Management of Data and Information in Research

Telethon Kids Institute's Approach

Rad Aniba

Head Of Data Strategy and Governance

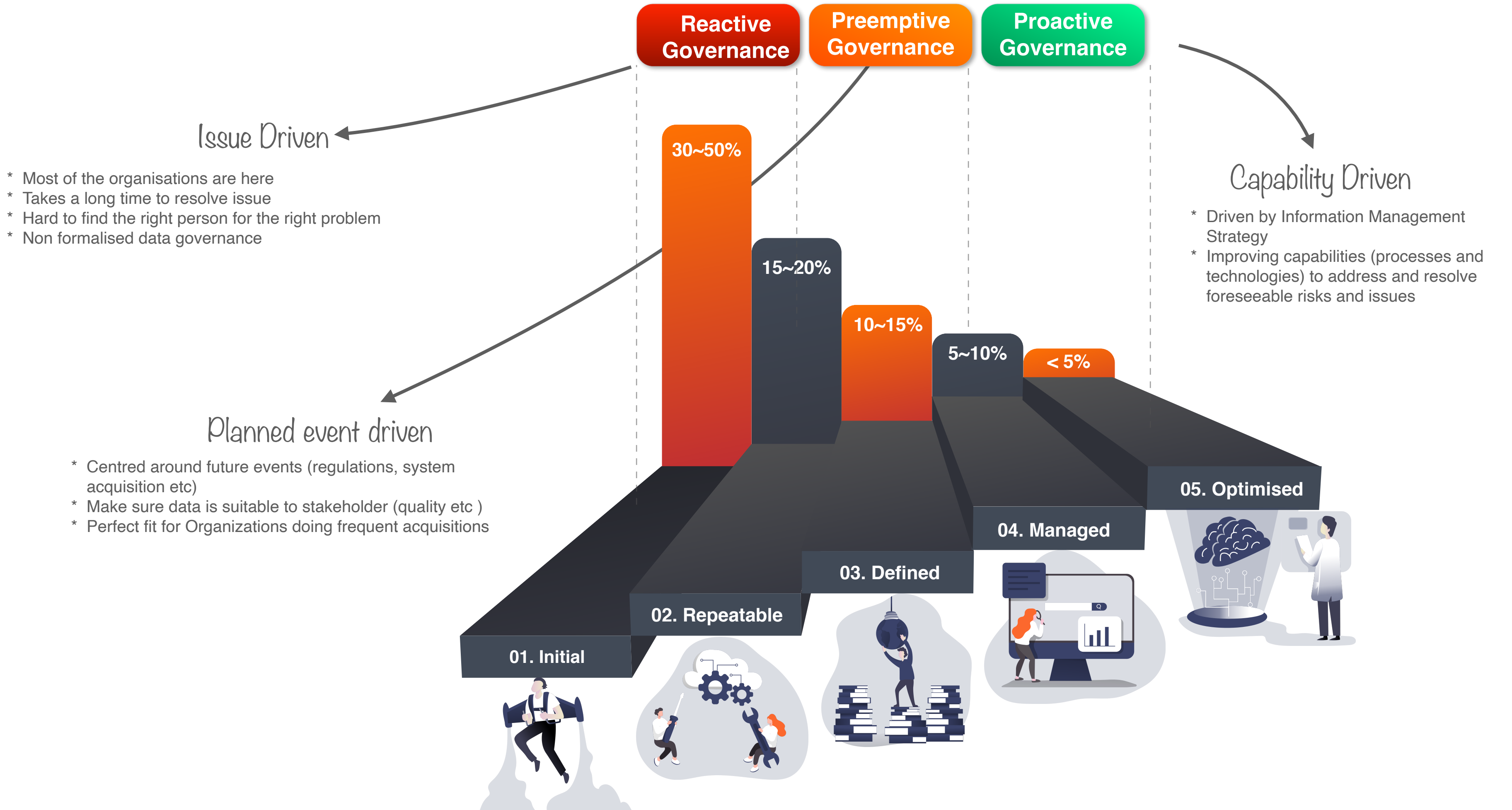Telethon Kids Institute

rad.aniba@telethonkids.org.au

Tara McLaren

Head Of Research Development

Telethon Kids Institute

tara.mclaren@telethonkids.org.au

TELETHON KIDS INSTITUTE

Data Maturity Model: Moving the needle ...

| Reactive Governance | Preemptive Governance | Proactive Governance |

Issue Driven
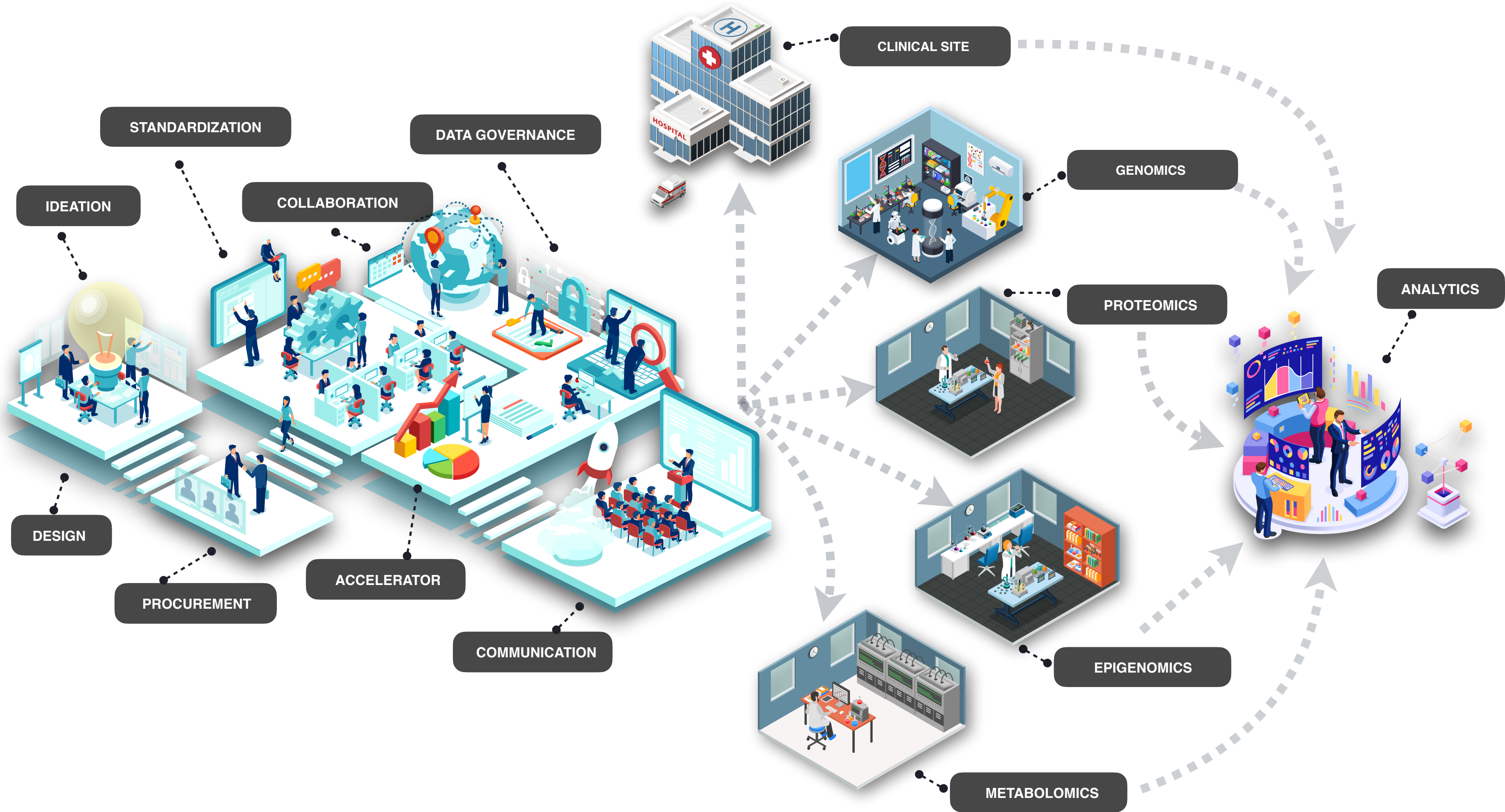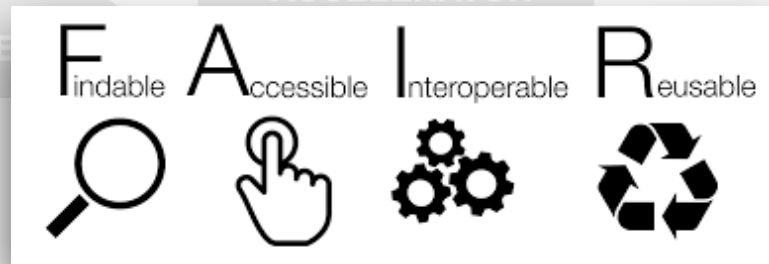
* Most of the organisations are here
* Takes a long time to resolve issue
* Hard to find the right person for the right problem
* Non formalised data governance

Capability Driven

* Driven by Information Management Strategy
* Improving capabilities (processes and technologies) to address and resolve foreseeable risks and issues

30~50%

15~20%

10~15%

5~10%

< 5%

Planned event driven

* Centred around future events (regulations, system acquisition etc)
* Make sure data is suitable to stakeholder (quality etc)
* Perfect fit for Organizations doing frequent acquisitions

05. Optimised

04. Managed

03. Defined

02. Repeatable

01. Initial

CLINICAL SITE

STANDARDIZATION

DATA GOVERNANCE

IDEATION

COLLABORATION

GENOMICS

PROTEOMICS

ANALYTICS

DESIGN

PROCUREMENT

ACCELERATOR

COMMUNICATION

EPIGENOMICS

METABOLOMICS

STANDARDI...

IDEATION

DESIGN

PROCUREM...

ACCELERATOR

...ICATION

CLINICAL SITE

GENOMICS

PROTEOMICS

ANALYTICS

EPIGENOMICS

METABOLOMICS

2
Data
Strategy

3
Data
Governance

1
Data
Principles

Findable Accessible Interoperable Reusable

COMPLIANCE

RULES

Principles of responsible research conduct

P1 Honesty in the development, undertaking and reporting of research • Present information truthfully and accurately in proposing, conducting and reporting research	**P2 Rigour** in the development, undertaking and reporting of research • Underpin research by attention to detail and robust methodology, avoiding or acknowledging biases.	**P3 Transparency** in declaring interests and reporting research methodology, data and findings • Share and communicate research methodology, data and findings openly, responsibly and accurately. • Disclose and manage conflicts of interest	**P4 Fairness** in the treatment of others • Treat fellow researchers and others involved in the research fairly and with respect. • Appropriately reference and cite the work of others. • Give credit, including authorship where appropriate, to those who have contributed to the research.
P5 Respect for research participants, the wider community, animals and the environment • Treat human participants and communities that are affected by the research with care and respect, giving appropriate consideration to the needs of minority groups or vulnerable people. …	**P6 Recognition** of the right of Aboriginal and Torres Strait Islander peoples to be engaged in research that affects or is of particular significance to them • Recognise, value and respect the diversity, heritage, knowledge, cultural property and connection to land of Aboriginal and Torres Strait Islander peoples. …	**P7 Accountability** for the development, undertaking and reporting of research • Comply with relevant legislation, policies and guidelines. • Ensure good stewardship of public resources used to conduct research. • Consider the consequences and outcomes of research prior to its communication.	**P8 Promotion** of responsible research practices • Promote and foster a research culture and environment that supports the responsible conduct of research.

Principles of responsible research conduct

FAIR Standards

P1 Honesty in the development, undertaking and reporting of research

• Present information truthfully and accurately in proposing, conducting and reporting research

F A I R

P2 Rigour in the development, undertaking and reporting of research

• Underpin research by attention to detail and robust methodology, avoiding or acknowledging biases.

F A I R S

P3 Transparency in declaring interests and reporting research methodology, data and findings

• Share and communicate research methodology, data and findings openly, responsibly and accurately.
• Disclose and manage conflicts of interest

F A S

P4 Fairness in the treatment of others

• Treat fellow researchers and others involved in the research fairly and with respect.
• Appropriately reference and cite the work of others.
• Give credit, including authorship where appropriate, to those who have contributed to the research.

F A R

P5 Respect for research participants, the wider community, animals and the environment

• Treat human participants and communities that are affected by the research with care and respect, giving appropriate consideration to the needs of minority groups or vulnerable people. …

F A S

P6 Recognition of the right of Aboriginal and Torres Strait Islander peoples to be engaged in research that affects or is of particular significance to them

• Recognise, value and respect the diversity, heritage, knowledge, cultural property and connection to land of Aboriginal and Torres Strait Islander peoples.
…

F A I R S

P7 Accountability for the development, undertaking and reporting of research

• Comply with relevant legislation, policies and guidelines.
• Ensure good stewardship of public resources used to conduct research.
• Consider the consequences and outcomes of research prior to its communication.

F A I S

P8 Promotion of responsible research practices

• Promote and foster a research culture and environment that supports the responsible conduct of research.

A S

F Findable

A Accessible

I Interoperable

R Reusable

S Secured

Responsibilities for Institutions

Recommendations	Telethon Kids Implementations
Provision of training for researchers	• Raising awareness about a better data management • Workshops and training on data management and security • Investment in Online training platforms and continuous education (Linkedin, Moocs etc)
Ownership, stewardship and control of research data and primary materials	• Project based strategy to create data stewards roles • Data stewardship platform, continuous follow up with extensive data management plans versioning • Data policies revisions according to the latest data policies and regulations
Storage, retention and disposal	• Data management and Information Management mapping (synergy) • Implement of controls to ensure the confidentiality, availability, and integrity of assets from threats and vulnerabilities (ISMS • framework implemented by ICT and backed by Data Governance) (The S component in FAIRS)
Safety, security and confidentiality	• Investment in technologies for effective data encryption and protection • Embedding data governance within our platform (gradual implementation of automated data governance) • Working backwards with project investigators and data stewards to revise and update consent forms to ensure compliance
Access by interested parties	• Extensive library of data sharing agreements to ensure data is shared and is accessible and in compliance with the conventions and contracts in place • Excellent partnership between the Legal team, the procurement team, data governance team and researchers • Extensive reviews of contracts and solid contract management
Facilities	• Effective data storage based on the scientific context (including on-premise Data Centres, Cloud Storage if necessary) • Continuous improvement of our data policies and procedures for data handling

Responsibilities for Researchers

Recommendations	Telethon Kids Implementations
Retention and publication	• Currently have an information and data retention & disposal policy • Creative Commons Attribution licence • Publishing or making research data available through data centres, national and international collections, or through online repositories maintained by institutions and research communities is encouraged
Managing confidential and other sensitive information	• Project based strategy to create data stewardship roles • Data stewardship platform, continuous follow up with extensive data management plans versioning • Data policies – with regular revisions according to the latest local, national and international data policies, guidelines and regulations
Acknowledging the use of others' data	• Publishers can contribute to an increase data quality and reproducible research by promoting transparency and openness, especially through open access publishing • "CRediT" (Contributor Roles Taxonomy) supported
Engagement with relevant training	• Currently employ a range of carrot and stick approaches

Breaches of the Code

*Research misconduct

Minor/less serious breach

Major/serious breach, or repeated breaches

Responsible conduct

- Building a strong voice safety culture to allow for concerns to be raised.
- Reviewing the roles and responsibilities of those involved in the management and investigation of potential breaches of the Code and ensuring that these are communicated to researchers.
- Ensuring processes for receiving and managing concerns and complaints are well defined and available on intern and external website.
- Currently reviewing our processes for managing CoI.

The Blueprint

A phased approach that is focusing on incremental disruptive but non invasive change

Data Governance

Definition of the rules and the legal framework to protect the Organization and the research community and increase compliance
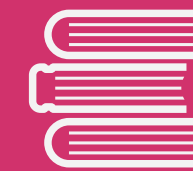
Data Integration

Simplify the daunting task of data integration and reduce siloed and isolated datasets. Integration is key to an effective data driven research
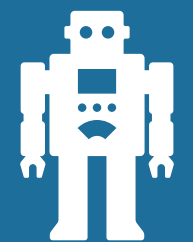
Data Tracking and Analysis

Traceability and Lineage are fundamental ingredients to research reproducibility

Data Cataloging and Streamlining

Data should be accessible to anyone within the Organization to increase collaborative work and awareness.

Advanced Data Analytics and AI

Leveraging AI capabilities to optimise processes, diversify research and reach strategic goals