Anne Cambon-Thomsen, MD, Emeritus Research director CNRS, RDA ambassador for health research and research ethics, Co-Chair of RDA SHARC IG and RDA-COVID-19 WG. UMR 1027, Inserm, Université Toulouse, France, CERPOP (Center of epidemiology and research in population health); Team BIOETHICS.

Insights from the RDA Covid-19 Working Group Guidelines and Recommendations

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

RDA P17
SHARC session

Contact: anne.cambon-thomsen@univ-tlse3.fr
Outline of presentation

- Introduction: 2 aims
  - The production of recommendations
  - The recognition of that work
- Context and characteristics of the RDA COVID-19 WG
- Methods, organisation and steps
- Outputs and other productions
- Recognising the contributions to the outputs of the group
- Discussion
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
Research Areas & Cross-cutting themes

- Clinical
- Omics
- Epidemiology
- Social Sciences
- Community
- Indigenous Data Guidelines
- Research Software
- Legal and Ethical Considerations
A 145 page document with context, general guidelines and recommendations, specific (per sub-group)

An executive summary

Supporting outputs: 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 (general and by sub-group), zotero library on COVID-vaccines, infographics, visualisation tools
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 » has produced 3 tools:
  - An infographics
  - A mindmap
  - A wizard
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Recognition of the work

- Internal discussion in the sub-groups
- Decision on policy for the group productions
  - Naming the people for the different roles (structural)
  - Alphabetical order, all active contributors, name + ORCID, no more subtle granularity (RDA traditional rule applied) – on demand/resp of moderators to check
  - Different from the names of group members on RDA site (those are more numerous)
  - List includes those who substantially contributed to the document through comments
- For articles no « one rule for all », depending on kind of articles (authors usually in alphabetical order except first author; contributions described)
- Other « recognition » by interviews, participation to sessions « about it » in various conferences
Lessons learnt

On recommendation production
- Importance of References library attached to document as an output
- Importance of differentiating guidelines and recommendations, target for those
- Gathering of standards used systems in a unique document, the usability of the document more important than « originality » of the recommendations themselves

On recognition of such a work
- Noticeable this has been discussed within the RDA COVID-19 WG
- Explicit simple rule, clearly described, not too much granularity
- DOI of the documents +++
- Dissemination strategy