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australian research data commons

Built from ands AUSTRALIAN NATIONAL DATA SERVICE nectar RDS www.rds.edu.au

Findable, Accessible, Interoperable, and Reusable (FAIR) data

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International Funders

National Institutes of Health

Turning Discovery Into Health

wellcome

European Commission | Horizon 2020 European Union funding for Research & Innovation

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Journals

ICMJE INTERNATIONAL COMMITTEE of MEDICAL JOURNAL EDITORS

ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly work in Medical Journals

The NEW ENGLAND JOURNAL of MEDICINE

BMJ

BMJ 2015;350:h2373
http://journals.plos.org/plosone/s/data-availability
http://www.nejm.org/doi/full/10.1056/NEJMe1601087#t=article
http://www.icmje.org/news-and-editorials/data_sharing_june_2017.pdf

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Australian Funders

National Statement on Ethical Conduct in Human Research

Human Research Ethics Application (HREA)

Australian Government
Australian Research Council

Data management statement required for national competitive grants
www.arc.gov.au/policies-strategies/strategy/research-data-management

Open access policies

Australian Code for the Responsible Conduct of Research

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Advantages for researchers

- Transparency and reproducibility
- Maximises value of investment
- Citations and impact
- Collaborations
- Secure ongoing storage
- Ethical obligation (clinical trials)
- Publications with data cited more often

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Data sharing/publication isn't all "open data"

Five Safes risk management framework

Image CCBY
http://archive.stats.govt.nz/browse_for_stats/snapshots-of-nz/integrated-data-infrastructure/keep-data-safe.aspx

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F.A.I.R. data principles

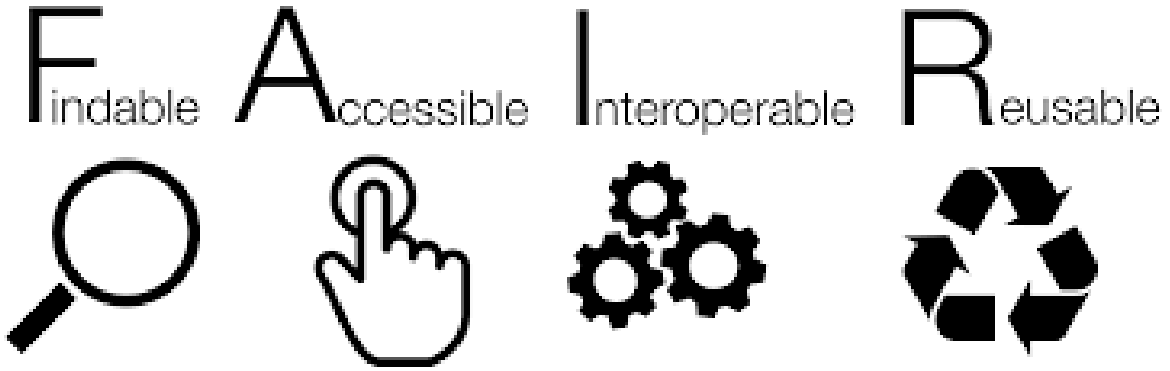

Image by Sanja Pundir CC-BY-SA

- Drafted in a workshop in 2014
- Nature article* and support by FORCE11
- Received international recognition
- Technology agnostic
- Discipline independent
- Both the data and the metadata
- Human readable and machine readable

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* Wilkinson, M. D. et al. The FAIR Guiding Principles for scientific data management and stewardship. Sci. Data 3:160018 doi: 10.1038/sdata.2016.18 (2016).

“FAIR principles provide ‘steps along a path’ toward machine-actionability; adopting, in whole or in part, the FAIR principles, leads the resource along the continuum towards this optimal state.”

Wilkinson, M. D. et al. The FAIR Guiding Principles for scientific data management and stewardship. Sci. Data 3:160018 doi: 10.1038/sdata.2016.18 (2016).

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Findable

- Describe your data
- Give it a persistent globally unique identifier
- Make it findable through discipline specific search routes and generic ones

F1. (meta)data are assigned a globally unique and eternally persistent identifier.
F2. data are described with rich metadata.
F3. (meta)data are registered or indexed in a searchable resource.
F4. metadata specify the data identifier.

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Accessible

- Accessibility is a spectrum

Open Mediated Closed

- Deposit in repository
- If not open, provide information how the researcher can get access to the data and background information (e.g. codebooks, methods, software, algorithms)

A1 (meta)data are retrievable by their identifier using a standardized communications protocol.

A1.1 the protocol is open, free, and universally implementable.

A1.2 the protocol allows for an authentication and authorization procedure, where necessary.

A2 metadata are accessible, even when the data are no longer available.

Interoperable

- Use a standard file format
- Use a community agreed vocabulary (MeSH, SNOMED CT, ICD-10…)
- Link to relevant information

I1. (meta)data use a formal, accessible, shared, and broadly applicable language for knowledge representation.
I2. (meta)data use vocabularies (and ontologies) that follow FAIR principles.
I3. (meta)data include qualified references to other (meta)data.

Reusable

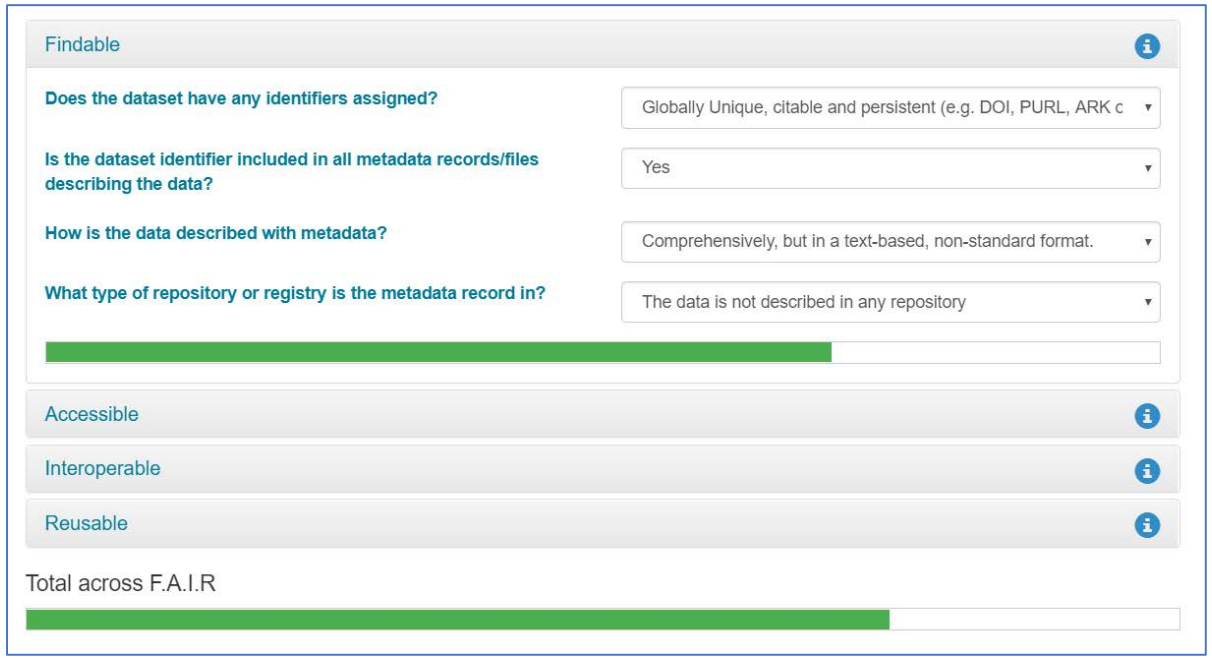
Other aspects on top of F.A.I. :

- Discipline specific information about the output
- Information on how the data was created
- A machine readable licence (Creative Commons recommended, see our licensing guide ands.org.au/guides/copyright-data-and-licensing)

R1. meta(data) have a plurality of accurate and relevant attributes.
R1.1. (meta)data are released with a clear and accessible data usage license.
R1.2. (meta)data are associated with their provenance.
R1.3. (meta)data meet domain-relevant community standards.

F.A.I.R resources

Self assessment tool



ands.org.au/working-with-data/fairdata

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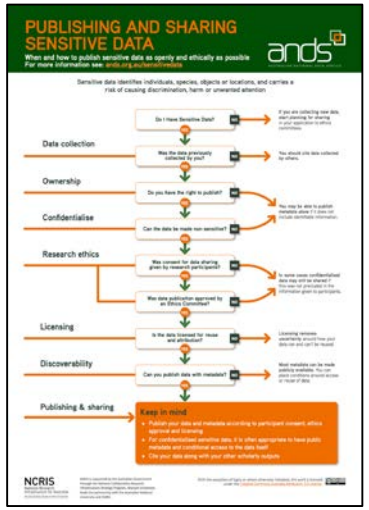
Sensitive data resources

ands.org.au/working-with-data/sensitive-data



Publishing and sharing sensitive data Guide

Data sharing considerations for Human Research Ethics Committees Guide

Safely sharing sensitive data
Sensitive data CAN be published: advice and examples

Ethics and data sharing
Ethical considerations when sharing human data

De-identifying your data
Processes for removing identifying information from datasets to protect privacy

De-identification Guide

10 medical and health research data Things
A flexible learning resource for people working with medical, clinical or health data

Medical and health data
ANDS hub for medical and health data issues and advice

Indigenous data
Data that pertains to Indigenous peoples is a complex legal and ethical terrain

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NCRIS

National Research Infrastructure for Australia

An Australian Government Initiative

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