

Data Governance in Health Research

12th March 2024



Acknowledgement of Country

Health Translation Queensland acknowledges the Traditional Owners and their custodianship of the lands on which we meet.

We pay our respects to their Ancestors and their descendants, who continue cultural and spiritual connections to Country.

We recognise their valuable contributions to Australian and global society.

Who are we?





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Who are you?

What is your background? (data manager, researcher, clinician etc)

223 responses



Plan for today



What is data?

What do we mean by
data?

Why do we care?



The data lifecycle

What happens with data?



Policies, processes, approvals

What is data?

Data are measurements / observations that are collected as a source of information. There are a variety of different types of data & different ways to represent data.

([Data](#) | [Australian Bureau of Statistics \(abs.gov.au\)](#))



What is research data?

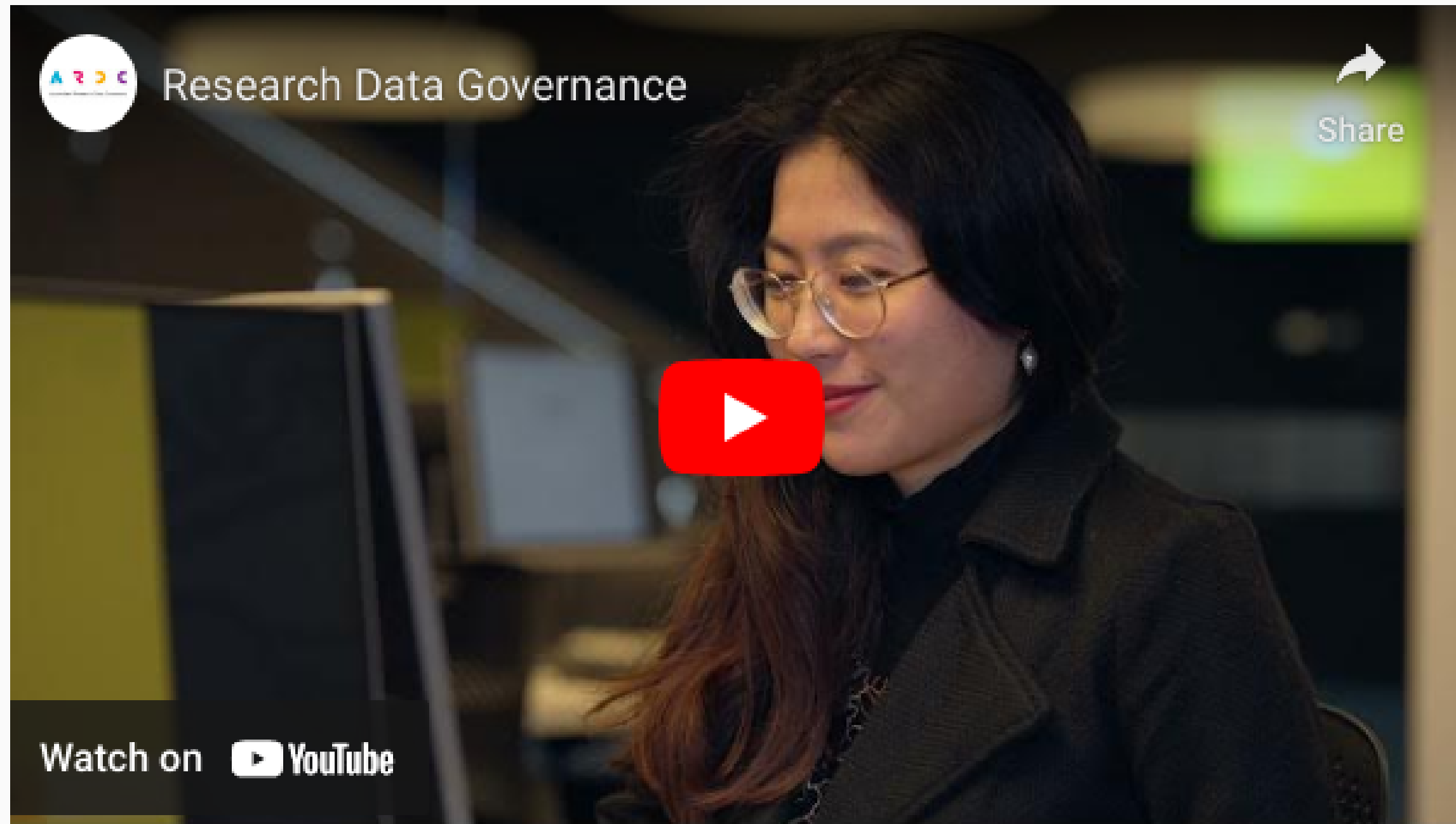
Research data is information generated through research methods. It means something different in every project. In health, it is often “sensitive”. Health research data is complicated due to laws, policies, and technology issues.

(Data | Australian Bureau of Statistics (abs.gov.au))

What is data governance?

Data governance is the approach to managing data throughout its life cycle, from acquisition to use to disposal. It is everything you do to ensure data is secure, private, accurate, available and usable.





*Australian Research Data Commons, 2021. Research Data Governance.
https://youtu.be/K_xVQRdgClc?si=hyxzFcWrxrPLAXDx*

A background image showing a business meeting. Several people in business attire are gathered around a table, looking at and pointing to various data visualizations. These include bar charts, pie charts, and a large table of numerical data. A calculator is also visible on the table. The overall scene suggests a professional discussion about data analysis and management.

**How does data
governance relate to
data management?**

Data governance



Good data governance will require the right people to follow the right processes with the support of the right technology throughout the data life cycle.

Principles of data governance

Existing
governance

Roles &
responsibilities

Data access

Data
sensitivity

Data
ownership

Storage

Reuse

Risk

The research data lifecycle



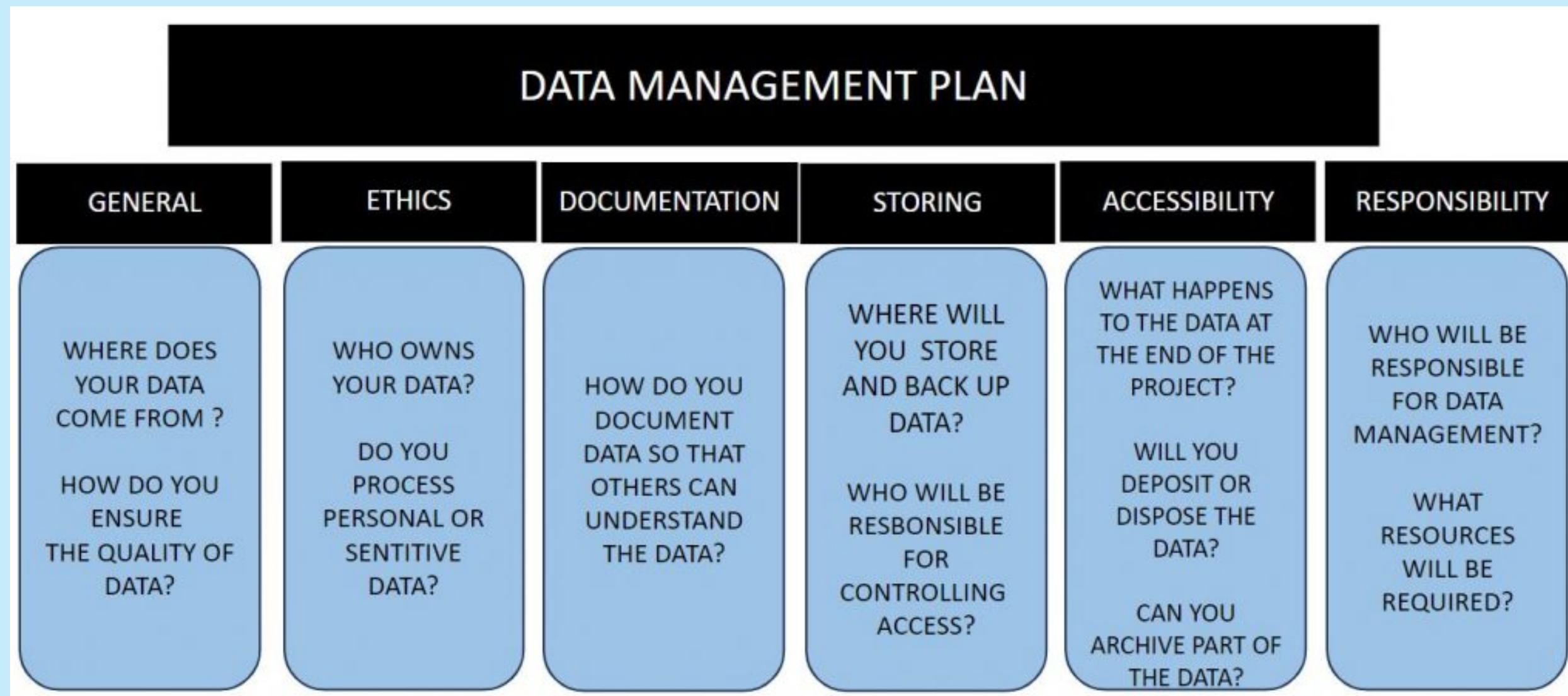
So, what's the plan?

Plan and design



Data management plans

Example



Useful links

ARDC

[Data
management
plans](#)
[Research data
management
framework](#)

UQ

[Research data
manager](#)

Griffith University

[Manage and plan](#)

NHMRC

[Management of
data and
information in
research](#)

Policies

There are many policies and guidelines for research data governance (institutional, state, national, etc). Consider jurisdictions related to your project before you begin.

Examples....

Topic	Institutional plans, policies and governance	Institutional procedures and tools	External links/ resources	Legislation and other official documents
Privacy, information and research data	<ul style="list-style-type: none"> • Privacy plan • IT plan • IT Code of Practice • Cloud Hosting Policies • Data Management Policy 	<ul style="list-style-type: none"> • Working with data • Research storage 	<ul style="list-style-type: none"> • Management of Data and Information in Research: A guide supporting the Australian Code for the Responsible Conduct of Research • Department of Education Higher Education Research Data Collection (HERDC) (website) • Health-Sector-Clinical-Records-Retention-and-Disposal-Schedule.pdf • Health sector (corporate records) retention and disposal schedule • TGA Data Management and Data Integrity • Queensland Health data management Dept of Health Policy 	<ul style="list-style-type: none"> • Public Records Act 2002 • Right to Information Act 2009 • Right to Information Regulation 2009 • Information Privacy Act 2009 • Information Privacy Regulation 2009 • Privacy Act 1988 (Cth) • Privacy Amendment (Enhancing Privacy Protection) Act 2012 (Cth) • Legislation-and-regulation-relating-clinical-quality-registries • Hospital and Health Boards Act 2011 • Public Health Act 2005 • Private Health Facilities Act 1999 • Mental Health Act 2016

**"We manage our data like
this here ..."**

Onboarding



Example RDM onboarding checklist (new project/person)



Planning

Projects:
Review grant
requirements
Write DMP
Est. metadata standard



Storage

Review storage
options



Sharing

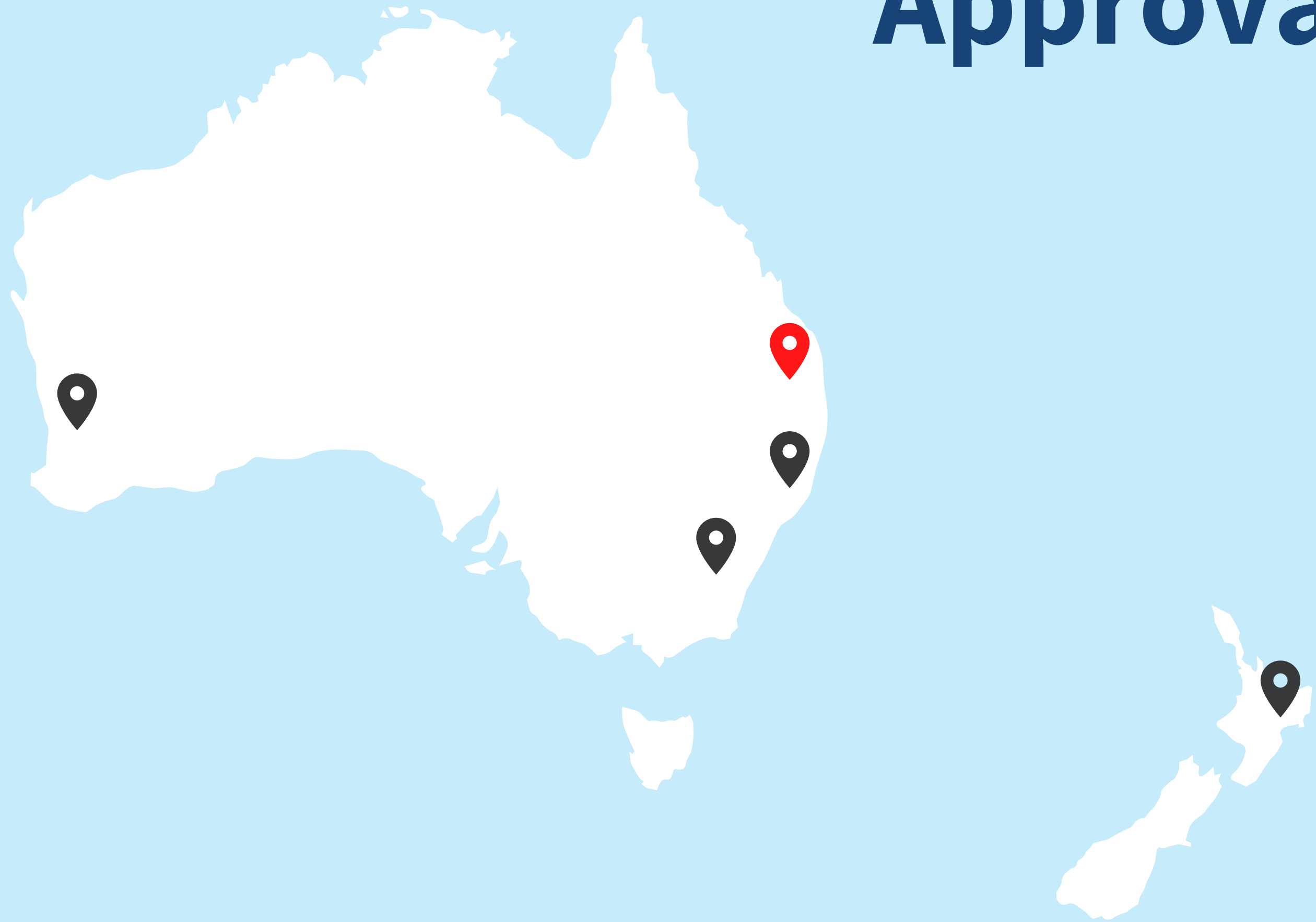
Review policies
Review tools
Consult sharing
agreements

Offboarding


Offboarding is also crucial for research data. Ensure data is securely stored in an accessible location when team members leave.



Approvals



Approvals

A woman with long blonde hair, wearing a white lab coat over a dark top, is shown from the chest up. She has a concerned or questioning expression on her face, looking slightly to the left. The background is a blurred indoor setting.

You have to go through
the proper channels.

Tips

01

Protocol

Don't copy paste
plan for data
management!

02

Consent

Think about
now... and the
future (avoid
need for
reconsent)

03

Contract

Use a template
contract. Think
about roles and
responsibilities
now and into the
future

04

Budget

Budget for data!!



What is sensitive data?

Often confidential, sensitive data can include identifiable personal and health/medical data, Indigenous data, ecological data concerning vulnerable species, and commercial-in-confidence data.

Data involving
Aboriginal and
TSI peoples has
many legal and
ethical
considerations
and needs to be
managed and
shared with
care.



What should I do?

Connect

Always check in with your collaborators who are Indigenous first. Do not progress without this step.

Listen

Collaboration, consultation, and listening. Individual organisations, roles, groups can be different so do not assume.



AIATSIS

[Australian Institute of
Aboriginal and Torres Strait
Islander Studies \(aiatsis.gov.au\)](https://aiatsis.gov.au)



NHMRC

[Ethical guidelines for research
with Aboriginal and Torres
Strait Islander peoples | NHMRC](#)



ARDC

[Indigenous Data | ARDC](#)

Useful links

CARE



Collective benefit

Data ecosystems shall be designed and function in ways that enable Indigenous peoples to derive benefit from the data.



Authority to control

Indigenous peoples' rights and interests in Indigenous data must be recognised and their authority to control such data be empowered.



Responsibility

Those working with Indigenous data have a responsibility to share how those data are used to support Indigenous peoples' self-determination and collective benefit.



Ethics

Indigenous peoples' rights and wellbeing should be the primary concern at all stages of the data life cycle and across the data ecosystem.

Data breach

Office of the Information Commissioner - <https://www.oaic.gov.au/>
Management of Data and Information in Research: A guide supporting the
Australian Code for the Responsible Conduct of Research (NHMRC and
Universities Australia, 2019) -
<https://www.nhmrc.gov.au/sites/default/files/documents/attachments/Management-of-Data-and-Information-in-Research.pdf>





Examples



Storage

Storage options - security, cost, software, hardware, backup



Retention

Data retention policies



Permissions

Accessibility , ownership

Store and manage

Data storage guides

UQ

	Key supported*						Unsupported		
Storage Platforms	UQ OneDrive	Network (Shared) Drives	SharePoint	Microsoft Teams	UQ RDM (including DRNs)	TRIM	Local DeviceStorage (e.g.laptop/ computer)	USB	Personal CloudStorage
Storage type	Day-to-day	Day-to-day	Day-to-day	Day-to-day	Day-to-day	Day-to-day to long term	Day-to-day	Day-to-day	Day-to-day
Primary storage use	Working documents & targeted collaboration	Working documents & group file sharing	Working documents & group file sharing	Group collaboration & discussion	Research data	Vital, high risk, high value documents & retention control	Personal	Personal	Personal
Suitable information security classification	OFFICIAL-PUBLIC OFFICIAL-INTERNAL SENSITIVE	OFFICIAL-PUBLIC OFFICIAL-INTERNAL SENSITIVE	OFFICIAL-PUBLIC OFFICIAL-INTERNAL SENSITIVE PROTECTED	OFFICIAL-PUBLIC OFFICIAL-INTERNAL SENSITIVE PROTECTED	OFFICIAL-PUBLIC OFFICIAL-INTERNAL SENSITIVE PROTECTED	OFFICIAL-PUBLIC OFFICIAL-INTERNAL SENSITIVE PROTECTED	OFFICIAL-PUBLIC	OFFICIAL-PUBLIC	OFFICIAL-PUBLIC
Stored in Australia	✓	✓	✓	✓	✓	✓	Device-dependent	Device-dependent	Plan-dependent
Backup / retention	✓	✓	✓	✓	✓	✓	x	x	Plan-dependent
Syncing with local copy	✓	N/A	✓	✓	✓	✓	N/A	x	Plan-dependent
Internal (within UQ)collaborator access	✓	✓	✓	✓	✓	✓	x	x	Plan-dependent
External collaborator access	✓	x	✓	✓	✓	x	x	x	Plan-dependent
Storage limit	1 TB	Location dependent	100 GB	100GB	1 TB+	Unlimited	Device-dependent	Device-dependent	Plan-dependent
Version control	✓	x	✓	x	x	✓	x	x	Plan-dependent
Recovery from deletion	60 days	60 days	60 days	60 days	60 days	Inbuilt compliance	x	x	Plan-dependent

Griffith

	SharePoint /Teams	Research Drive	Research Space	OneDrive	Research Vault
What data is appropriate?	✓ All	✓ All	✓ All	✓ All	✓ All
What is the storage limit?	25 TB* per site	3* TB	1 TB	1 TB* per user	5 TB*
When should it be used?	⌚ Day-to-day	⌚ Day-to-day	⌚ Day-to-day	⌚ Day-to-day	📅 Long-Term
Does it sync with local copies?	✓ Yes	✗ No	✓ Yes	✓ Yes	⊖ Not Applicable
Does it have version control?	✓ Yes	✗ No	✗ No	✓ Yes	✗ No
Can external collaborators have access?	✓ Yes	✓ Yes*	✓ Yes	✓ Yes	✗ No
Does it support backup & disaster recovery?	✓ Yes	✓ Yes	✓ Yes	✓ Yes	✓ Yes
Is there a way to recover from deletion?	7 Years	30 days	30 days	60 days	⊖ No Data Deletion
Is it stored in Australia?	✓ Yes	✓ Yes	✓ Yes	✓ Yes	✓ Yes
Does Griffith approve the Platform?	✓ Yes	✓ Yes	✓ Yes	✓ Yes	✓ Yes
What is the post-project data retention?	>7 Years	As per ethics requirement	As per ethics requirement	1 Year after person left	As per ethics requirement

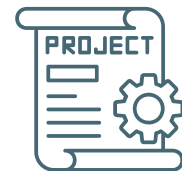
* Requires consultation with eresearch advisory team

**Sharing &
reusing data**

Five Safes



People



Projects



Settings



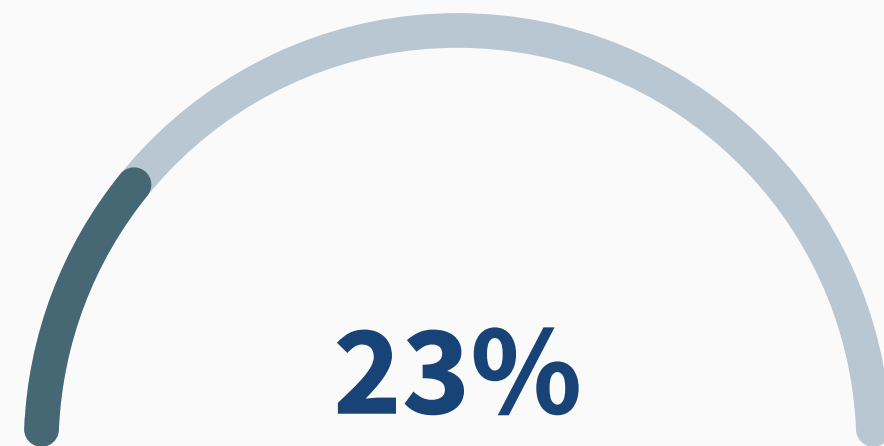
Data



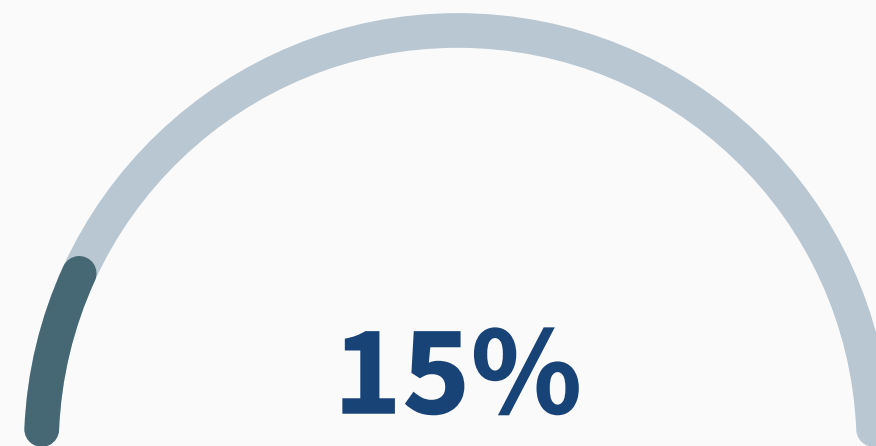
Outputs

Data Sharing

The past 10 years have witnessed a significant growth in sharing of health data .



**Increase in sharing
of health data**



**Increase in health
research data
repositories**



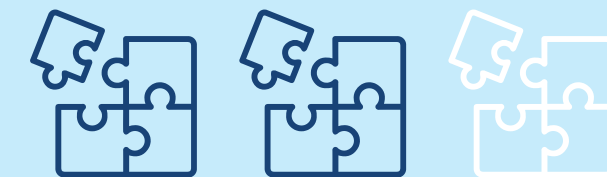
**Clinical trials and
research studies
are being
conducted
worldwide at a
rampant pace
leading to
generation of large
amount of data.**

National clinical quality registry program

\$ \$ \$

40 million

Forty million over 4 years



National strategy

Roadmap for how to collect
and use clinical data to
improve patient care

TRUST



Transparency



Responsibility



User focus



Sustainability



Technology



HeSANDA

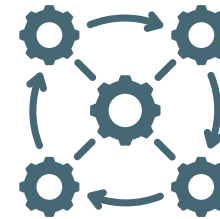
FAIR



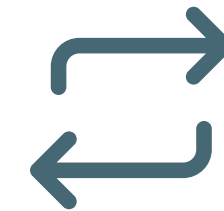
Findable



Accessible



Interoperable



Reusable

EXAMPLES OF RESEARCH DATA BY CLASSIFICATION



Highly Sensitive	Sensitive	Private	Public
<ul style="list-style-type: none"> data containing identifiable personal health/medical information personal data about participants from cultural or ethnic groups (e.g., Aboriginal and Torres Strait Islander peoples) interviews, and/or video recordings involving children data involving participants with disabilities data relating to people living under politically unstable regimes, and/or war zones any password information 	<ul style="list-style-type: none"> non-identifiable/re-identifiable health/medical information data with identifiable personal information (e.g., address and phone details) data relating to UNSW systems and security (e.g., network and access logs) 	<ul style="list-style-type: none"> drafts of research papers laboratory instrumental data (e.g., microscopy images, and spectra) student-related information that does not contain identifiable personal information certain types of blueprints and building plans internal university data (e.g., telephone communication logs) 	<ul style="list-style-type: none"> publicly available third party datasets open or published data

GOOD DATA MANAGEMENT

IS GOOD RESEARCH

OneDrive is a UNSW-supported research data storage platform for the above data classifications
For more information, go to <https://research.unsw.edu.au/research-data-management-unsw>

Ver. Aug 2019

Data classification

Retention Periods for Research Data

CATEGORY	EXAMPLES Data & Datasets	Retention Period
A	<ul style="list-style-type: none"> that are controversial that are the subject of extensive debate arousing widespread scientific or other interest having the potential to cause major adverse impacts on the environment, society or human health involving eminent researchers involving the use of major new or innovative technique relating to the acquisition or donation, care, storage, maintenance, management and disposal of anatomy or specimens. 	Permanent
B	<ul style="list-style-type: none"> from clinical trials 	Minimum 15 Years after completion of clinical research/trial AND Minimum 10 Years after last patient service provision or medico-legal action
C	<ul style="list-style-type: none"> records relating to the acquisition, management, maintenance and care of animals resulting in patent 	Minimum 7 years after last action or after expiry of patent
D	<ul style="list-style-type: none"> General research data not covered by Category A, B or C 	Minimum 5 years after last action
E	<ul style="list-style-type: none"> For assessment purposes only (Reference 601.3/C91) Not covered by Category A, B, C or D 	Minimum 1 year * after last action
		*Aligned to the QLD State Archives University Sector Retention and Disposal Schedule 2014 - Section 8, Page 36 onwards

Griffith University's Schedule of Retention Periods for Research Data and Primary Materials
 Research Data Retention Guide | October 2023

Data retention

Consumers in Research

Roles and responsibilities



Data access



Sharing

Agreements.
Secure file transfer



Repositories

Institutional.
Discipline specific.
National/International



Archiving

What about when the
project ends?

Summary

- Take time to think
- Plan your plan
- Talk to all your stakeholders and consider their needs
- Look at policies and legislation

**What was one thing you
didn't know that you
learned today?**

What is one thing your learned today?

Lots of resources
available

Great overview of good
data governance
principles

Tips for data
management plan

Onboarding and
offboarding

Im a little concerned
about Consumer data
privacy

Data management plans
are essential

Take your time

Resources available to
support good
governance practice

What is one thing your learned today?

The FAIR principles

There are many other ways that data can be breached

vulnerable species data bring sensitive

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Acronyms (that are useful)

Importance of Data management plan

On/off boarding

Resources for data management

What is one thing your learned today?

Doing the DMP, I better
get to it!

Data Management bits
and pieces

Data management plan
details

Increase sharing of data
sharing .. and .. thoughts on
breaches associated with
sharing of email addresses

QUESTIONS?