

# ardc

australian research data commons

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

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

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# International Funders



**wellcome**



Journals

**ICMJE** INTERNATIONAL COMMITTEE of  
MEDICAL JOURNAL EDITORS

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



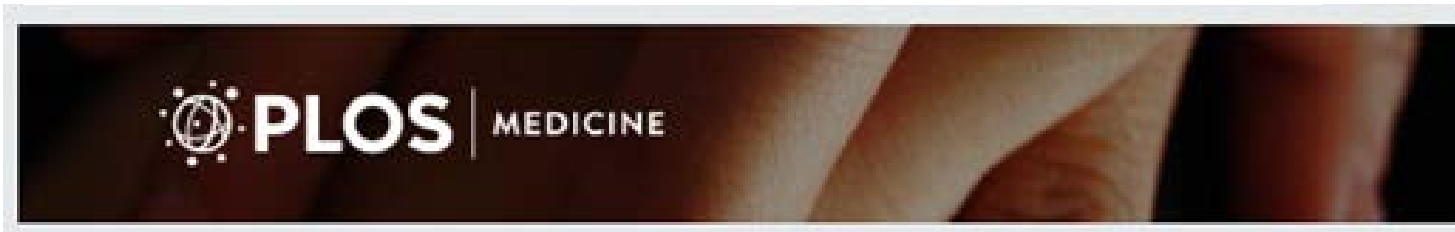
The NEW ENGLAND  
JOURNAL of MEDICINE

**BMJ**

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*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](http://www.icmje.org/news-and-editorials/data_sharing_june_2017.pdf)

# Australian Funders



National Statement on Ethical Conduct  
in Human Research

Human Research Ethics Application  
(HREA)

Open access policies

Australian Code for the Responsible Conduct of Research



**Australian Government**  
**Australian Research Council**

Data management statement  
required for national competitive  
grants

[www.arc.gov.au/policies-strategies/strategy/research-data-management](http://www.arc.gov.au/policies-strategies/strategy/research-data-management)

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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](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

- 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

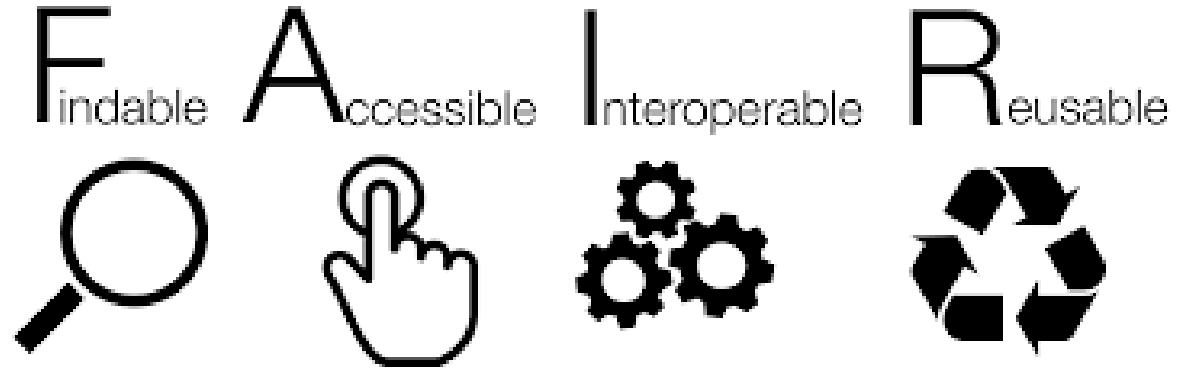


Image by Sanja Pundir CC-BY-SA

\* 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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“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



- 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.

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# 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.

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# 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](https://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.

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# F.A.I.R resources



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## Self assessment tool

Findable i

Does the dataset have any identifiers assigned?

Is the dataset identifier included in all metadata records/files describing the data?

How is the data described with metadata?

What type of repository or registry is the metadata record in?

Accessible i

Interoperable i

Reusable i

Total across F.A.I.R.

[ands.org.au/working-with-data/fairdata](https://ands.org.au/working-with-data/fairdata)

# Sensitive data resources

[ands.org.au/working-with-data/sensitive-data](https://ands.org.au/working-with-data/sensitive-data)

**PUBLISHING AND SHARING SENSITIVE DATA**  
When and how to publish sensitive data as openly and ethically as possible. For more information see [ands.org.au/working-with-data/sensitive-data](https://ands.org.au/working-with-data/sensitive-data)

Sensitive data identifies individuals, specific objects or locations, and carries a risk of causing discrimination, harm or unwanted attention.

**Do I need sensitive data?**  
If you are collecting raw data, you should consider whether you need sensitive data.

**Do you have the data primarily intended for research?**  
Yes: You should only use collected data for research purposes.

**Do you have the right to publish?**  
Yes: You need to be able to publish. Consider whether you have the right to publish.

**Can the data be de-identified?**  
Yes: You need to be able to de-identify. Consider whether you have the right to de-identify.

**Has research ethics approval been obtained?**  
Yes: You need to be able to publish. Consider whether you have the right to publish.

**Has your publication approved by an ethics committee?**  
Yes: You need to be able to publish. Consider whether you have the right to publish.

**Is the data licensed for reuse?**  
Yes: You need to be able to publish. Consider whether you have the right to publish.

**Can you publish raw data with sensitive data?**  
Yes: You need to be able to publish. Consider whether you have the right to publish.

**Keep in mind**  
Publish your data and metadata according to participant consent, ethics approval and licensing.  
For confidential sensitive data, it is often appropriate to have public releases and confidential access to the data.  
The data you are using may have other copyright issues.

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Publishing and sharing sensitive data Guide



Data sharing considerations for Human Research Ethics Committees Guide

**Sharing Data Ethically**

**Why share data**

**Data sharing**

- Encourage research integrity and promote innovation
- Provide credit to the researcher as a research output
- Lead to new collaborative research opportunities
- Improve the transparency and accountability of research
- Reduce the cost of collecting data

**Meeting your obligations**

The Australian Code for the Responsible Conduct of Research states:  
"Researchers have a responsibility to their colleagues and the wider community to disseminate their research as broadly as possible"  
Both the NHMRC and HRETC encourage the dissemination of all research outputs.

**What kind of data are we talking about?**

We mean data which is created in the course of research on human subjects and which is subject to ethical approval and oversight. This includes data generated in research which involves human participants, including personal, financial, health, genetic, and other information, before, during, and after the research process.

**Research Administrators**

- Encourage data sharing by ensuring that ethics forms include relevant questions
- Support institutional policies to encourage data sharing
- Support the resolution of institutional data policies which may impede data sharing

**Human Research Ethics Committees**

- Recognise that good data management enables careful data management practices
- Provide advice to researchers about designing their research so that the data can be shared
- Advise a path to your ethics form: "Is there any reason NOT to share the data that we propose?"

**Researchers**

- Consider the need to share data when they design their project
- Seek approval from their HRETC to share their data
- Use techniques to support data sharing
- Obtain consent
- Consider accessibility considerations
- Annotate the data

ands.org.au

**10 things**  
medical & health

A flexible learning resource for people working with medical, clinical or health data. Visit [ands.org.au/medicalthings](https://ands.org.au/medicalthings)

Do as many as you like in any order, by yourself or in a group.

- Getting started with research data
- Issues in research data management
- Data sharing & discovery
- Sharing sensitive data
- What are publishers & funders saying about data?
- Identifiers for data & people
- Data citation for access & attribution
- Licensing data for reuse
- Describing data: metadata & controlled vocabularies
- Planning to publish
- 10

ands.org.au/medicalthings

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**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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