... > RDA Covid-19 Data Sharing Rec... > Objectives and Foundational El... > Would you need guidance on th... > Yes

Expand all Collapse all

- [-] RDA Covid-19 Data Sharing Recommendations: Omics
  - [-] Objectives and Foundational Elements
    - [-] Would you need guidance on the main challenges?
      - No
      - Yes
    - Do you need guidance on the coordinated, cross-jurisdictional...
    - Do you need guidance on infrastructure investment & econom...
    - Do you need guidance on the FAIR and timely requirements?
    - Do you need guidance on data management planning?
    - Do you need guidance on metadata?
    - Do you need guidance on documentation of research outputs?
    - Do you need guidance on the use of trustworthy data reposi...
    - Do you need guidance on data publications?
  - Guidelines for Researchers
  - Recommendations for Policymakers
  - Recommendations for Funders
  - Recommendations for Publishers
  - Recommendations for Providers of Data Sharing Infrastructures
  - Recommendations for Community Participation
    - Planning Research
    - Collecting Data
    - Processing and Analysis
    - Publishing and Sharing
    - Preserving Data
    - Reusing Data
    - Clinical
    - Omics
    - Epidemiology
    - Social Sciences
    - Community Participation
    - Legal and Ethical
    - Indigenous Peoples

Help >

Mark Leggett >

Collapse sidebar

### Answer

95w28e01 [Move](#) [Delete](#)

**Label**

Yes

**Advice**

Editor Preview

The availability of research data is a key component of pandemic preparedness and response. The timeliness of accessing data and the harmonisation across information systems are currently major roadblocks.

**Critical Need for Data Sharing --**

The unprecedented spread of the virus has prompted a rapid and massive research response. To make the most of global research efforts, findings and data need to be shared equally rapidly, in a way that is useful and comprehensible. Raw data, algorithms, workflows, models, software and so on are required inputs to research studies and are essential to the scientific discovery process itself. New findings and understandings need to be disseminated and built upon at a pace that is faster than usual; due to decisions being taken by healthcare practitioners and governments on a daily basis, it is crucial that they are well-informed.

The rapid pace of the disease and the immense and rapid mobilisation of resources could create an environment for inaccurate or low-quality data, which could have considerable implications. Shortcuts with

*You can use Markdown and see the result in the Preview tab.*

**Follow-up Questions**

+ Add follow-up question

# About the DS Wizard

- > DS Wizard was originally created to help making data management choices
- > Started from a 600 question mind map
- > An “Expert system” to **help researchers** find the right information
- > Not primarily “Data Management Plan” for the **funder!**
- > Suitable to update data management during a whole project
- > Supporting (RDA standards for) machine actionable Data Management Plans
  
- > Very suitable to make local derivatives pointing to local resources
  
- > Also available to host your own expert systems; open source



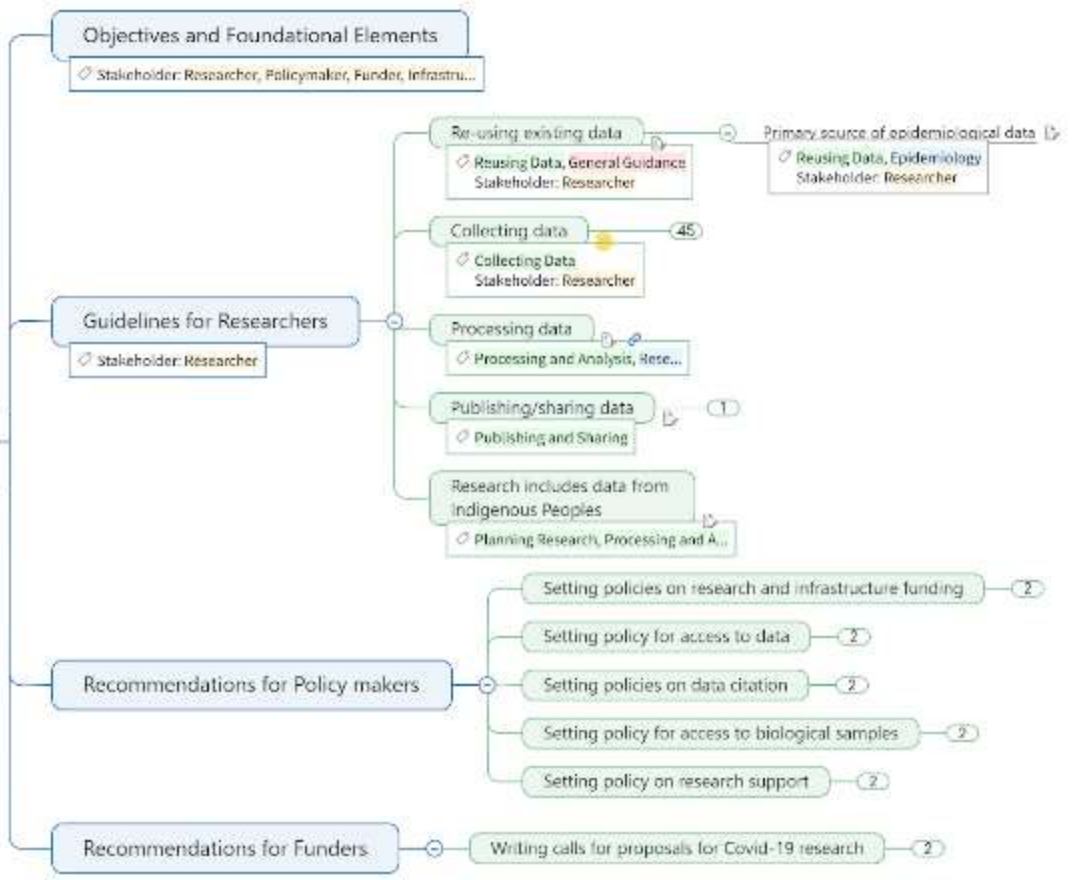
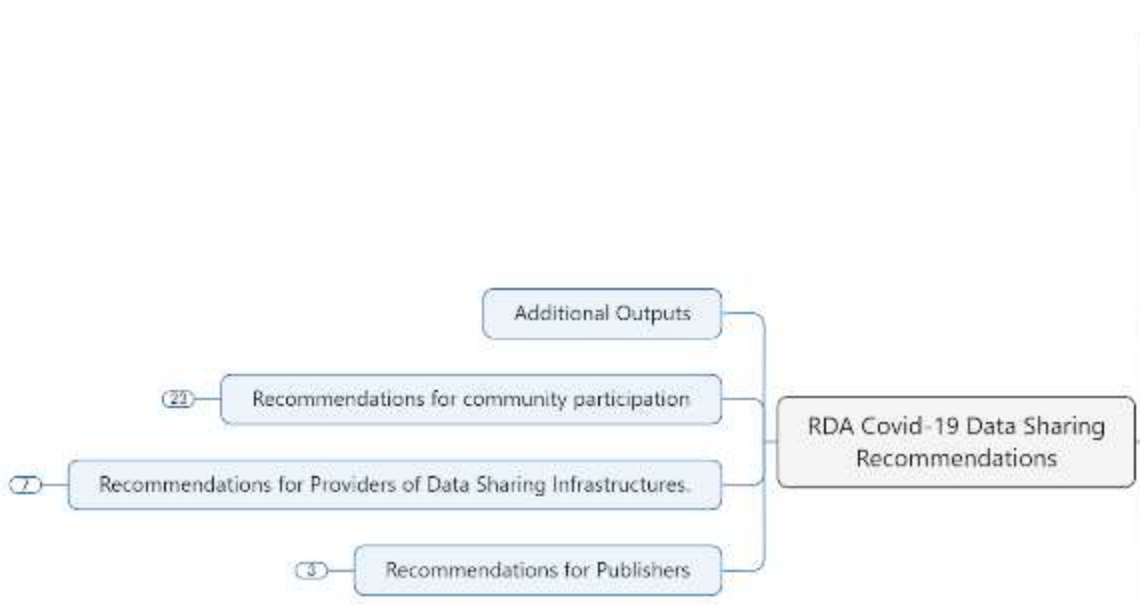


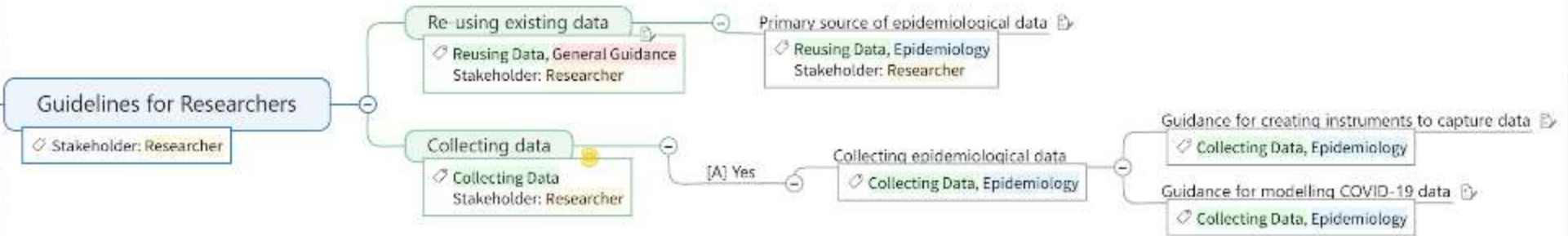
# Mindmap

- > A single view of the Rs&Gs using a mindmap approach
- > Includes the full text of the Rs&Gs as notes attached to nodes that correspond to Questions from the DS Wizard version
- > Intended to provide a high-level view, and the ability to drill down
- > Can filter nodes by tags that include
  - stakeholder group
  - section and topic
  - fulltext search of all nodes and notes
  - web-accessible view

<https://bit.ly/RDA-COVID19-Guidelines>







Filter ▼ ×

Show

**▼ General**

**Stakeholder**

- Funder
- Infrastructure Provider
- Policymaker
- Publishers
- Researcher

**General Tags**

- COVID-19 Specific Guidance
- Clinical
- Collecting Data
- Community Participation
- Data Sharing Guidance
- Epidemiology
- General Guidance
- Indigenous Peoples
- Legal and Ethical
- Devices
- Pandemic Specific Guidance
- Planning Research
- Preserving Data
- Processing and Analysis
- Publishing and Sharing
- Research Software
- Reusing Data
- Social Sciences

Match  All  Any



#### 5.4.2 Interoperable COVID-19 Epidemiological Surveillance: Clinical and Population-based Instruments

International efforts are currently underway to create COVID-19 instruments/ questionnaires (Tables 3-4). These COVID-specific tools are concentrated at person-level for clinic/hospital surveillance (e.g. Case Report Forms-CRFs), or community surveillance (e.g. questionnaire for general population), and do not necessarily collect the same data. Adherence of new studies to already introduced instruments will strongly enhance the comparability of results.

Table 3 - Questionnaire instruments: Reference

##### 1. CLINICAL

1. Australia: [NSW Case questionnaire](#)
2. Austria: [EMS](#)
3. Europe: [TESSy](#)
4. Germany: [Covid-19 research dataset](#)
5. Uganda: [Perinatal COVID-19 Uganda](#)
6. US: [Human Infection with 2019 Novel Coronavirus Person Under Investigation \(PUI\) and Case Report Form](#)
7. Worldwide: [Global COVID-19: clinical platform: novel coronavirus \(COVID-19\): rapid version\] - NEED CORRECT URL](#)

##### 2. POPULATION BASED

1. Brazil: [Brazil Prevalence of Infection Survey](#)
2. Europe: [Questionnaire by WHO Europe](#)
3. Germany: [GESIS Panel Special Survey on the Coronavirus SARS-CoV-2 Outbreak in Germany](#)
4. Germany: [NAKO COVID-19 Survey tool](#)
5. Israel: [One-minute population wide survey](#)
6. LMICs: [LMIC Covid Questionnaire](#)
7. South Africa: [South African Population Research Infrastructure \(SAPRI\) COVID-19 Screening Form](#)
8. South Asian Countries: [National Institute for Health Research \(NIHR\) Global Health Research Unit](#)
9. UK: [UK COVID-19 Questionnaire](#)
10. Worldwide (WHO): [Population-based age-stratified sero-epidemiological investigation protocol for COVID-19 virus infection](#)

Table 4 - Questionnaire instruments: Resources

1. NIH: [Public Health Emergency and Disaster Research Response \(DR<sub>2</sub>\)](#)
2. NIH: [COVID-19OBSSR Research Tools](#)
3. PhenX: [PhenX COVID-19 Toolkit](#)

Some of the questionnaire initiatives shown in Tables 3 and 4 are currently feeding into the construction of a COVID-19 demographic and epidemiological surveillance question bank that can be used to form locality specific surveys with both common and distinct questions by domains and cohorts (Wellcome Trust). Some, such as the UK COVID-19

# Ongoing Work and Future Steps – Outputs and Articles

## > Supplementary Outputs

- A number of the COVID-19 Sub-Groups have published more detailed documents that build on the primary Rs&Gs document
  - [Data Sharing in Epidemiology](#)
- Other Sub-Group documents are available in Google folders

## > Journal Articles and Endorsements

- A number of articles in preparation by COVID-19 WG Members
  - Summary of the findings of the Rs&Gs
  - Description of the process used to create the Rs&Gs
  - Community Participation article
- Summaries of the Rs&Gs in various journals (e.g. [Cell Patterns](#), [HealthCare IT News](#), etc.)



# Ongoing Work and Future Steps – Endorsements/Statements

## > Stakeholder support happening in various ways

- Adoption and implementation of the recommendations and guidelines
- Promotion by policymakers, funders and publishers
- Use and promotion by researchers

## > Statements

- STM Publishers
- Global Indigenous Data Alliance (GIDA)
- Duty to Document Statement



# Ongoing Work and Future Steps – Events/Survey

## > Webinars

- RDM organizations
  - Research Data Alliance and National Nodes (e.g. [Ireland](#))
  - [Research Data Canada](#)
- Other Organizations
  - [FAPESP](#) (Brazil)
  - [European Open Science Forum](#)
  - [Scottish Council on Archives](#)

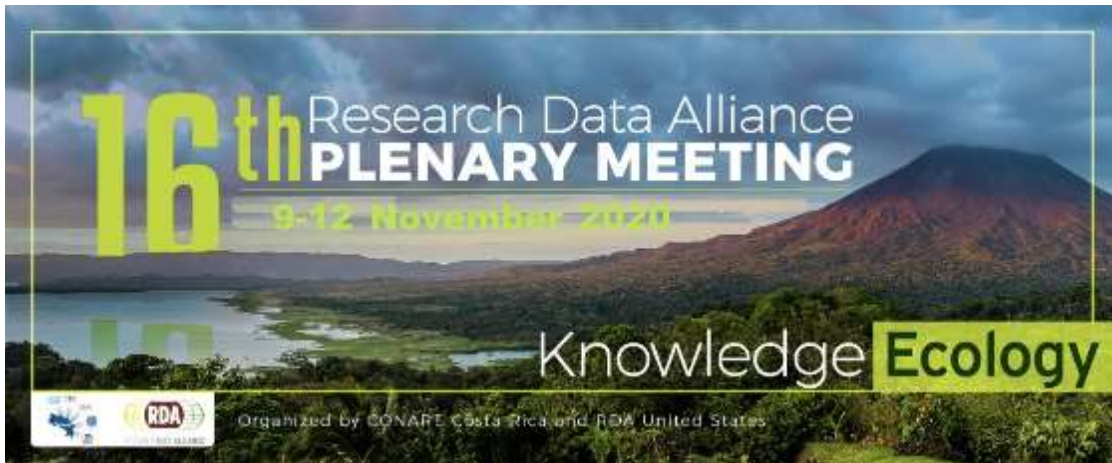
## > Impact Survey

- Survey to measure use and impact of the Rs&Gs is under development
- Will be distributed broadly when completed



# Ongoing Work and Future Steps – RDA Plenary Sessions

- > VP16 (Virtual Plenary P16) was going to be in Costa Rica, will now be virtual
- > Various sessions will discuss elements of COVID-19 and/r infectious disease
  - Broader efforts under RDA WGs
  - Infectious Disease BOF (goal to create a WG/CoP)
  - Community Participation BoF / Citizen Science
  - COVID-19 Epidemiology WG / Epidemiology WG



<https://www.research-data-alliance.org/plenaries/rda-16th-plenary-meeting-costa-rica>

# Value of RDA for COVID-19

Building the social and technical bridges to enable open sharing and re-use of data

RDA EU RDA US CONTACT US LOGIN REGISTRATION

**RDA** RESEARCH DATA ALLIANCE

**O&A Members** 63  
Active Organisational & Affiliate members.

**MEMBERSHIP** Members: 10966  
Becoming a member of RDA is simple and open to both individuals and organisations.  
[Register now](#)

**RDA Groups** WG & IGs: 96  
Discover what RDA Working and Interest Groups and all other Groups are up to and find out how to join them. [Explore Groups](#)

ABOUT RDA GET INVOLVED GROUPS RECOMMENDATIONS & OUTPUTS RDA FOR DISCIPLINES PLENARIES & EVENTS NEWS & MEDIA

## The Value of RDA for COVID-19

Home » Get involved » The Value of RDA for... » The Value of RDA for COVID-19

13 July 2020 | 862 reads | Facebook | Twitter

Under public health emergencies, and particularly the COVID-19 pandemic, it is fundamental that data is shared in both a timely and an accurate manner. 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.

In late March, RDA received a direct request from one of its funders, the European Commission, to create global guidelines and recommendations for data sharing under COVID-19 circumstances. Over 600 data professionals and domain experts signed up and began work in early April 2020. They have produced a rich set of 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; coupled with recommendations to help policymakers and funders to maximise timely, quality data sharing and appropriate responses in such health emergencies.

On 30 June 2020, RDA published the final version of the RDA COVID-19 Recommendations and Guidelines on data sharing covering four research areas – clinical data, omics practices, epidemiology and social sciences – complemented by overarching areas focusing on legal and ethical considerations, research software, community participation and indigenous data.

### The Outputs

The COVID-19 WG, from April 1st through June 30th, 2020, created more than five releases of the recommendations and guidelines, leading to the final endorsed version, "RDA COVID-19 Recommendations and Guidelines for Data Sharing," with ongoing efforts to add and review materials.

### The Value of RDA for...

- COVID-19
- Funders
- Individuals
- Infrastructure Providers
- Libraries
- Organisations performing Research
- Regions
- Student/Early Career Programms
- The European Open Science Cloud (EOSC)
- Request for Comments
- Call for Papers: Research Data Alliance
- Results Special Collection

### The Outputs

The COVID-19 WG, from April 1st through June 30th, 2020, created more than five releases of the recommendations and guidelines, leading to the final endorsed version, "RDA COVID-19 Recommendations and Guidelines for Data Sharing," with ongoing efforts to add and review materials.

- RDA COVID-19 Recommendations and Guidelines for Data Sharing, final release, published 30 June 2020
- RDA COVID-19 Recommendations and Guidelines for Data Sharing Infographic
- RDA COVID-19 Guidelines and Recommendations - the prior 5 releases
- RDA COVID-19 WG Zetoro Library

**Citation: RDA COVID-19 Working Group. Recommendations and Guidelines on data sharing. Research Data Alliance, 2020. DOI: <https://doi.org/10.15497/rda00052>**

### Resources

- Final executive summary
- RDA COVID-19 Press Release 30 June 2020 final - June 2020

### Joint Statements

- RDA COVID-19 Recommendations and Guidelines for Data Sharing: How STM Publishers can Contribute (July 2020)
- GIDA-RDA COVID-19 Guidelines for Data Sharing Respecting Indigenous Data Sovereignty (July 2020)
- The Duty to Document does not Cease in a Crisis, it becomes more Essential (May 2020)
- Data Together: COVID-19 Appeal And Actions (March 2020)

### RDA FOR COVID-19 Events

A series of weekly "RDA COVID-19 Update Webinar" occurred almost every Tuesday between April and June 2020 and provided updates on the overarching COVID-19, Legal and Ethical, Research Software, Community Participation Working Groups, Indigenous Data contribution, and the four research themes (clinical, omics, epidemiology, social sciences), along with an opportunity for members to ask questions. Recordings and presentations from these sessions are posted on the **Events** meeting links.

#### Upcoming events include:

- RDA Ireland Meet The Experts Webinar - Data Sharing for COVID-19 Research: Recommendations and Guidelines from the RDA COVID-19 Working Group - 29 July 2020

<https://www.rd-alliance.org/value-rda-covid-19-0>





# RDA as a Community Platform

- > The COVID-19 Rs&Gs demonstrate the core RDA value
  - Ability to gather a knowledgeable grassroots group
- > Easy to get engaged!
  - Membership is free
  - Engagement opportunities are rich and diverse
- > 100+ Interest Groups and Working Groups
- > New Communities of Practice group type
- > Virtual Plenary 16 a good chance to engage

## RDA's guiding principles:

- ✓ Openness
- ✓ Consensus
- ✓ Balance
- ✓ Harmonization
- ✓ Community-driven
- ✓ Non-profit and technology-neutral



**...by the community for the community.**

**RDA**

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**LinkedIn - [www.linkedin.com/in/ResearchDataAlliance](http://www.linkedin.com/in/ResearchDataAlliance)**

**Slideshare - <http://www.slideshare.net/ResearchDataAlliance>**

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Thank you! Questions?