SEQ FIRST NATIONS HEALTH EQUITY

IN ACTION CONFERENCE

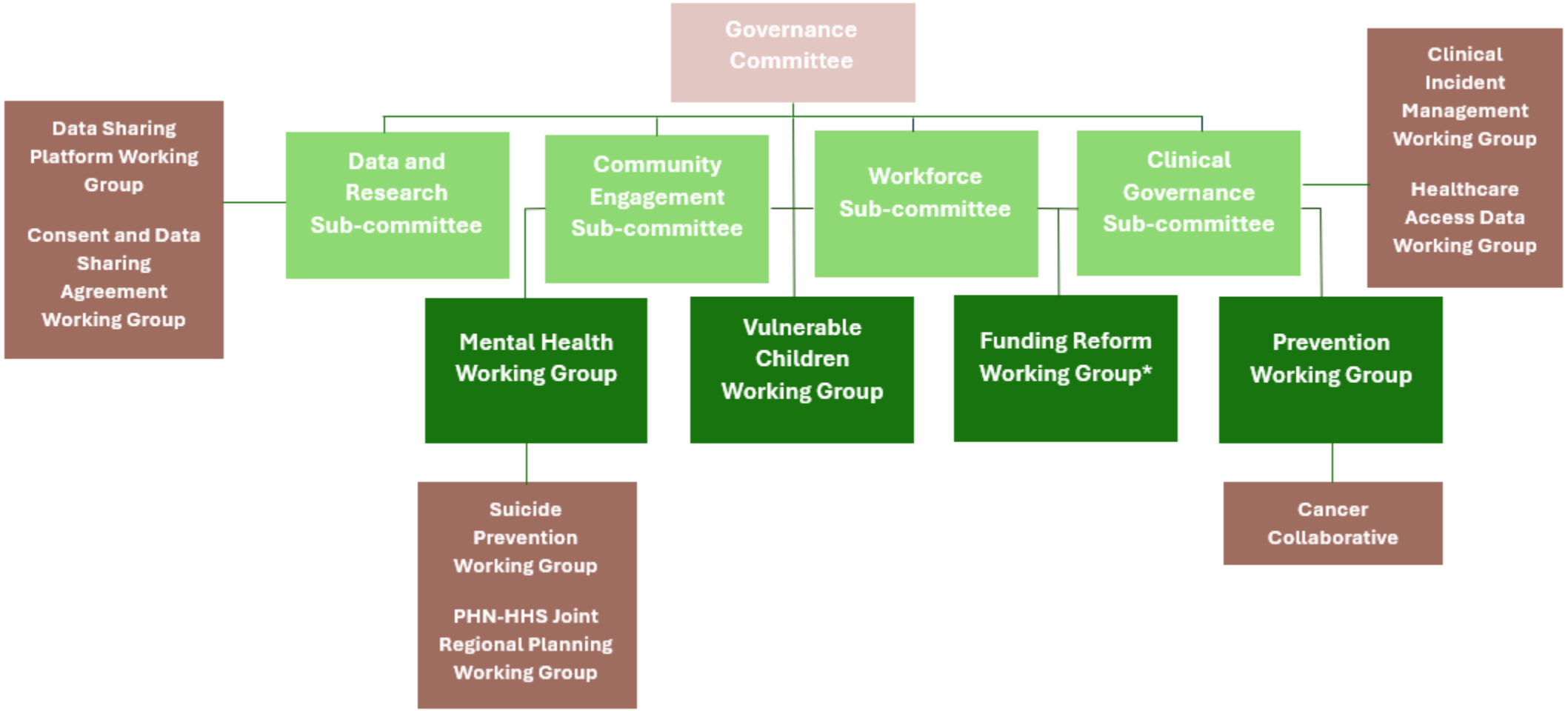
Championing Indigenous Data Sovereignty for Health Equity

Key Priority Areas

SEQ First Nations Health Equity Strategy Key Priority Areas

- **KPA1 Cultural Safety:** Actively eliminating racial discrimination and institutional racism within services.
- **KPA2 Access:** Increasing access to healthcare services.
- **KPA3 Determinants:** Influencing the social, cultural, and economic determinants of health.
- **KPA4 Delivering Quality Healthcare:** Delivering sustainable, culturally safe, and responsive healthcare services.
- **KPA5 Service Delivery Partnerships:** Working with First Nations people, communities, and organisations to design, deliver, monitor, and review health services.
- **KPA6 A Strong and Capable Workforce:** Strengthening the First Nations health workforce.

Governance


Governance Committee
Data Sharing Platform Working Group
Consent and Data Sharing Agreement Working Group
Data and Research Sub-committee
Community Engagement Sub-committee
Workforce Sub-committee
Clinical Governance Sub-committee
Clinical Incident Management Working Group
Healthcare Access Data Working Group
Mental Health Working Group
Vulnerable Children Working Group
Funding Reform Working Group*
Prevention Working Group
Suicide Prevention Working Group
PHN-HHS Joint Regional Planning Working Group
Cancer Collaborative

Setting the scene

- IDS = buzzword

Our yarns with Community

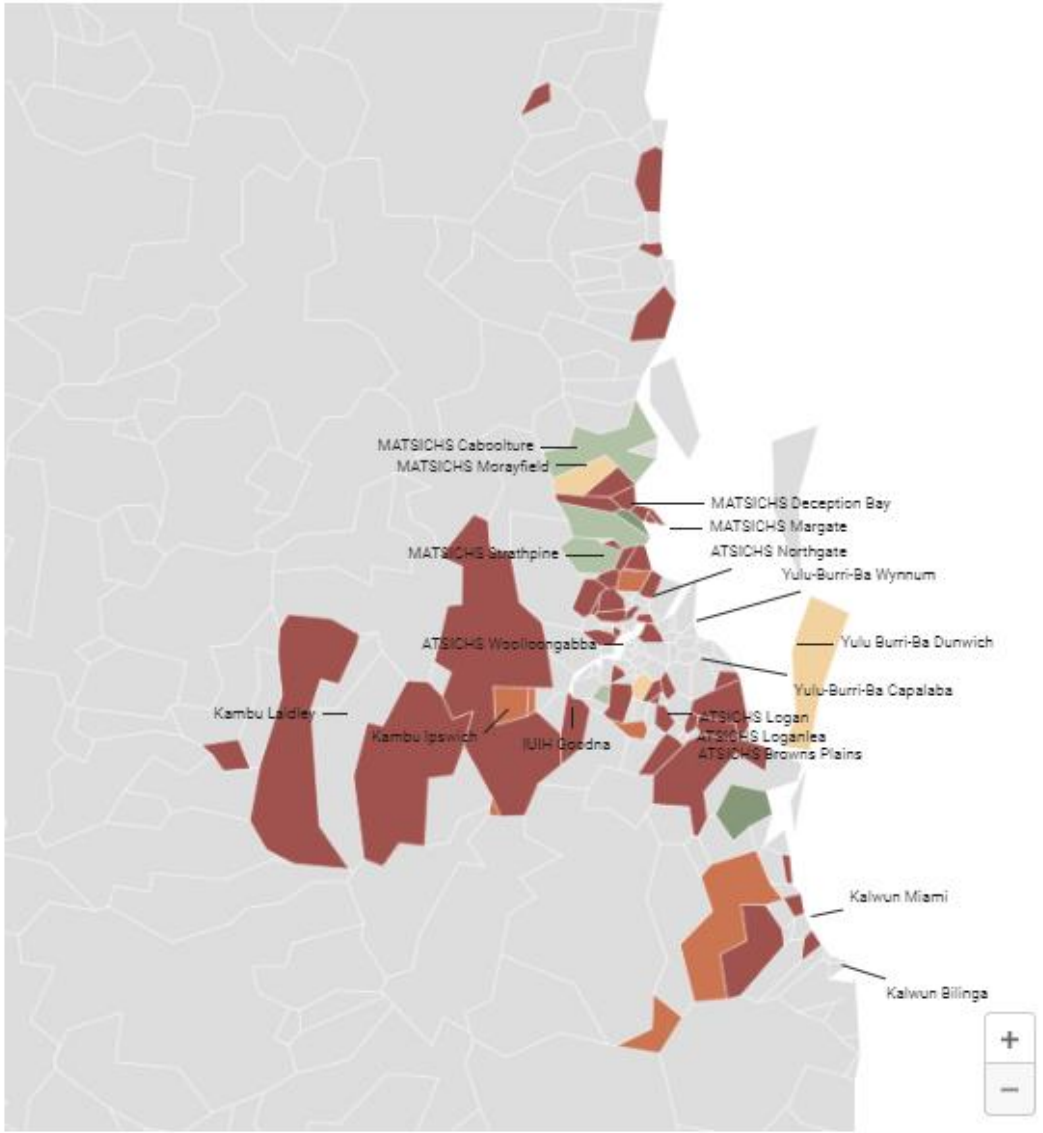
- 2024 QMC-JMC
  - Yarned with 180 different Mob who came from all over Qld
    - 108 particularly about IDS
  - Awareness, usage, trust and custodianship

IUIH Regional Community Engagement - Southeast Queensland inc. Sunshine Coast

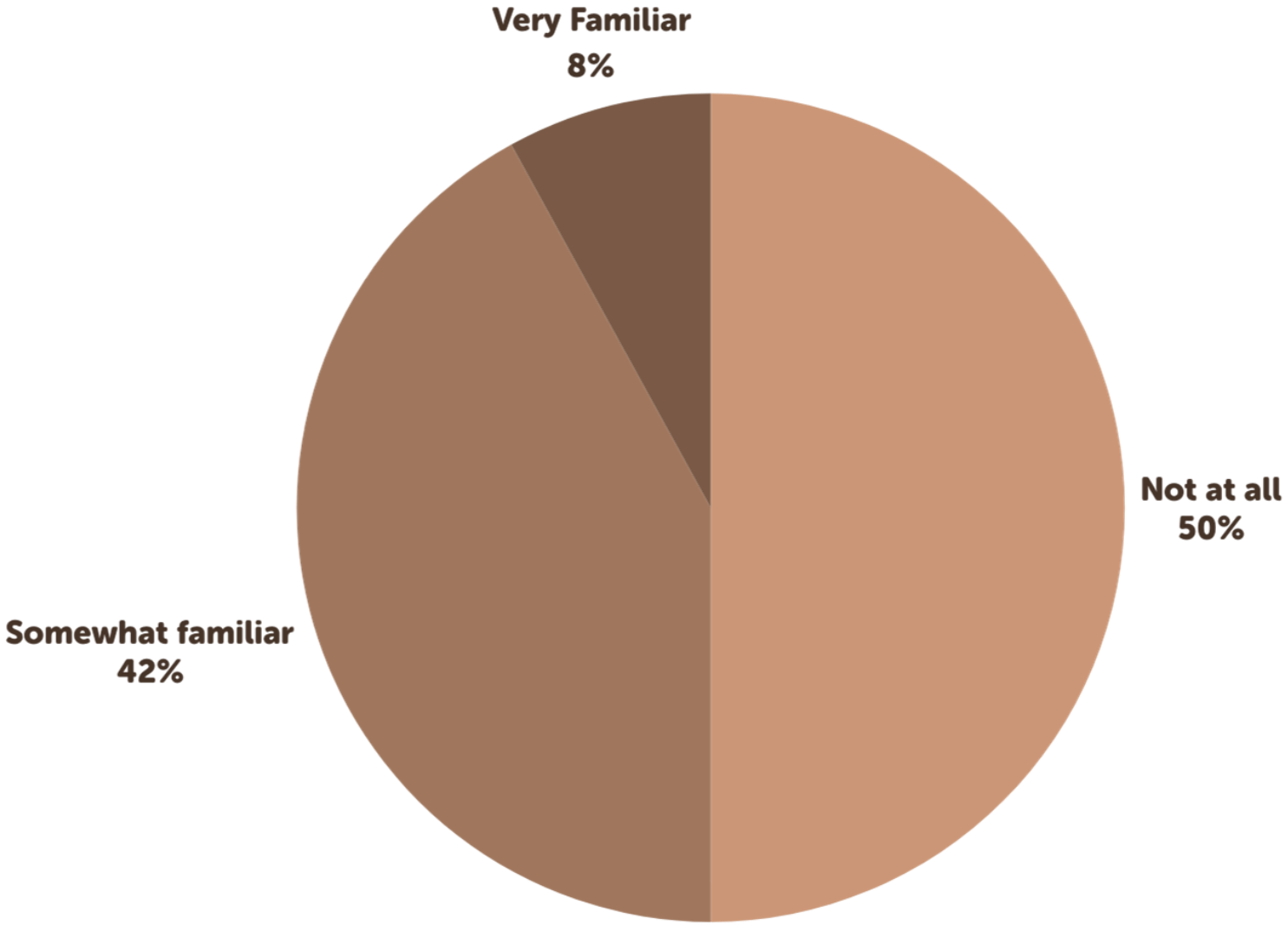
Residential Postcode of Mob yarned with during the 2024 Qld Murri and Junior Murri Carnivals 20-27/09/2024.

*Number of yarnees (n=116)

2.2 3.4 4.6 5.8



What did they say?



Data Governance and Custodianship

19%

Academic Institutions

74%

Aboriginal Community Controlled Organisations

63%

Elders and Traditional Owners

12%

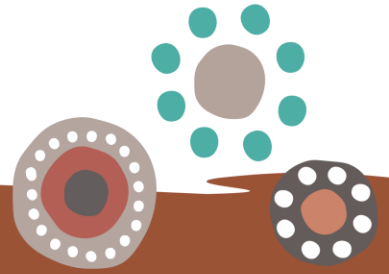
Government Institutions

24%

Individuals*

Questions for us and how we should be championing IDS?

- Education and awareness campaigns
- Engagement with community
- Invest in *PROPA* Governance Frameworks
- Empower community agency
- Ensure data privacy and protection
- Partnership and Advocacy



SEQ FIRST NATIONS HEALTH EQUITY

IN ACTION CONFERENCE

Queensland's design phase for the National Primary and Acute Care Data Linkage Project

An Overview

Trisha Johnston

Director, Statistical Analysis and Linkage

Queensland Health

1. Background and context

Problem statement:

In Australia, health services data is collected and managed by various government levels and private organisations with little data sharing or linkage. **This creates a fragmented view of patient journeys** between primary and acute care services **making it difficult to gain a comprehensive understanding of healthcare across the system**.

Proposed solution:

The National Primary and Acute Care Data linkage project seeks to establish a national health data-sharing system that spans across both primary and acute care, providing deeper insights into patterns of service access and outcomes across the health system. The core objective of this integrated data system is to drive improvements in population health planning, service delivery, and patient outcomes at various levels — including individual practices, PHNs, ATSICCHOs, jurisdictional health departments, and national strategic priorities.

Key features of the **design phase** include:

- a national approach that enables cross-jurisdictional and federal-state sharing of data.
- a '**hub and spoke**' approach, where jurisdictions can engage locally to design an approach that is adaptable to their local context (**'spokes'**), while meeting national needs (**'hub'**).

1. Background and context

Why this is important:

‘We will be able to demonstrate what is being done at the moment in primary care is having an impact. At the moment it is deficit-based but we can change that **to see the way things are being done that are improving the system and let us focus on doing that more**.’

‘I would like to be able to show how my patient’s status and my patient population compares with the local and state **benchmarks**.’

‘We would like to leverage data to show gaps in First Nations services and **advocate for appropriate funding in response to health deficits**.’

‘We can understand if patients are seeing their GP after they are discharged from hospital and what impact this has. For example, we can understand who benefits from seeing a GP within 24 hours vs 2 weeks vs 6 months and **refine the discharge plan** depending on patient risk. We can’t do this kind of thing at the moment.’

‘…this can be about big data algorithms where once we connect primary and acute care data, we can fine-tune the algorithms and **target the intervention that works for particular cohorts and to those at risk.** We can demonstrate that **when you put targeted insights to GPs and Nurses in primary care, they can put that to use**’

1. Background and context

Why this is important:

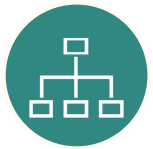
- **Targeting treatments:** using linked data to identify what works best for patients based on diagnosis and risk factors and **designing services across the care pathway** to optimise treatments and outcomes.
- **Population Health Planning and Service Improvement:** Deliver an improved health system by Identifying population health needs and addressing deficits across the care continuum.
- **Service Evaluation and Quality Improvement:** identify excellence in care models and service delivery to improve patient outcomes across the continuum.
- **System Navigation and Decision Making:** access to data for better decision making and comprehensive insights into patient health journeys and service utilisation.
- **First Nations Outcomes:** leverage data to show gaps in First Nations services and advocate for appropriate funding in response to health deficits.
- **Resource allocation and efficiency:** allocating funds to areas of high and unique health needs and funding services that work – providing evidence to break down service funding silos.
- **System and Culture Change**: influence a healthcare system that engenders efficient flow of data for patients' benefit.

2. Project Design Domains

The design phase for the Project will focus on five key design domains.

The five key design domains include:

Scope
(e.g. identifying the priority services, datasets, specifications, standards, potential to leverage existing assets)



Data sharing governance
(e.g. defining how data will be managed, shared and governed across jurisdictions, oversight over reporting and sovereignty)

Privacy and legal
(e.g. ensuring legal compliance and safeguarding privacy across all data sharing activities, identifying legal barriers, ethics requirement and privacy assessment)

Data management and technology
(e.g. exploring technical solutions and infrastructure for extraction, transfer and storage, Privacy Preserving Record Linkage, multi-way sharing, systems for secure data access)

Funding and implementation
(e.g. costs of building the data linkage infrastructure and management, user interface, building a business case)

3. Project Objectives and scope

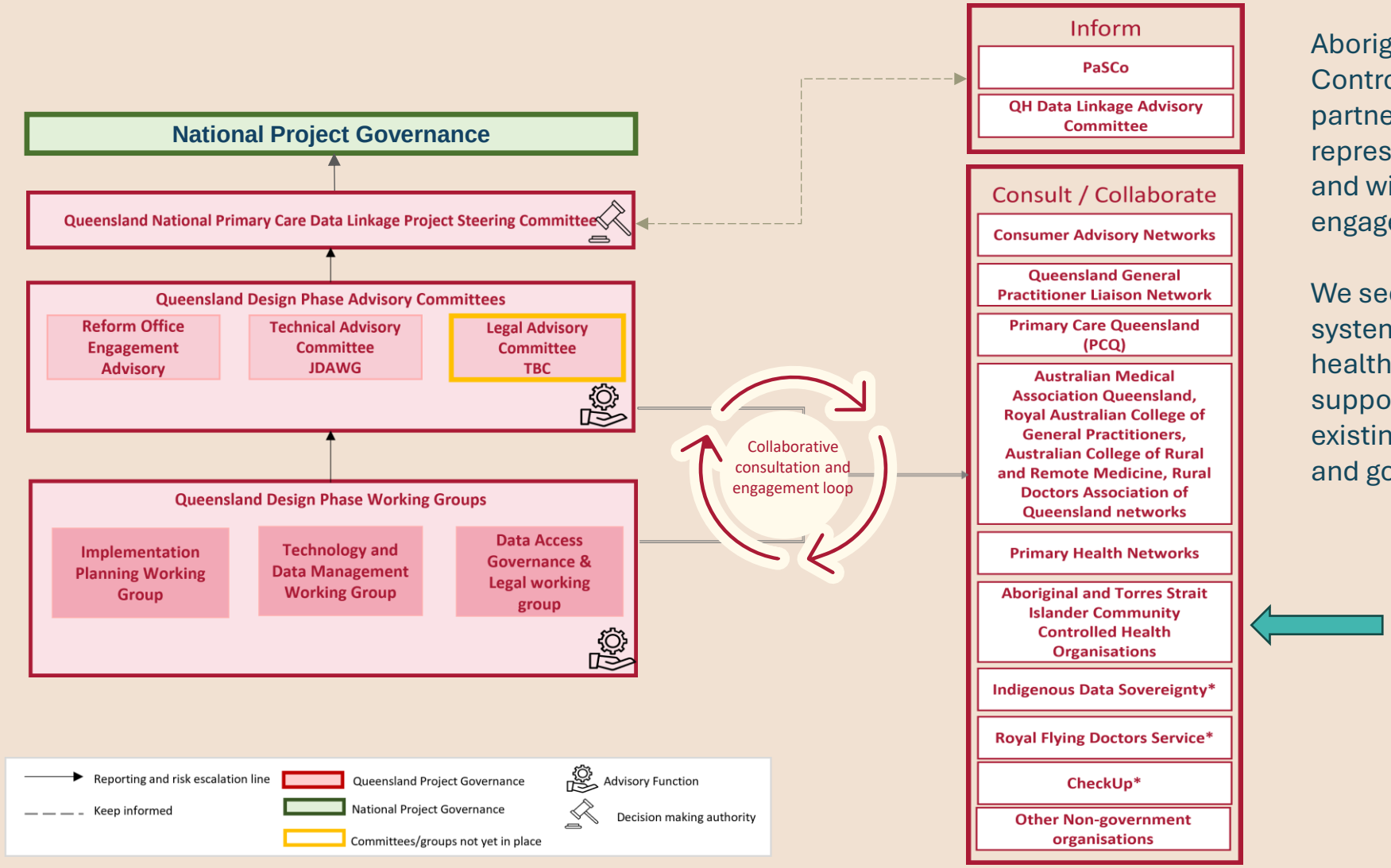
Objectives:

1. Establish data sharing and linkage to better understand patient flows and outcomes across the health system.
2. Design a system that provides value for state and territory stakeholders (individual practices, PHNs, ATSICCHOs, jurisdictional health departments) while meeting national needs.

Scope:

In-Scope	Out of Scope
Engagement and collaborative design across project domains (scope, governance, privacy, legal, technical), costing for implementation, business case to seek funding	Implementation of the design
System and service planning, improvement and population health use cases	Linkage and system interoperability for direct patient care
Privacy Preserving Record Linkage (PPRL) at the patient level	Linkage of identifiable patient data

4. Governance – Queensland's Design Phase for the National Primary and Acute Care Data Linkage Project

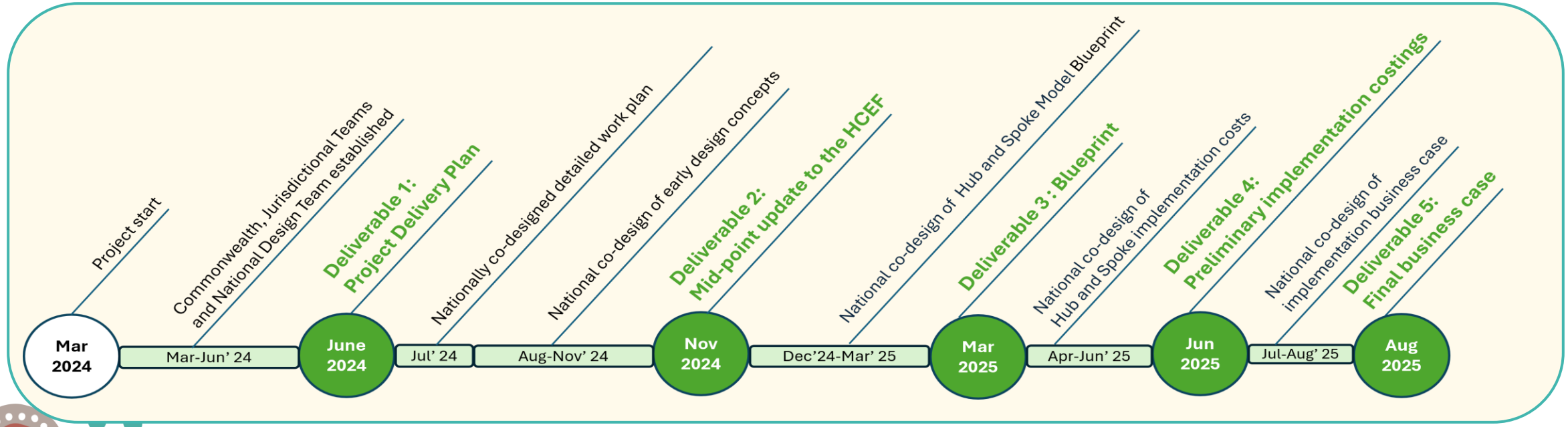


Aboriginal and Torres Straight Islander Community Controlled Health Organisations are crucial partners in shaping the project. ATSICCHOs are represented on the project Steering Committee and within the collaborative consultation and engagement loop.

We see this project as an opportunity to design a system collaboratively that will provide value for health services and the people services are supporting. We are seeking to identify and build on existing models and processes – both technical and governance.

5. Deliverables

- The timeline below outlines the key deliverables for the project, from initiation through to the final business case submission in August 2025.
- It highlights major milestones, including co-design stages, where service providers will play a major role, ensuring a collaborative and structured approach to project delivery



6. Next steps

Queensland will feed into the national project with jurisdiction-specific components. The key next steps to achieve this are:

- **Stakeholder engagement** to identify existing data and models and to understand what will add value for different stakeholders in Queensland
- Development of a high-level **design blueprint**
- Development of a **Business Case to seek funding for implementation**

For more information, or to engage further with Queensland's design phase for the National Primary and Acute Care Data Linkage Project, please contact Halima Akanbi via qld_pcp@health.qld.gov.au

Website: https://www.health.qld.gov.au/hsu/qld-primary-care-project

SEQ FIRST NATIONS HEALTH EQUITY IN ACTION CONFERENCE

Research Alliance for Urban Goorie Health (RAUGH)

A research collaboration aimed at achieving health equity for First Nations peoples in SEQ

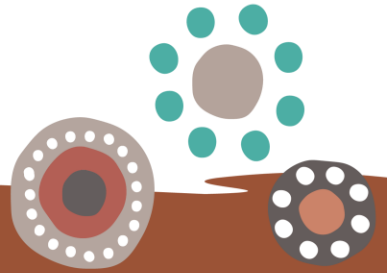
Professor James Ward

Executive Director, Research Alliance for Urban Goorie Health

Director, UQ Poche Centre for Indigenous Health

Research Alliance for Urban Goorie Health (RAUGH) Partnership

1. Institute for Urban Indigenous Health (IUIH)
2. Metro North Hospital and Health Service
3. Poche Centre for Indigenous Health (UQ)
4. Queensland Health



UQ Poche Centre for Indigenous Health

IUIH institute for urban indigenous health

RAUGH
The Research Alliance for Urban Goori Health

Metro North Hospital and Health Service

Queensland Government

Research Alliance for Urban Goorie Health Objectives

A key objective of RAUGH is to understand the whole healthcare system rather than a single service provider, in this case healthcare pathways between primary and tertiary care for Indigenous people.

RAUGH also evaluates current service delivery models, co-designs new services, programs and policies, builds workforce capacity, and ultimately accelerates progress towards achieving health equity and improved health outcomes for urban Indigenous peoples.

RAUGH Establishment Phase-October 2021

- Priority areas workshop November 2021 (HiTH, COVID, Cancer, Rehab programs, Mental health)
- Officially launched May 2022
- Roundtables (Cancer, Mental Health, Indigenous Data Sovereignty)
- Consultations (HTQ, H&WBQLD, Child Health, STARS)
- RAUGH Strategic Plan
- Website development
- Governance Groups established
- Two PhD students, one Master's thesis, three honours

Research Grants submitted and funded under RAUGH Collaboration

- ✓ CRE Urban First Nations Health (NHMRC)
- ✓ Mental Health Care Pathways (MRFF)
- ✓ Anti-racism intervention at Caboolture (MRFF)

RAUGH Seed Grants

1. Models of Integrated Primary, Secondary and Tertiary Care – Effective partnerships to address health equity for First Nations People - Dr Katrina Campbell, Prof Roxanne Bainbridge, Dr Halina Clare
2. A conceptual model of integrated care pathways between primary and tertiary mental health care - Dr Katrina Campbell, Prof Roxanne Bainbridge, Dr Halina Clare
3. Unmet needs in prostate cancer care for Indigenous men and their communities- Dr Natasha Roberts, Professor Gail Garvey
4. Laying the foundations for a whole-of health-care-system approach to addressing inequities in bowel cancer outcomes for First Nations people in Metro North- Dr Mark

RAUGH Data Linkage Study

UQ Poche Centre for Indigenous Health

IUIH institute for urban indigenous health

RAUGH The Research Alliance for Urban Goori Health

Metro North Hospital and Health Service

Queensland Government

Study Aims

Primary Aims

1. To link the IUIH (Moreton ATSICHS and selected services of ATSICHS Brisbane) clients' health records with Metro North Health data.

2. To identify and link Indigenous health clients' data of Metro North Health who are not clients of IUIH and ATSICHS Brisbane.

3. To establish, monitor and evaluate an Indigenous-led governance system to enact Indigenous Data Sovereignty.

Study Methods

Methods	Features	
Study Design	Retrospective Cohort Study	
Data Collection	Primary Care Service	1.Moreton ATSICHS 2.Selected services of ATSICHS Brisbane (including Northgate and Woolloongabba only)
	Tertiary Care Service: 11 Data Sources of Metro North Hospital and Health Service including	1.Caboolture Hospital 2.Community 3.Kilcoy Hospital 4.Mental Health 5.Oral Health 6.Public Health 7.Redcliffe Hospital 8.Royal Brisbane and Women's Hospital 9.Surgical, Treatment & Rehabilitation Service (STARS) 10.The Prince Charles Hospital 11.Other
Timeline	1 January 2010 – 31 December 2022	

Study Methods

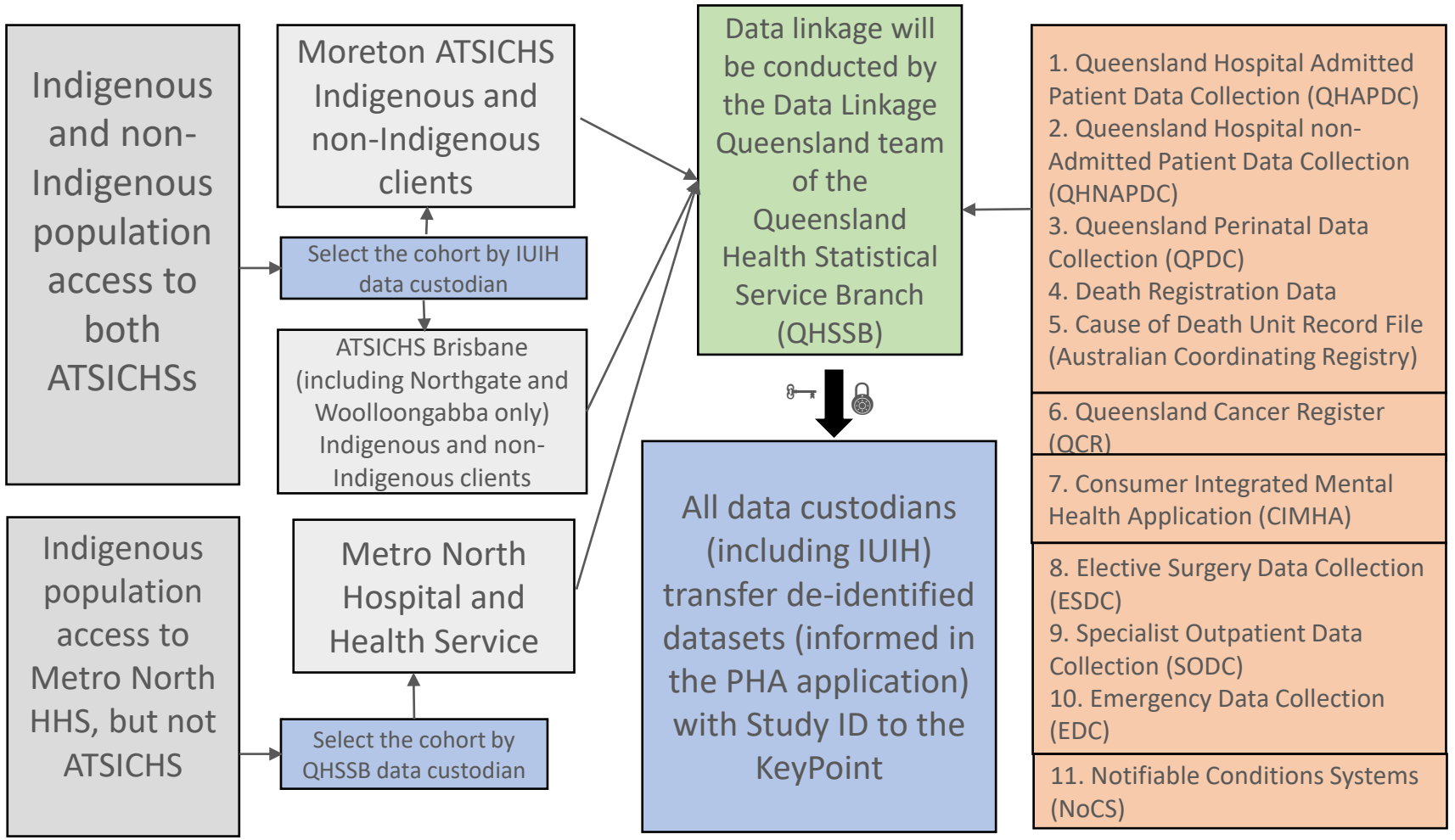
IUIH data to be linked with Metro North Health Data Sources		
QHSSB as Data Custodian	**External Data Custodian**	
1. Cause of Death Unit Record File 2. Death Registration data 3. Queensland Hospital Admitted Patient Data Collection 4. Queensland Hospital Non-admitted Patient Data Collection 5. Queensland Perinatal Data Collection	6. Specialist Outpatient Data Collection 7. Elective Surgery Data Collection 8. Emergency Department Collection	10.Notifiable Conditions Systems
	9. Consumer Integrated Mental Health Application	11.Queensland Cancer Registry

Study Methods

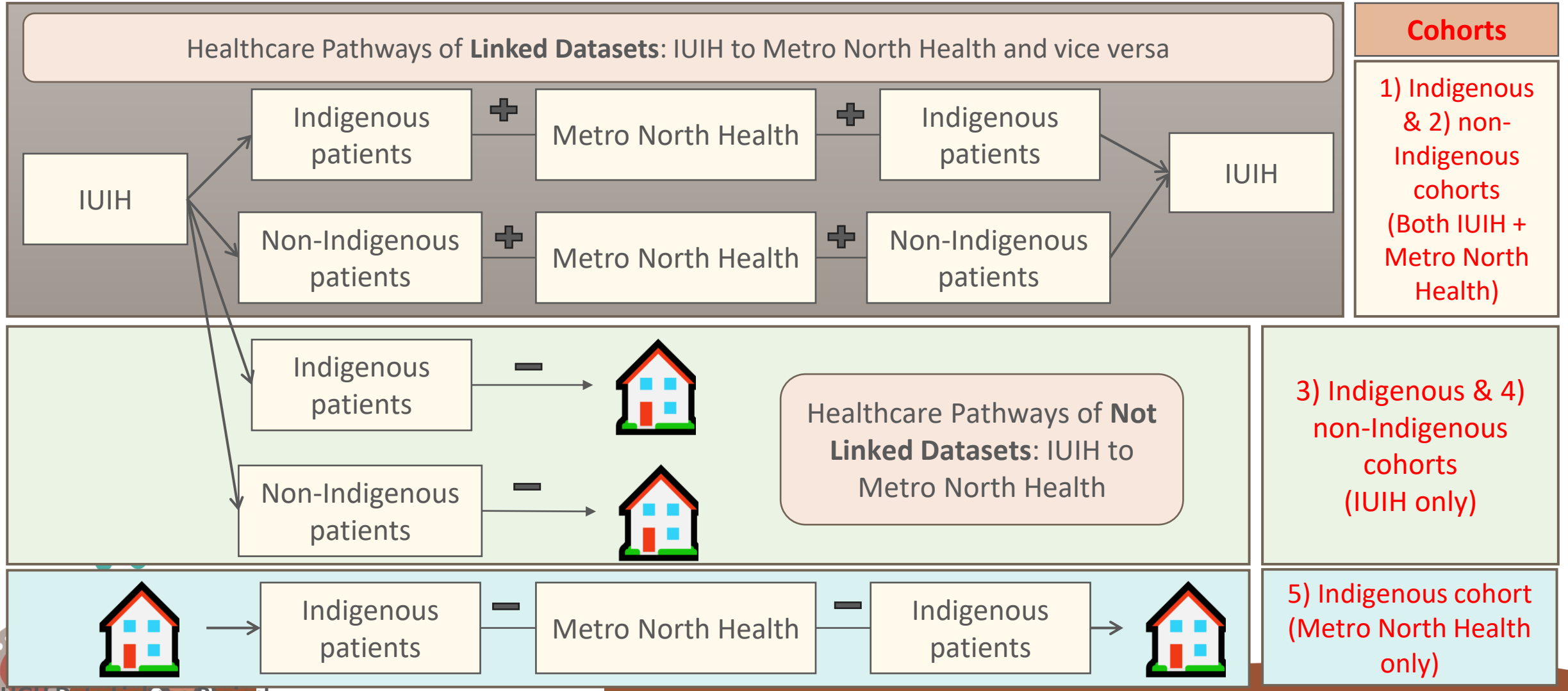
Data Linkage Methods

IUIH Cohorts data		Metro North Health Cohorts data		QHSSB
Study ID First name Middle name(s) Surname Sex Date of birth Address Postcode	+	Project/Facility ID/URN First name Middle name(s) Surname Sex Date of birth Address Postcode	→	Project-specific ID Linked output Demographic data Clinical data

Primary outcomes: Data linkage pathways



Secondary outcomes: Healthcare Pathways



Indigenous Data Governance Plan

UQ Poche Centre for Indigenous Health

IUIH institute for urban indigenous health

RAUGH The Research Alliance for Urban Goori Health

Metro North Hospital and Health Service

Queensland Government

Indigenous Data Governance Principles

CARE	Collective benefit, Authority to Control, Responsibility, and Ethics
FAIR	Findable, Accessible, Interoperable, Reusable
OCAP	ownership, control, access and possession

Proposed Governance Groups

RAUGH Indigenous Governance Group

Assesses applications for analysis

Manages storage of data, vault manager ingress, egress managers of KeyPoint

IUIH (4 members), Poche and MNH (2 members each)

Aboriginal and TSI members only

Review outcomes of analysis and any output

RAUGH Investigator Group

Named investigators approved by the ethics committee

Meets frequently throughout to ensure the project is on track and progressing as per ethics and protocol

Ensures resourcing for project

Reporting requirements

Organisational Governance Groups

IUIH R&D GG
MNH ATSI Oversight Group
RAUGH GG
Poche Board

RAUGH Operations Group

Operationalises project

Leads development of protocol and ethics applications

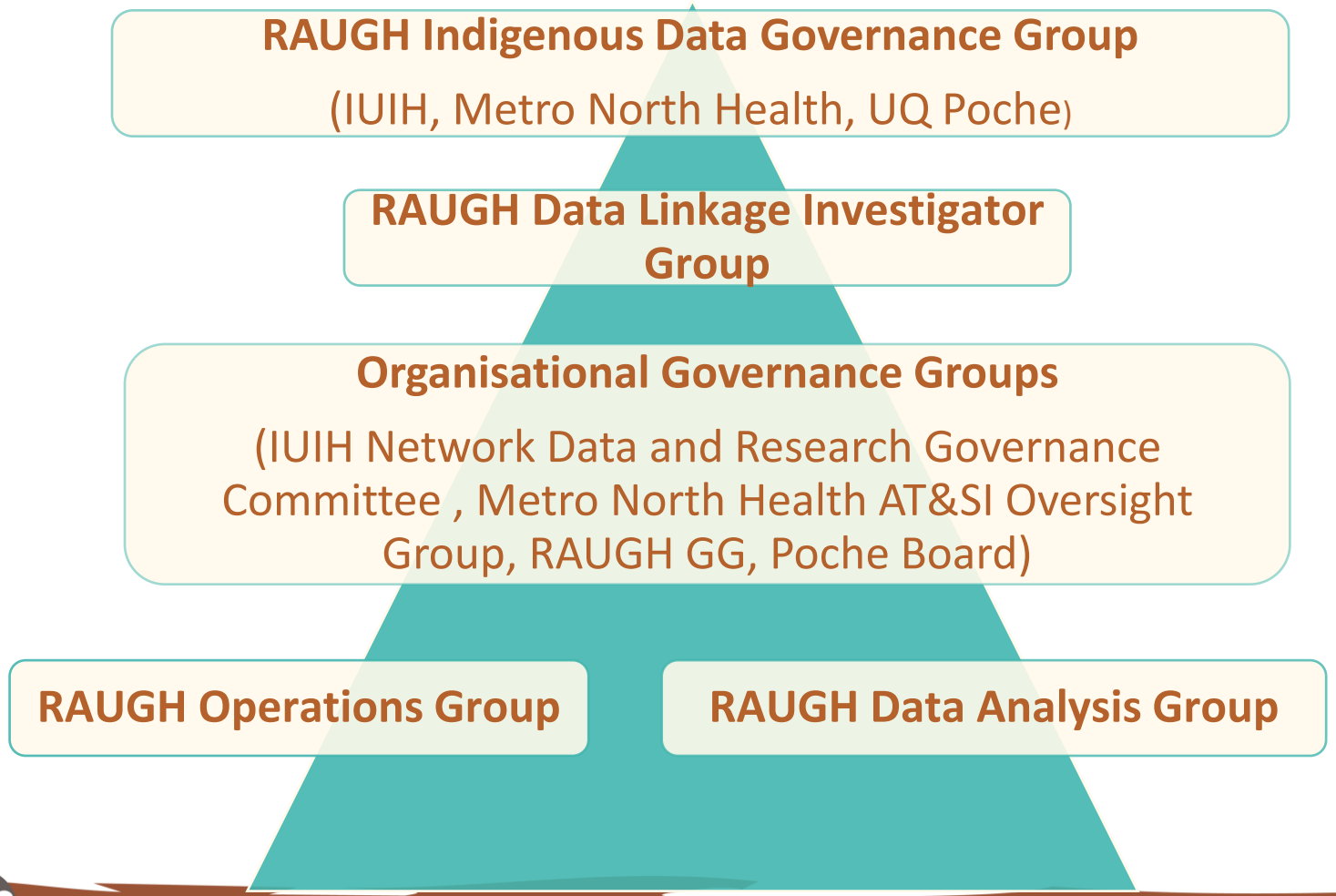
Ethics amendments

Reporting & Analysis

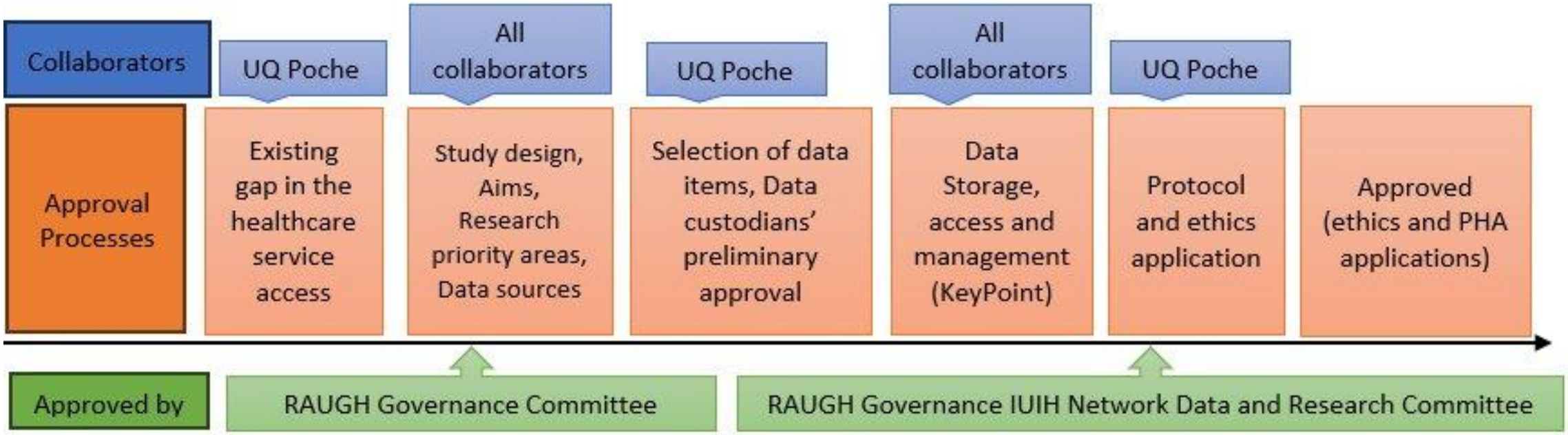
Data Analysis Group

Includes data analysts from each organisation
Develops data dictionary
Checking and Validating
Decisions to be bought to RAUGH Indigenous GG and organisational GGs

RAUGH Data Linkage Project Governance



Current status of the RAUGH Data Linkage project



Summary

- RAUGH is a resource for the sector
- Data linkage study is an Australian first
  - assessing data quality
  - Will create three cohorts of clients
  - understanding pathways
  - impact of service delivery
  - identify points for intervention

RAUGH

The Research Alliance for Urban Goori Health

Thank You!

UQ Poche Centre
for Indigenous Health

IUIH institute for urban indigenous health

Metro North
Hospital and Health Service

Queensland
Government

SEQ FIRST NATIONS HEALTH EQUITY

IN ACTION CONFERENCE

A *KeyPoint* of DIFFERENCE.

A trusted research environment for Digital Infrastructure For improving First Nations matERNal and Child hEalth

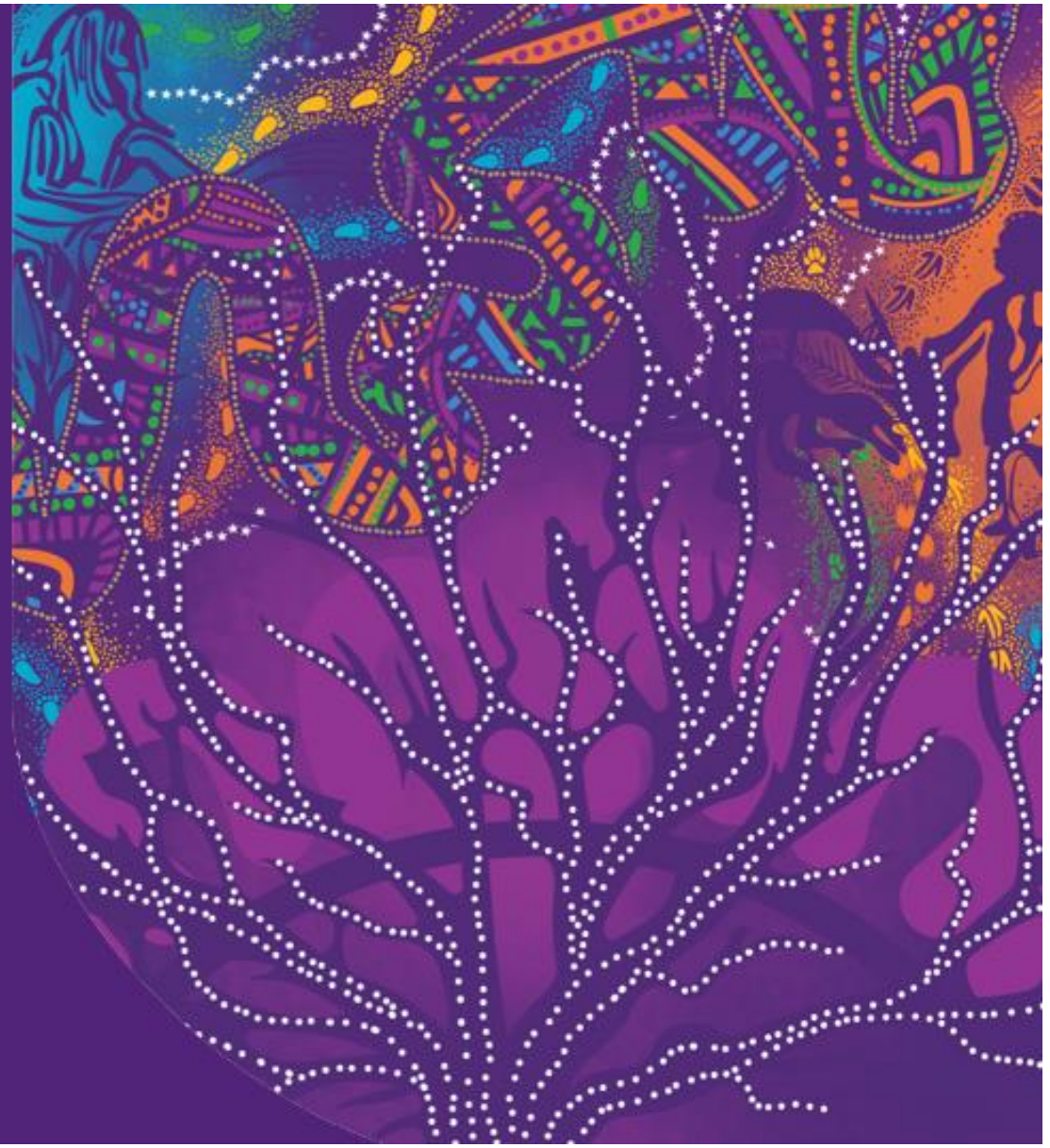
Jason Ferris

Acknowledgment of Country

The University of Queensland (UQ) 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.



First Nations Australians have poorer maternal and perinatal health outcomes

Factors impacting First Nations mother and babies receiving best health care delivery include:

- Discrimination and racism
- Social inequities in:
    - education
    - income
    - housing
- Insufficient access to culturally appropriate healthcare

Image: Caro Telfer/Adobe

First Nations Australians have poorer maternal and perinatal health outcomes

Some facts:

- First Nations mothers are 3 times more likely to die during childbirth
- First Nations mothers have a preterm birth rate of 13.6% compared to 8.4% among non-Indigenous mothers
- First Nations children have a mortality rates 2.4 times higher than non-Indigenous children

Image: Caro Telfer/Adobe

- A First Nations led birthing service delivered by Institute for Urban Indigenous Health (IUIH), Aboriginal and Torres Strait Islander Community Health Service (ATSICHS) Brisbane in partnership with Mater Mothers' Hospital
- The BiOC model offers Midwifery group practice, 24/7 access to pregnancy, birthing and postnatal care, support from Aboriginal and Torres Strait Islander Family Support Practitioners
  + transport access, social support and many other features

https://yarnitup.iuih.org.au/your-services-and-programs/birthing-our-communities-bioc

BiOC Data Connectivity

BiOC Data Connectivity

BiOC Data Connectivity

DIFFERENCE

Share patient data between clinicians to improve clinical care

E.g. Medications, Care Plans, Test results

Primary care

IUIH institute for urban indigenous health

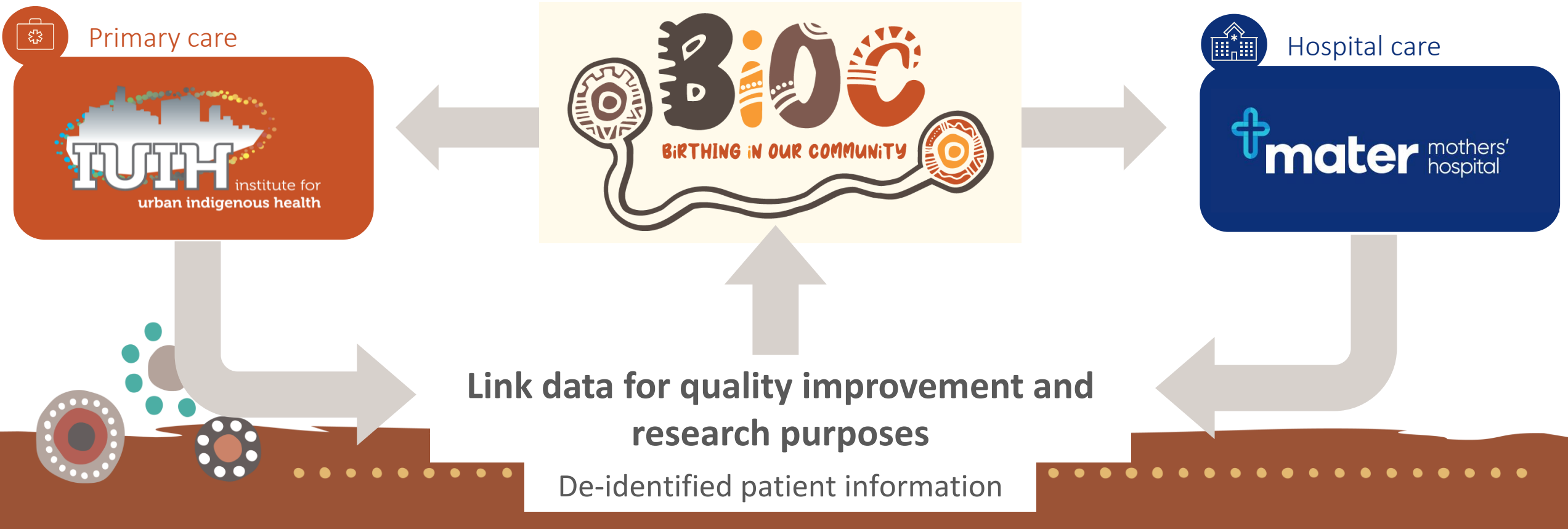
Hospital care

mater mothers' hospital

DIFFERENCE

Share patient data between clinicians to improve clinical care

E.g. Medications, Care Plans, Test results



Link data for quality improvement and research purposes

De-identified patient information

DIFFERENCE

DIFFERENCE Aims

Aim 1

New Digital infrastructure and Digital workflows

To examine, define and map the data currently being routinely collected for First Nations pregnancies at our two healthcare settings.

Aim 2

Data and analytics

a) to create an identifiable (but restricted) data stream to connect care for mothers who access care across primary and tertiary settings; and

b) to develop deidentified descriptive, predictive and prescriptive analytics from Aim 1 data in near real-time for connected clinical care across primary and tertiary care and for research purposes to allow iterative quality improvement and high-quality research outputs.

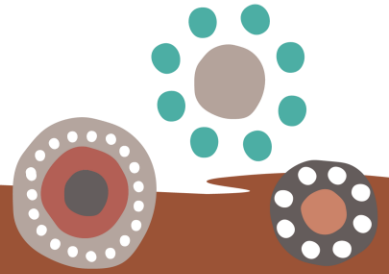
Aim 3

New models of care

To redesign care based on data-driven analysis of outcomes (from Aim 2) to facilitate better maternal and perinatal health outcomes for this population.

DIFFERENCE

BEST PRACTICE
DATA GOVERNANCE
KEYPOINT

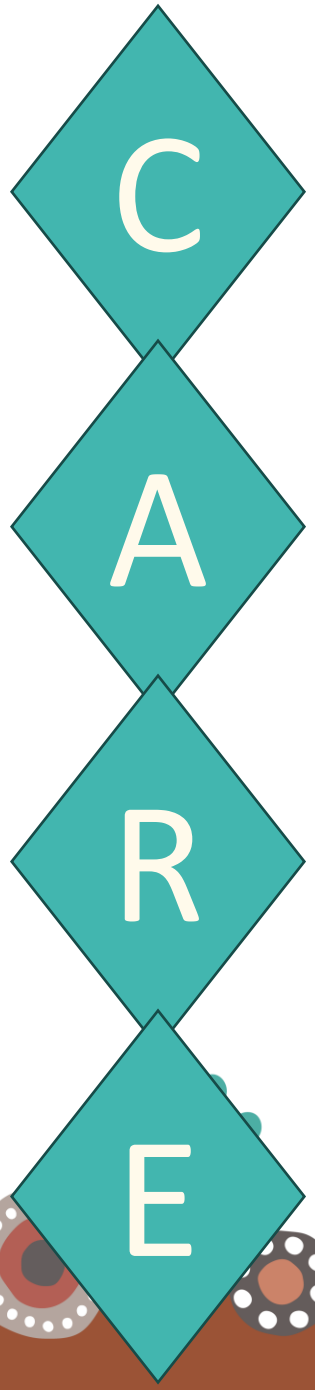


How can we:

- Work collaboratively on sensitive data?
- Allow external organisations to analyse sensitive data whilst ensuring data sovereignty at all times?

The Five Safes are used as the basis for the Five Data Sharing Principles by the Australian Government and its agencies.

© Commonwealth of Australia, Department of the Prime Minister and Cabinet, *Sharing Data Safely*



Collective benefit

- For inclusive development and innovation
- For improved governance and citizen engagement
- For equitable outcomes

Authority to control

- Recognising rights and interests
- Data for governance
- Governance of data

Responsibility

- For positive relationships
- For expanding capability and capacity
- For indigenous languages and worldviews

Ethics

- For minimising harm and maximising benefit
- For justice
- For future use

CARE Principles

KEYPOINT

No one in without permission
Nothing in and out without permission

The University Of Queensland
AUSTRALIA

QCIF

Secure environment for accessing and analysing sensitive data ALWAYS within the control and governance of the data steward

Data steward governed

- Fine-grained access controls and permissions
- Highly governed environment

Secure remote access from anywhere

- Organisational and KeyPoint's MFA challenges
- Encrypted remote desktop access; NO access to local systems

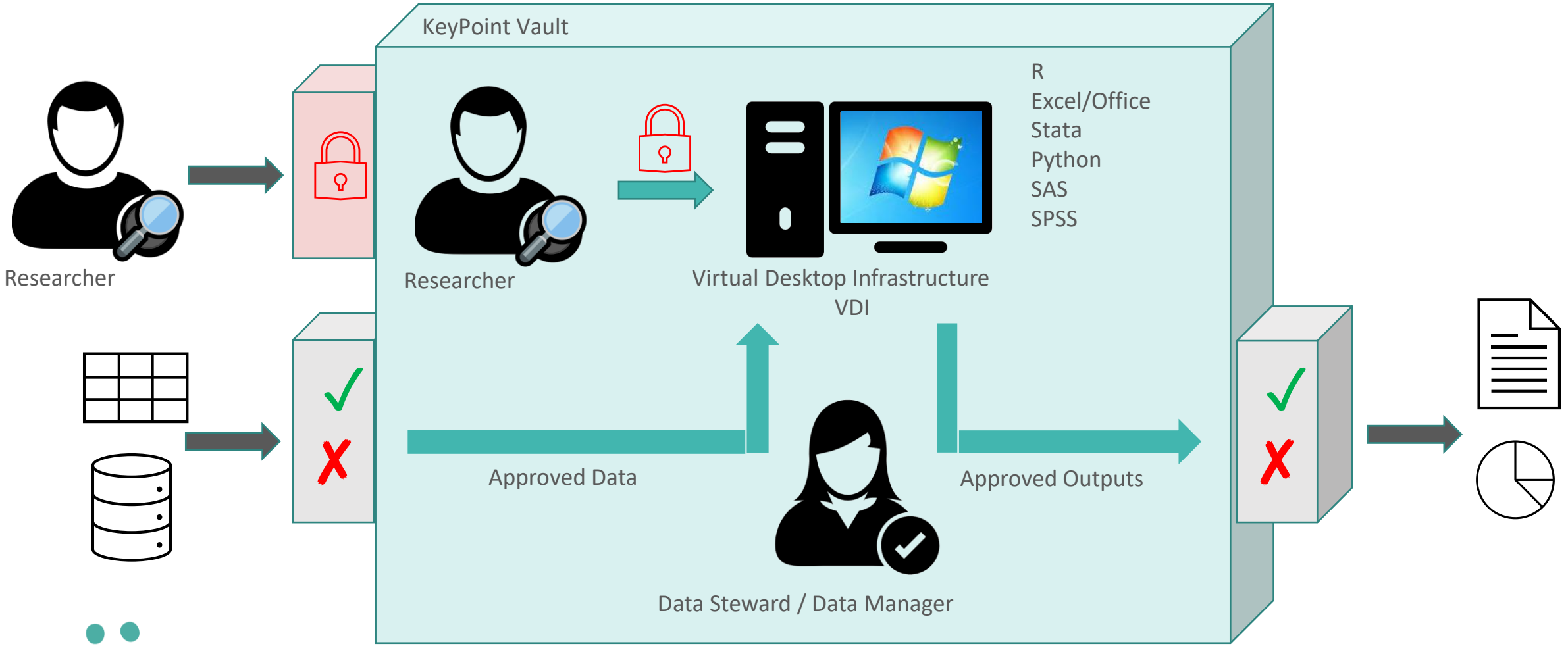
Pre-installed suite of software available

- Customisable to the project and user
- Office/Excel, STATA, R, Python, SPSS and SAS

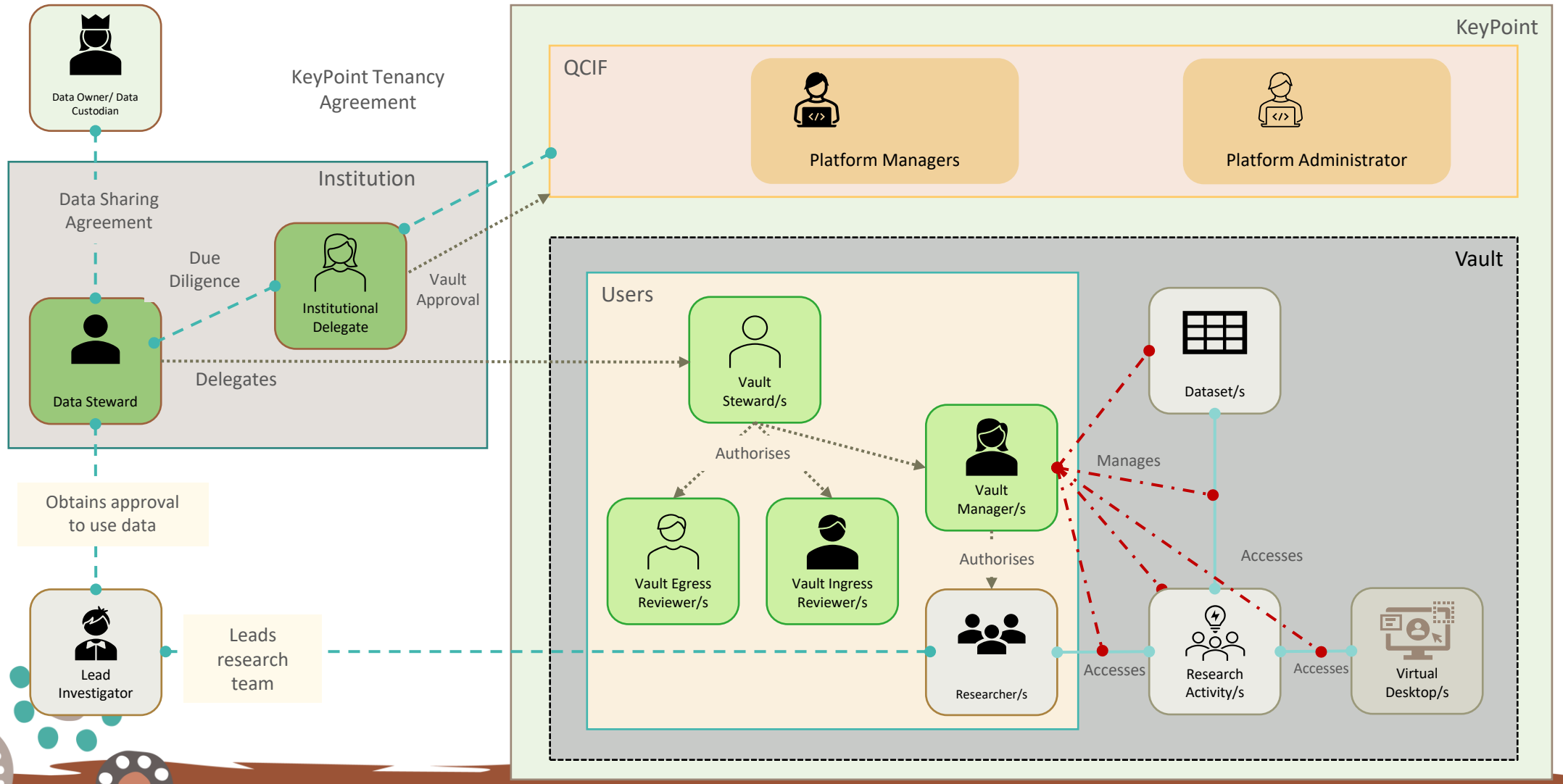
High-powered computing

- Various flavours Windows Virtual Machines (VDI)
- High memory and GPU nodes (prioritised for UQ)

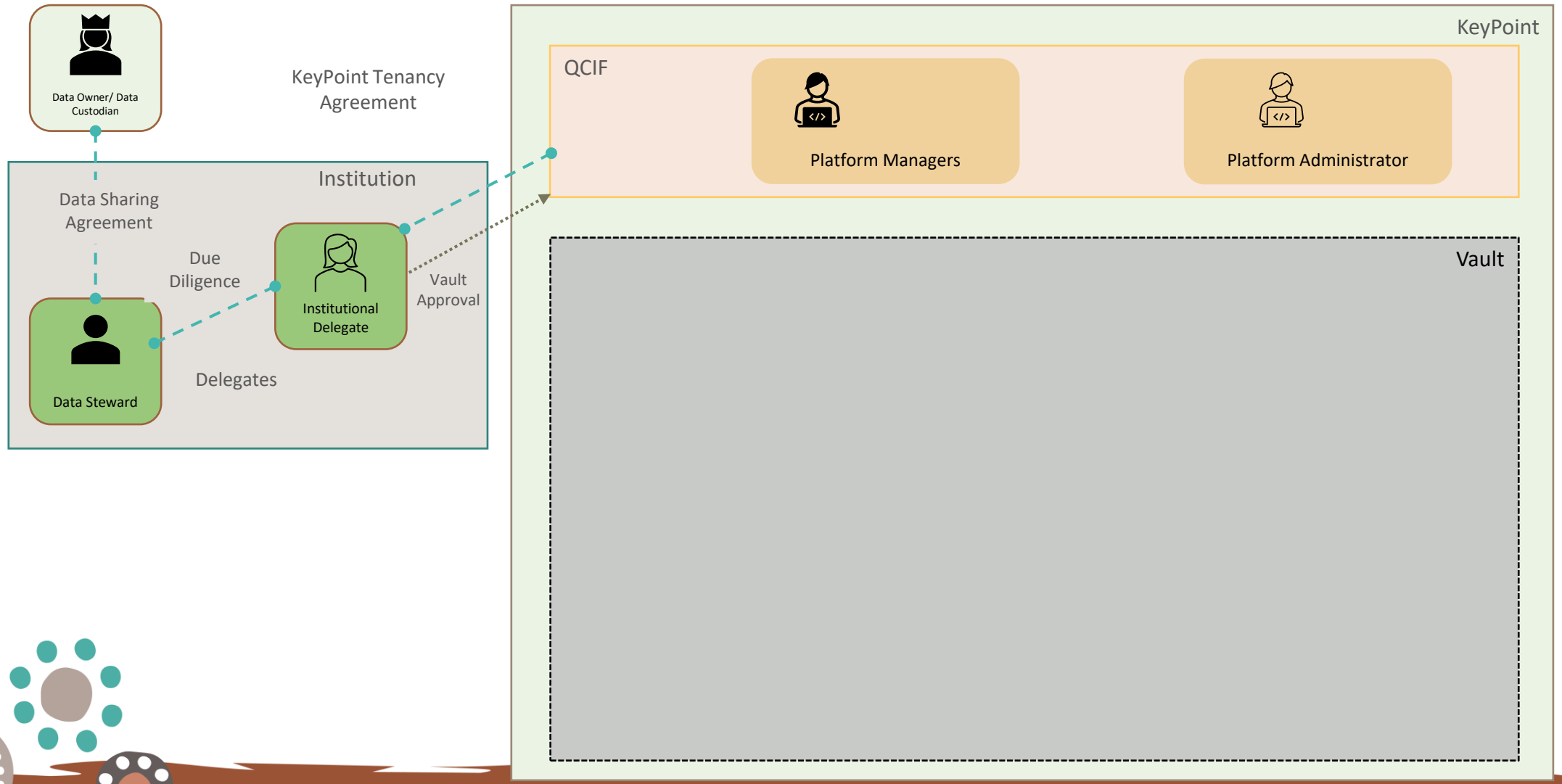
KeyPoint in Action



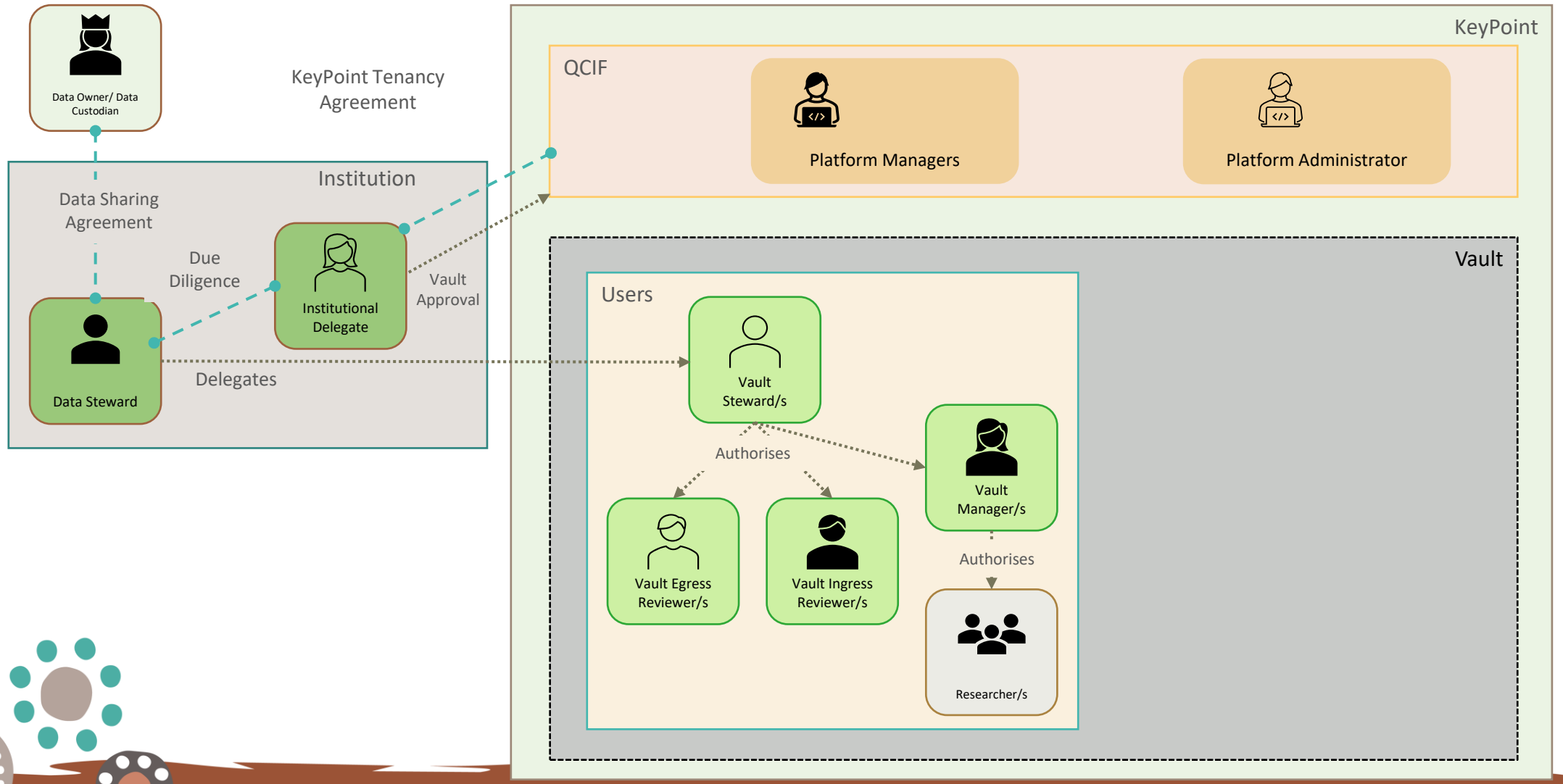
Scalable governance



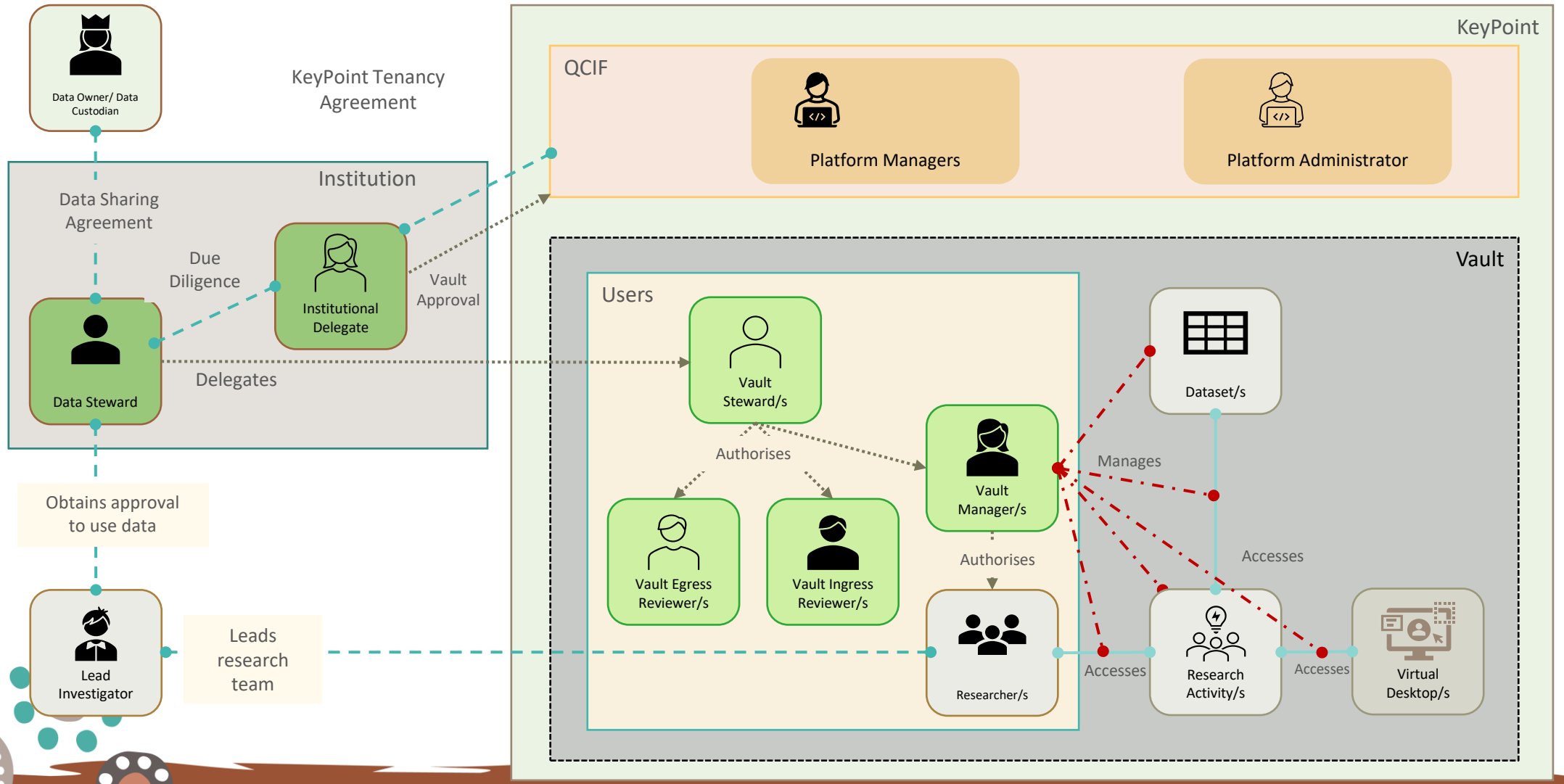
Scalable governance



Scalable governance



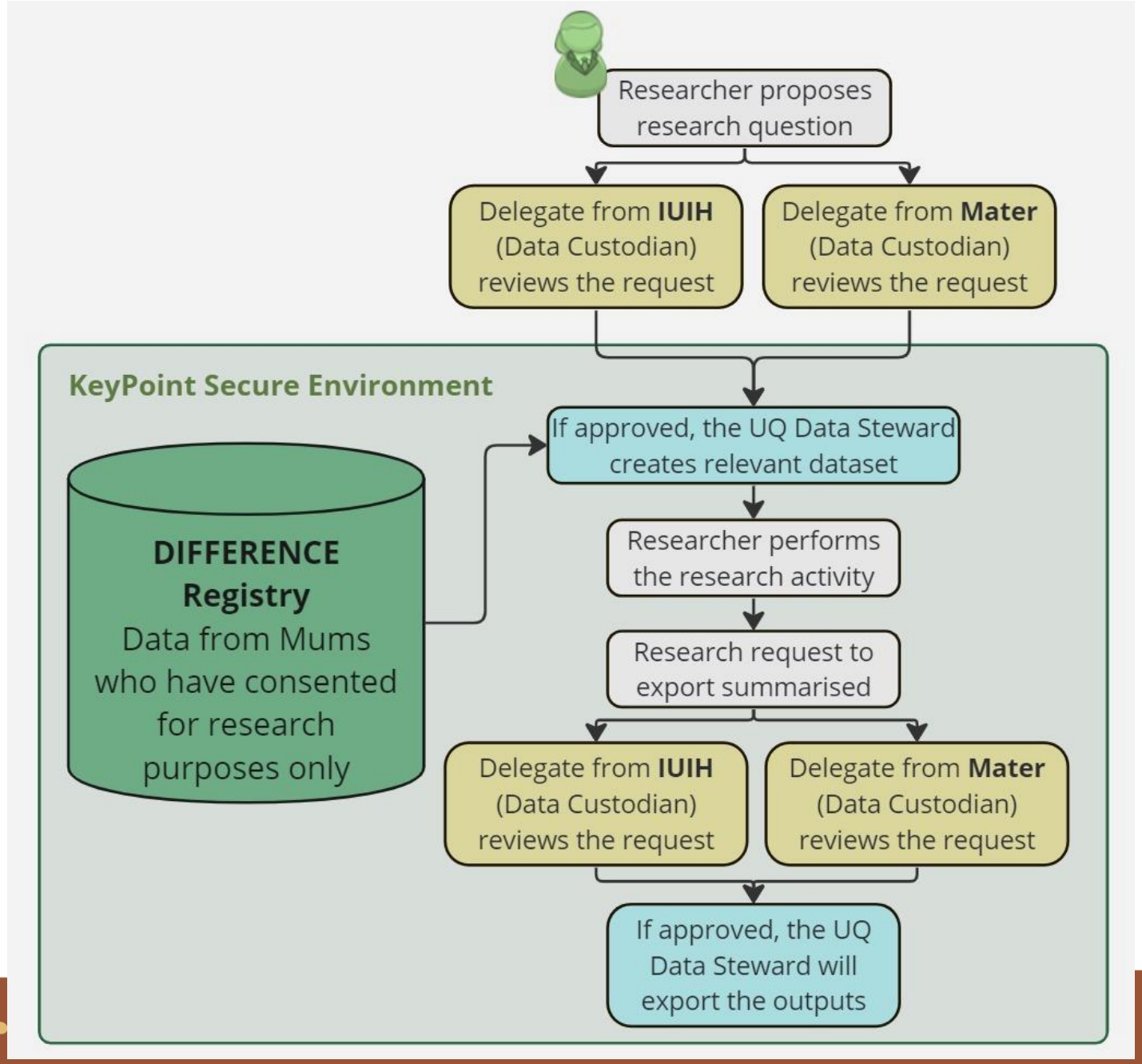
Scalable governance



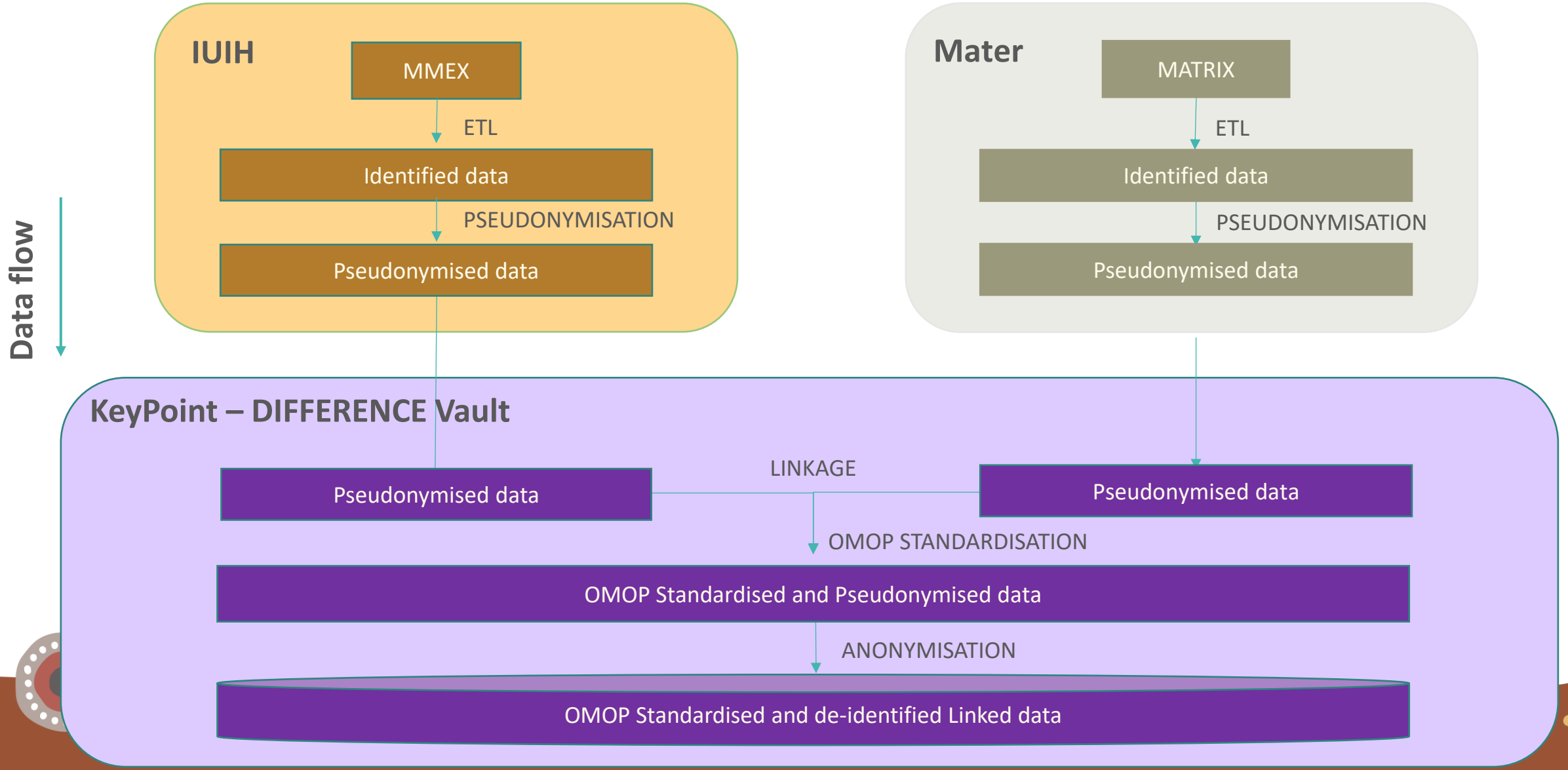
Data Governance

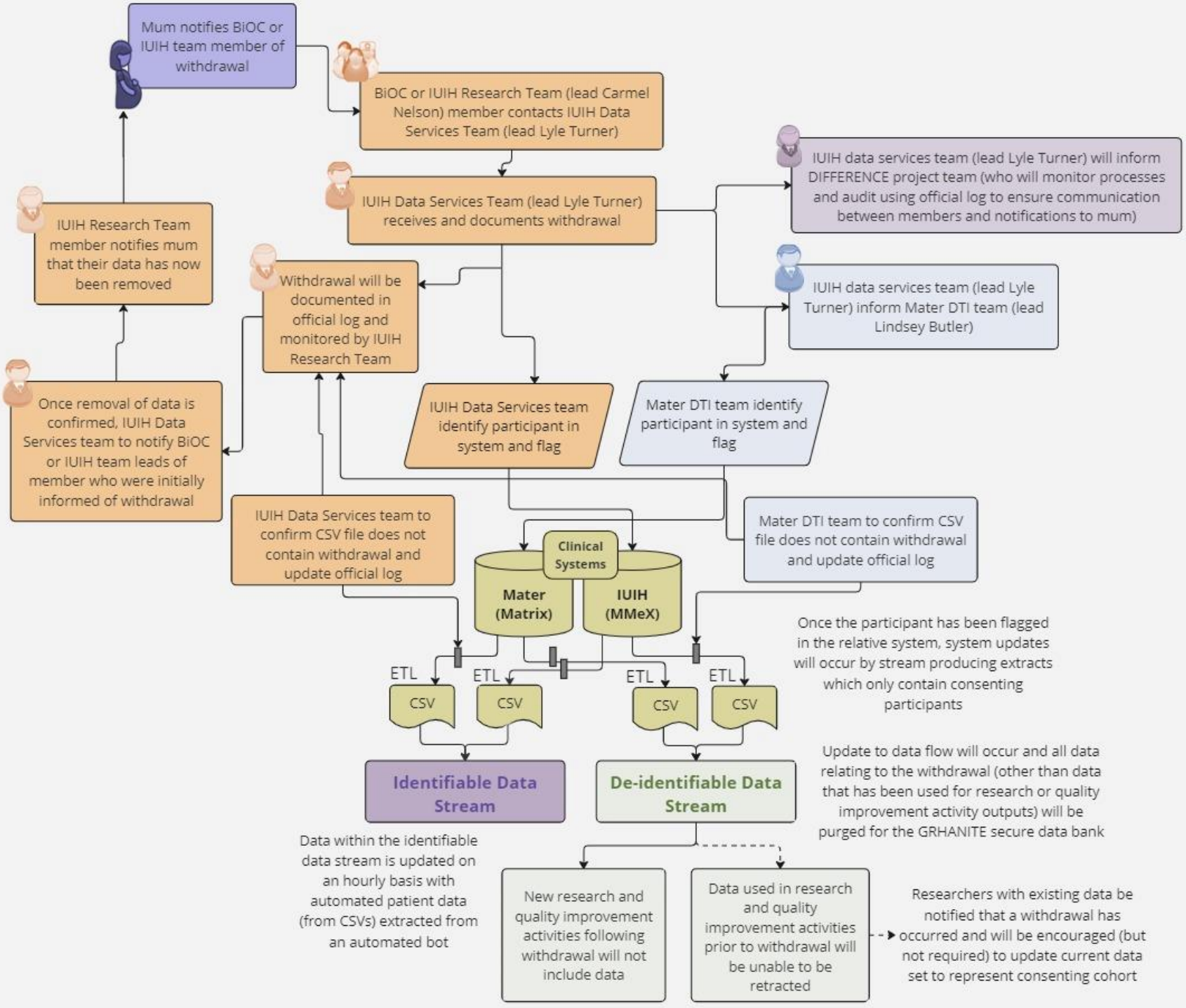
Data will be managed according to Queensland Health, Mater and IUIH information management procedures

Data will be governed by best-practice First Nations data governance principles.



Data linkage within KeyPoint




Mum notifies BiOC or IUIH team member of withdrawal
BiOC or IUIH Research Team (lead Carmel Nelson) member contacts IUIH Data Services Team (lead Lyle Turner)
IUIH Data Services Team (lead Lyle Turner) receives and documents withdrawal
IUIH data services team (lead Lyle Turner) will inform DIFFERENCE project team (who will monitor processes and audit using official log to ensure communication between members and notifications to mum)
IUIH Research Team member notifies mum that their data has now been removed
Withdrawal will be documented in official log and monitored by IUIH Research Team
IUIH data services team (lead Lyle Turner) inform Mater DTI team (lead Lindsey Butler)
Once removal of data is confirmed, IUIH Data Services team to notify BiOC or IUIH team leads of member who were initially informed of withdrawal
IUIH Data Services team identify participant in system and flag
Mater DTI team identify participant in system and flag
IUIH Data Services team to confirm CSV file does not contain withdrawal and update official log
Mater DTI team to confirm CSV file does not contain withdrawal and update official log
Clinical Systems
Mater (Matrix)
IUIH (MMeX)
Once the participant has been flagged in the relative system, system updates will occur by stream producing extracts which only contain consenting participants
ETL
CSV
ETL
CSV
ETL
CSV
ETL
CSV
Identifiable Data Stream
De-identifiable Data Stream
Update to data flow will occur and all data relating to the withdrawal (other than data that has been used for research or quality improvement activity outputs) will be purged for the GRHANITE secure data bank
Data within the identifiable data stream is updated on an hourly basis with automated patient data (from CSVs) extracted from an automated bot
New research and quality improvement activities following withdrawal will not include data
Data used in research and quality improvement activities prior to withdrawal will be unable to be retracted
Researchers with existing data be notified that a withdrawal has occurred and will be encouraged (but not required) to update current data set to represent consenting cohort

DIFFERENCE: Outcomes

Utilising cutting edge informatics and technology to deliver better outcomes for First nations pregnancies through:

- Standardising digital workflows in clinical information systems that are geographically boundless and aligned with best-practice First Nations data
- Delivering a consumer centred information flow agnostic of setting.
- Deliver real-time exchange of information for consenting people
- Develop culturally appropriate processes for de-identified data for precision medicine using AI and ML techniques.
- Redesigning healthcare through integrating digital workflows

Thank you and questions

Jason Ferris
DIFFERENCE (Chief Investigator)
j.ferris@uq.edu.au