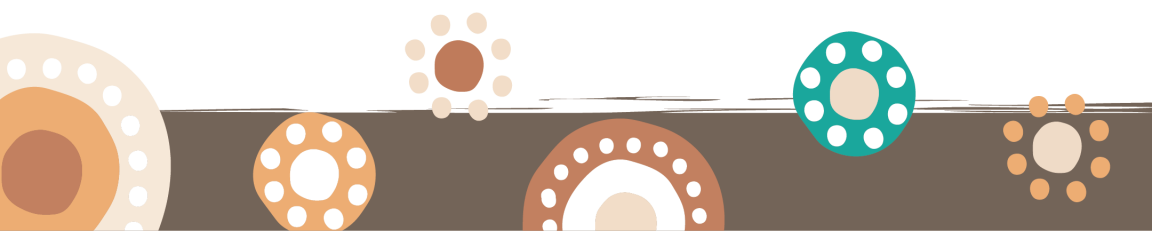


DIFFERENCE Project

Digital Infrastructure For improving First Nations matERNal and Child hEalth

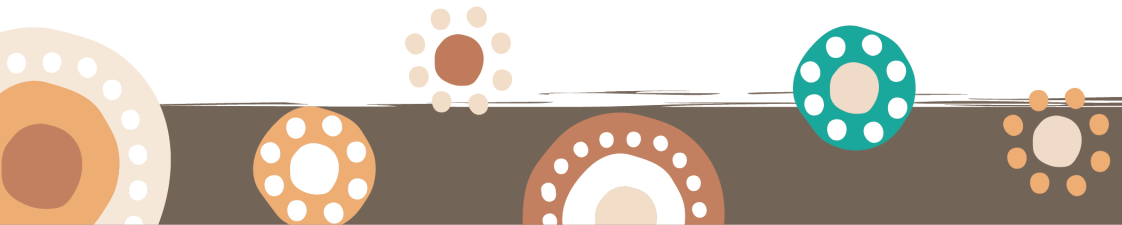
Queensland Health Data Linkage Symposium
Nov 2024



Acknowledgement of Country

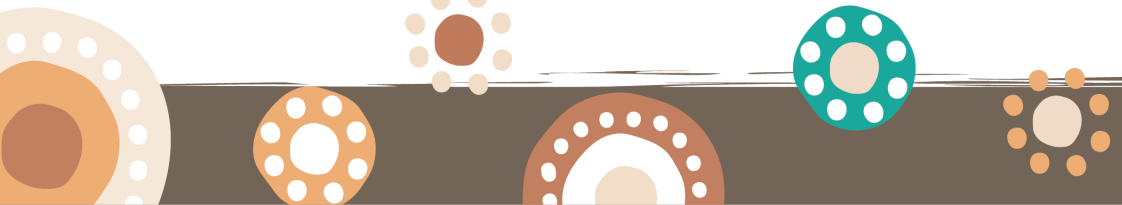
We acknowledge the Traditional Owners and their continued custodianship of the lands from which we meet - we are joining today from the lands of the Turrbul and the Yuggera people.

We pay our respects to their Ancestors past and present.





- Birthing in Our Community (BiOC) is a strengths-based model of ACCHS-led pregnancy, birthing and early childhood care in urban Southeast Queensland (SEQ)
- The BiOC model was established in 2013 in partnership between the Institute for Urban Indigenous Health (IUIH), the Aboriginal and Torres Strait Islander Community Health Service (ATSICHS) Brisbane, and the Mater Mothers' Hospital, following a 10-year review of Aboriginal and Torres Strait Islander births at the Mater which highlighted a growing gap in perinatal outcomes, in particular, rates of preterm birth
- 5-year NHMRC research project identified that BiOC:
 - Halved rates of preterm birth, effectively closing the gap
 - Economic analysis identified savings to the healthcare system of \$4,810 per mother-baby pair
 - Associated with a three-fold reduction in the risk of child removal at birth



Key BiOC Publications:

Sue Kildea, Yu Gao, Sophie Hickey, Carmel Nelson, Sue Kruske, Adrian Carson, Jody Currie, Maree Reynolds, Kay Wilson, Kristie Watego, Jo Costello, Yvette Roe. ***Effect of a Birthing on Country service redesign on maternal and neonatal health outcomes for First Nations Australians: a prospective, non-randomised, interventional trial.*** Lancet Glob Health 2021 - Published Online March 17, 2021. [https://doi.org/10.1016/S2214-109X\(21\)00061-9](https://doi.org/10.1016/S2214-109X(21)00061-9)

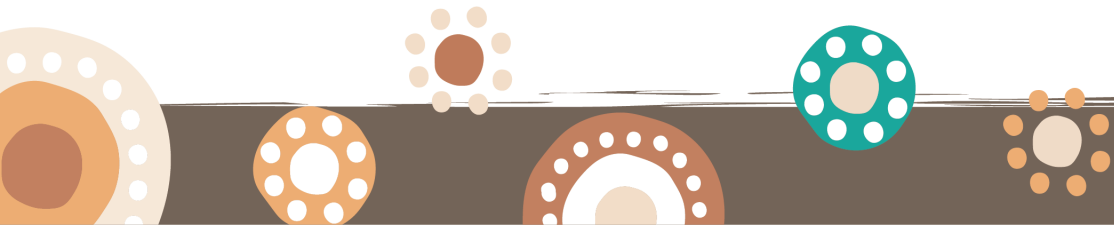
Birri O'Dea, Yvette Roe, Yu Gao, Sue Kruske, Carmel Nelson, Sophie Hickey, Adrian Carson, Kristie Watego, Jody Currie, Renee Blackman, Maree Reynolds, Kay Wilson, Jo Costello, Sue Kildea. Breaking the cycle: ***Effect of a multi-agency maternity service redesign on reducing the over-representation of Aboriginal and Torres Strait Islander newborns in out-of-home care: A prospective, non-randomised, intervention study in urban Australia***, Journal of Child Abuse & Neglect, Volume 149, 2024. ISSN 0145-2134. <https://doi.org/10.1016/j.chiabu.2024.106664>

Gao, Y., Roe, Y., Hickey, S., Chadha, A., Kruske, S., Nelson, C., Carson, A., Watego, K., Reynolds, M., Costello, J., Tracy, S., Kildea, S. (2023). ***Birthing on Country service compared to Standard Care for First Nations Australians: a cost-effectiveness analysis from a health system perspective***, The Lancet Regional Health-Western Pacific. March 2023. <https://doi.org/10.1016/j.lanwpc.2023.100722>

Yvette Roe, Jyai Allen, Penny Haora, Sophie Hickey, Melanie Briggs, Liz Wilkes, Carmel Nelson, Kristie Watego, Rebecca Coddington, Sarah Ireland, Sue Kruske, Yu Gao, Sue Kildea. ***Enabling the context for Aboriginal and Torres Strait Islander Community Controlled Birthing on Country services: Participatory action research.*** Women and Birth 2023. ISSN 1871-5192. <https://doi.org/10.1016/j.wombi.2023.11.007>

Sue Kildea, Yu Gao, Sophie Hickey, Sue Kruske, Carmel Nelson, Renee Blackman, Sally Tracy, Cameron Hurst, Daniel Williamson, Yvette Roe (2019). ***Reducing preterm birth amongst Aboriginal and Torres Strait Islander babies: A prospective cohort study Brisbane, Australia.*** The Lancet – EclinicalMedicine 23 June 2019. <https://doi.org/10.1016/j.eclinm.2019.06.001>

Hickey, S., Roe, Y., Gao, Y., Nelson, C., Carson, A., Currie J., Reynolds, M., Wilson, K., Kruske, S., Blackman, R., Passey, M., Clifford, A., Tracy, S., West, R., Williamson, D., Kosiak, M., Watego, S., Webster, J. and S. Kildea (2018) ***The Indigenous Birthing in an Urban Setting study: the IBUS study.*** BMC Pregnancy and Childbirth 18:431 <https://doi.org/10.1186/s12884-018-2067-8>

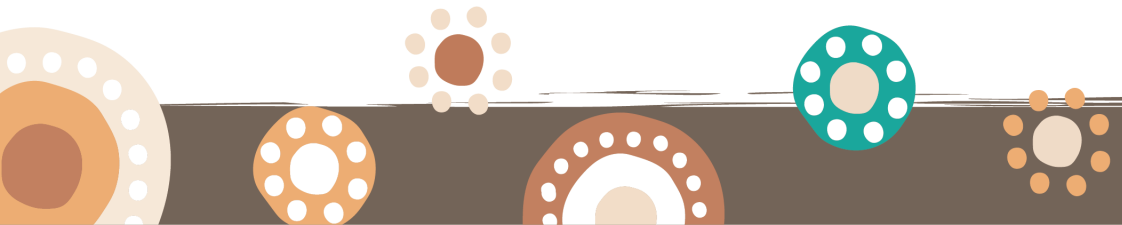


BiOC Data Connectivity

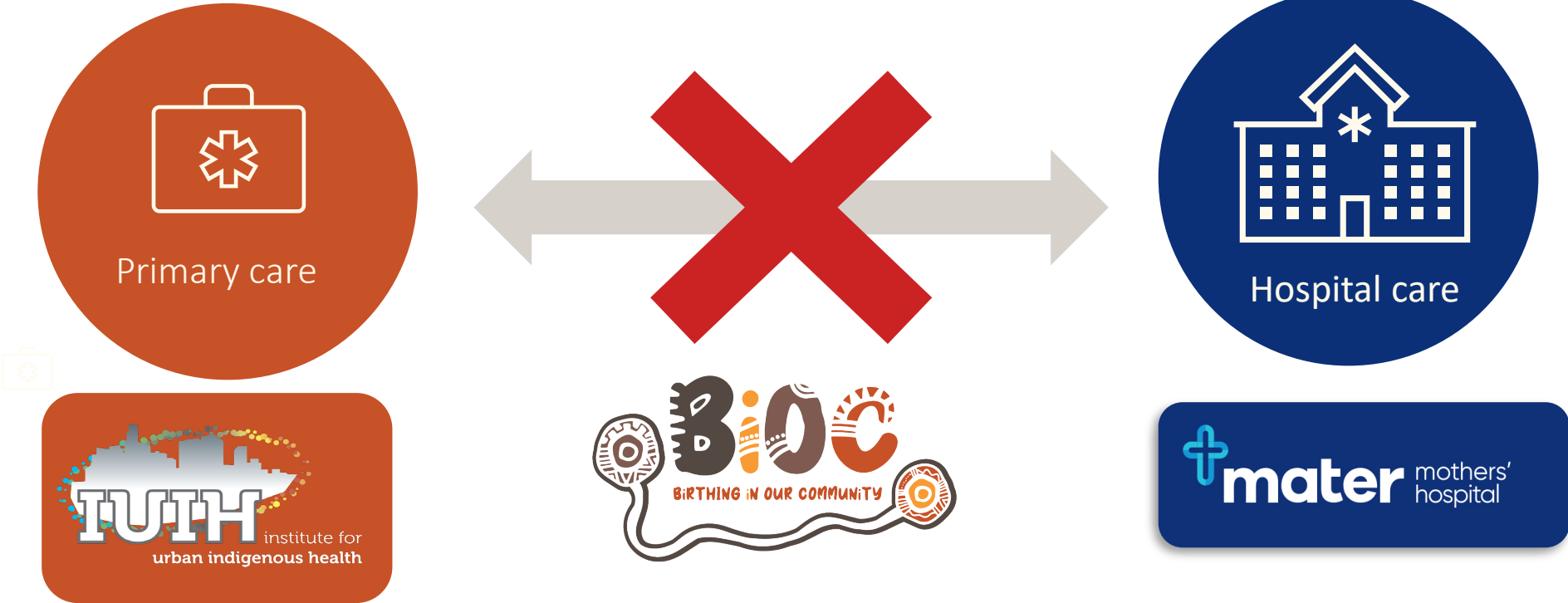




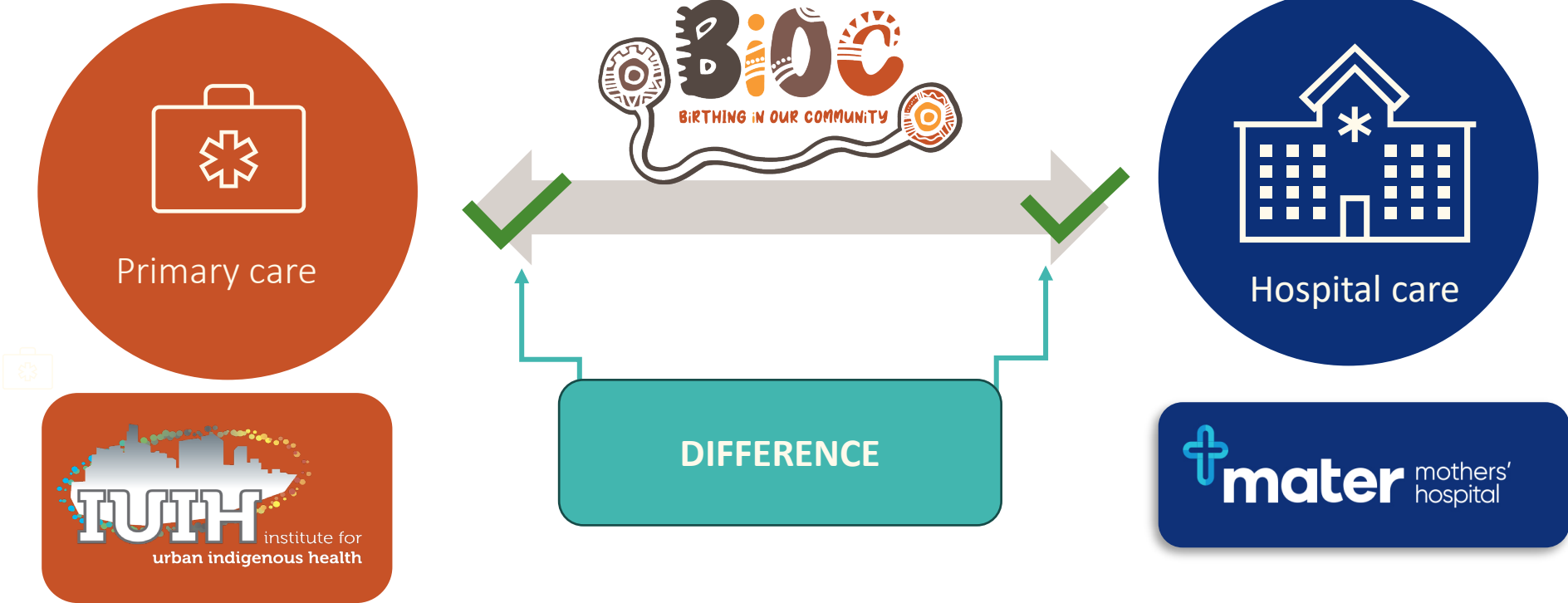
HOWEVER ...



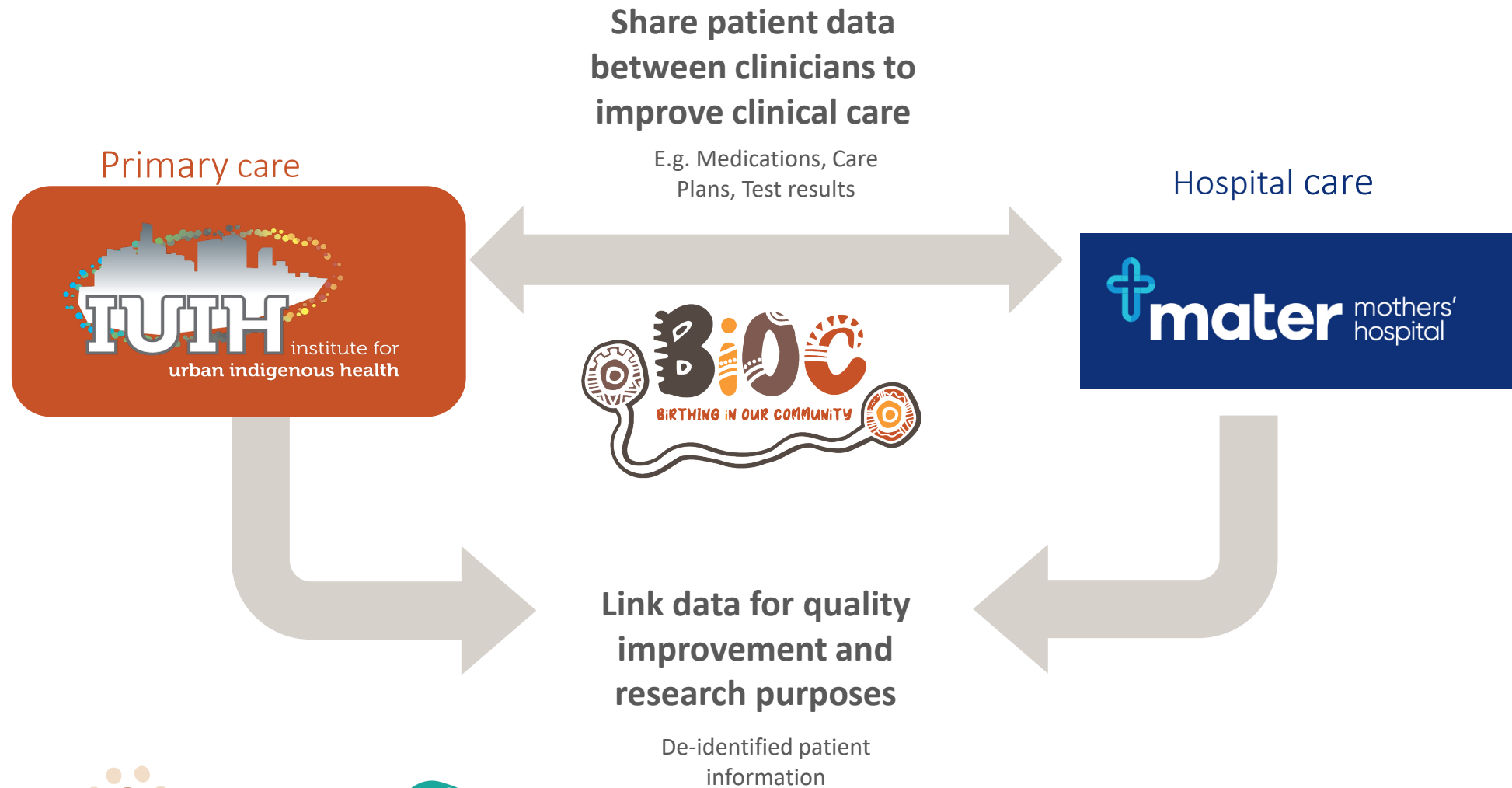
BiOC Data Connectivity



BiOC Data Connectivity



DIFFERENCE



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 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

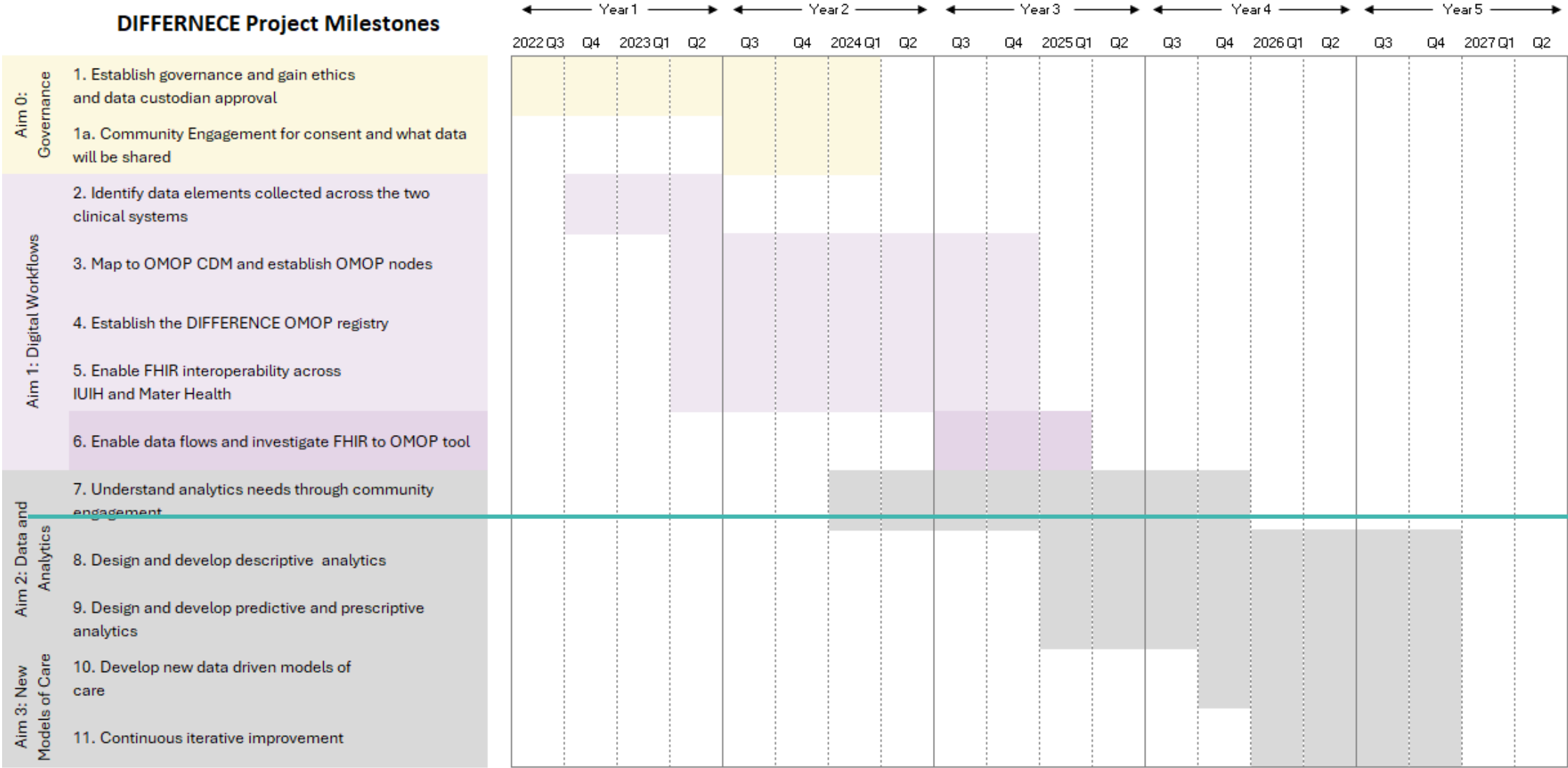
New Models of Care

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



Project Milestones

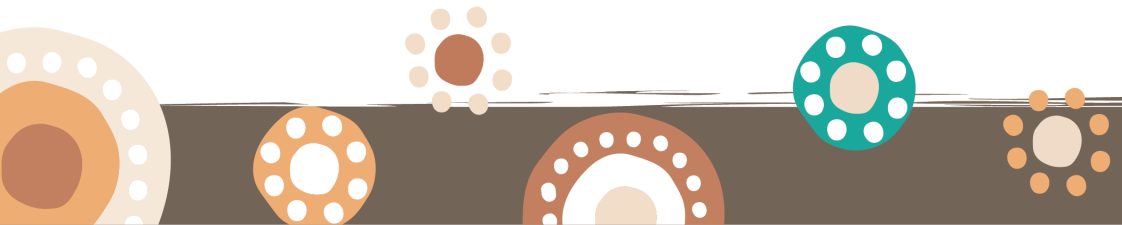
DIFFERNECE Project Milestones





Community determination of consent model

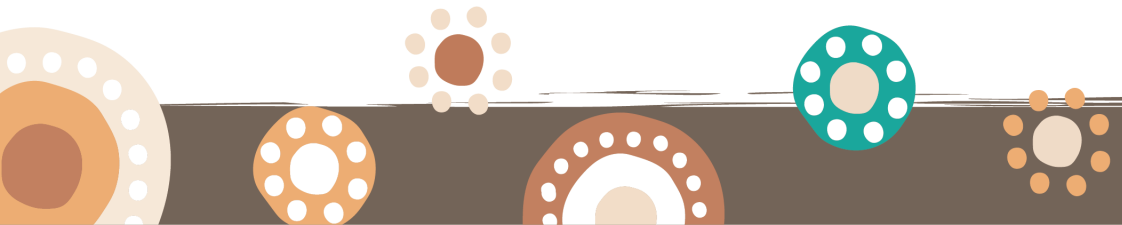
- Qualitative sub-study
- Individual in-depth interviews and group-based yarning circles, with BiOC women and with Family Support Practitioners, conducted by Aboriginal researchers
- Asked about research, appetite for information sharing, requirements for consent





In Summary / Outcomes:

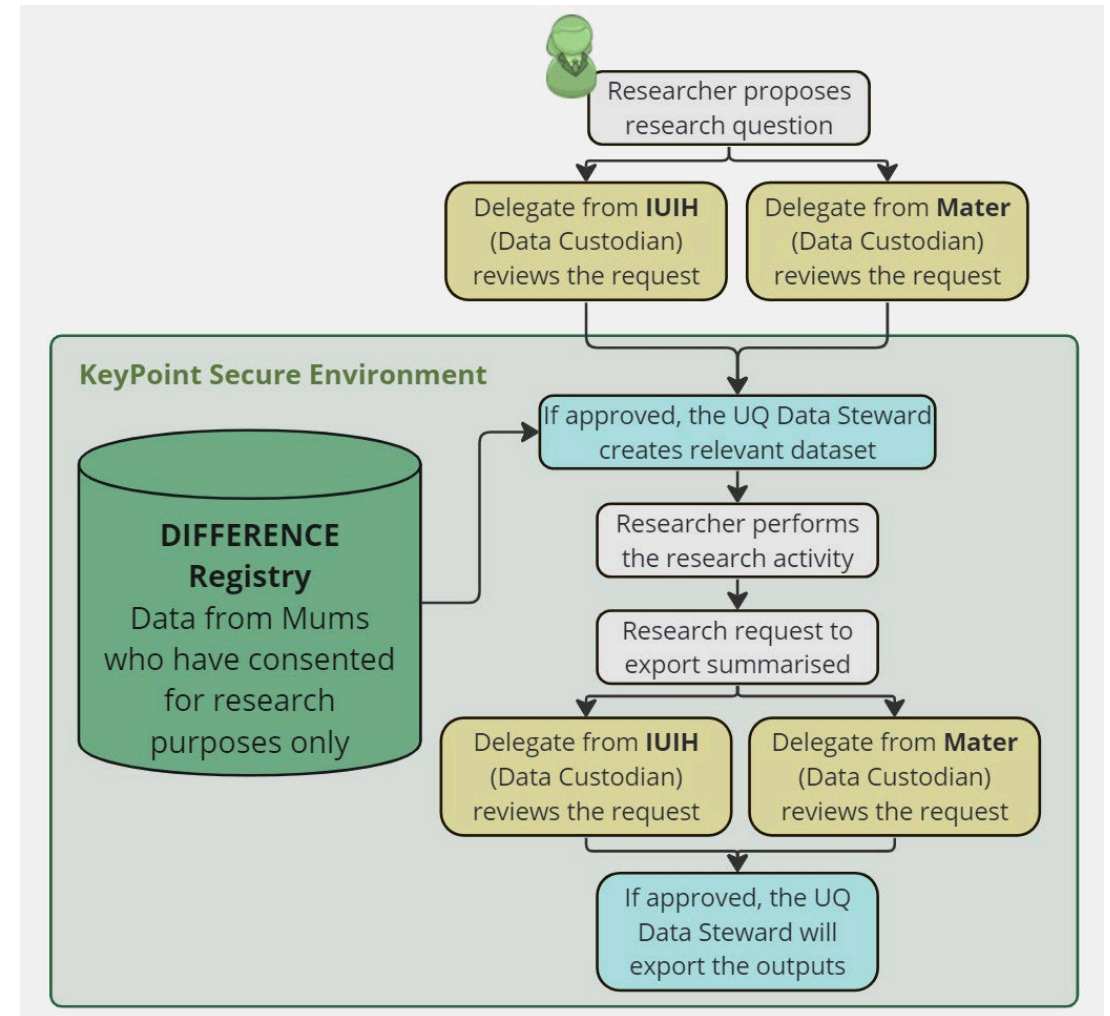
- Individual consent will be sought for identified data sharing stream
- Individual consent will be sought for participation in de-identified data stream
- Data considered by women to be more sensitive is excluded from sharing – with potential to review and revisit if confidence of women grows with the experience of data sharing in time
- Next stages include developing methodology for ongoing engagement of BiOC women and families, along with healthcare providers, in determining what questions will be asked of the de-identified data stream



Best Practice Data Governance

Approach and governance to data access via KeyPoint (Secure Environment) established and infrastructure build in progress.

The data generated as a result of this project will be managed according to Queensland Health, Mater and UIH information management procedures and governed by best-practice First Nations data governance principles.



KeyPoint



DIFFERENCE Vault is:

- **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
- **Equipped with pre-installed suite of software available**
 - Customisable to the project and user
 - Office/Excel, STATA, R, Python, SPSS and SAS
- **Enabled with high-powered computing**
 - Various flavours Windows Virtual Machines (VDI)
 - High memory and GPU nodes (prioritised for UQ)

5 Safes Framework

Safe Projects

Safe People

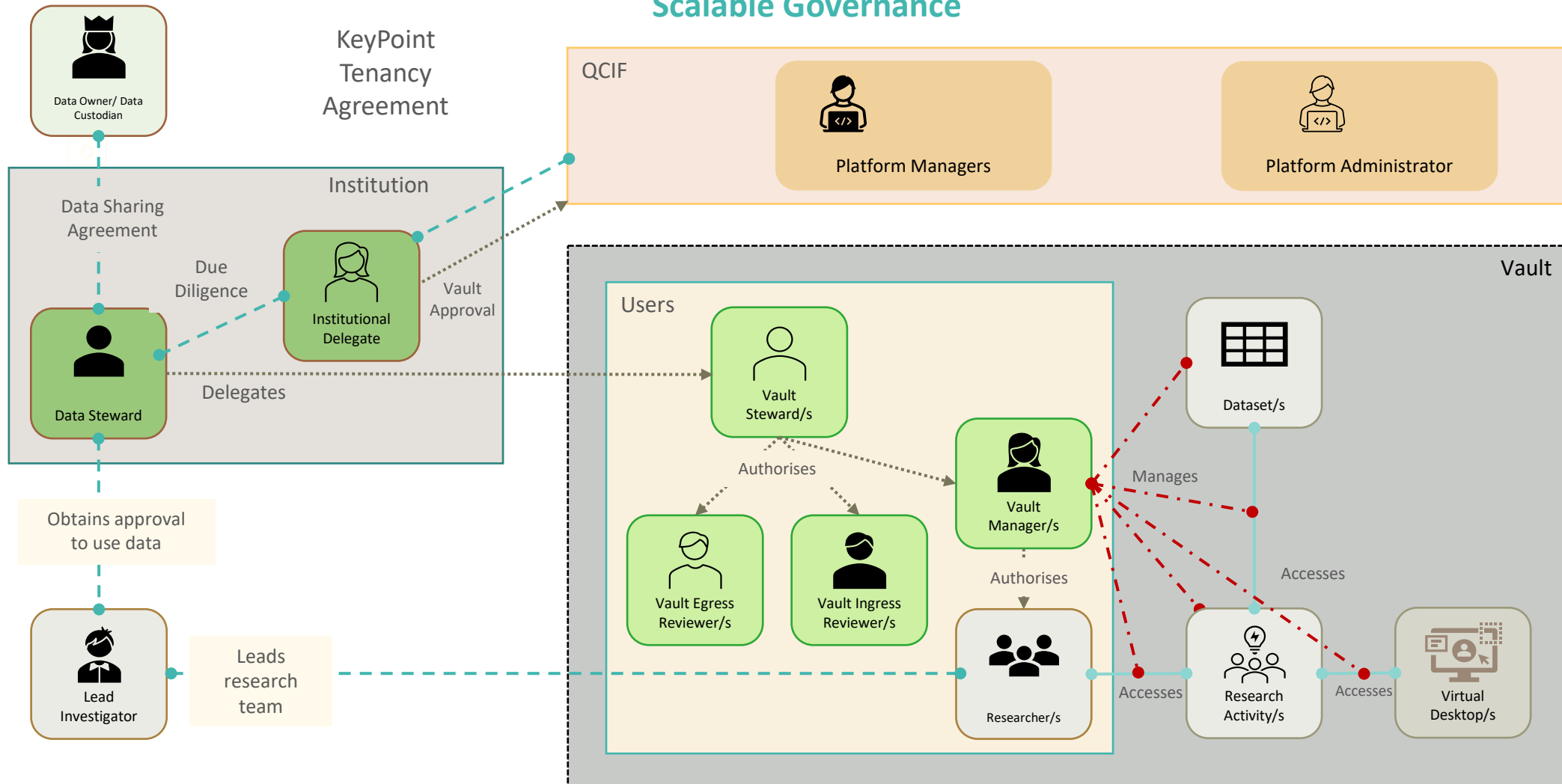
Safe Setting

Safe Data

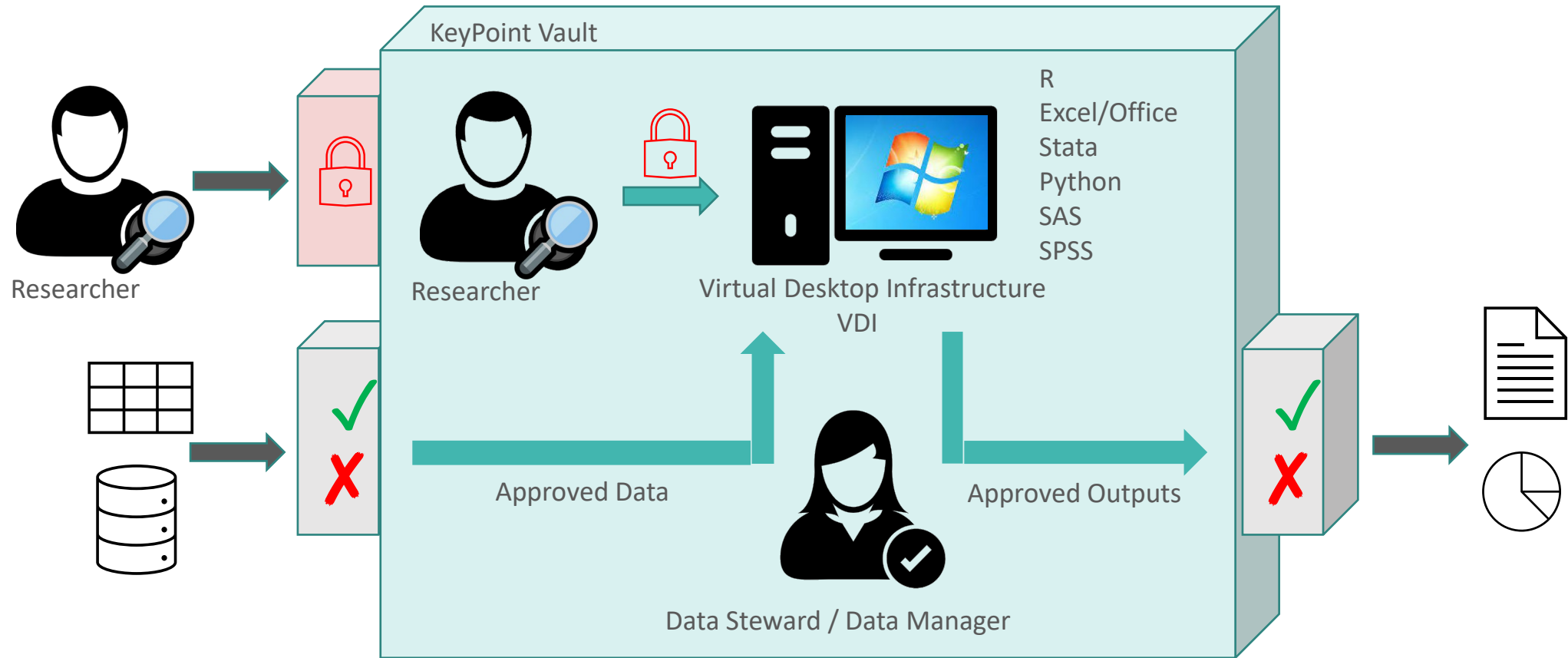
Safe Outputs

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

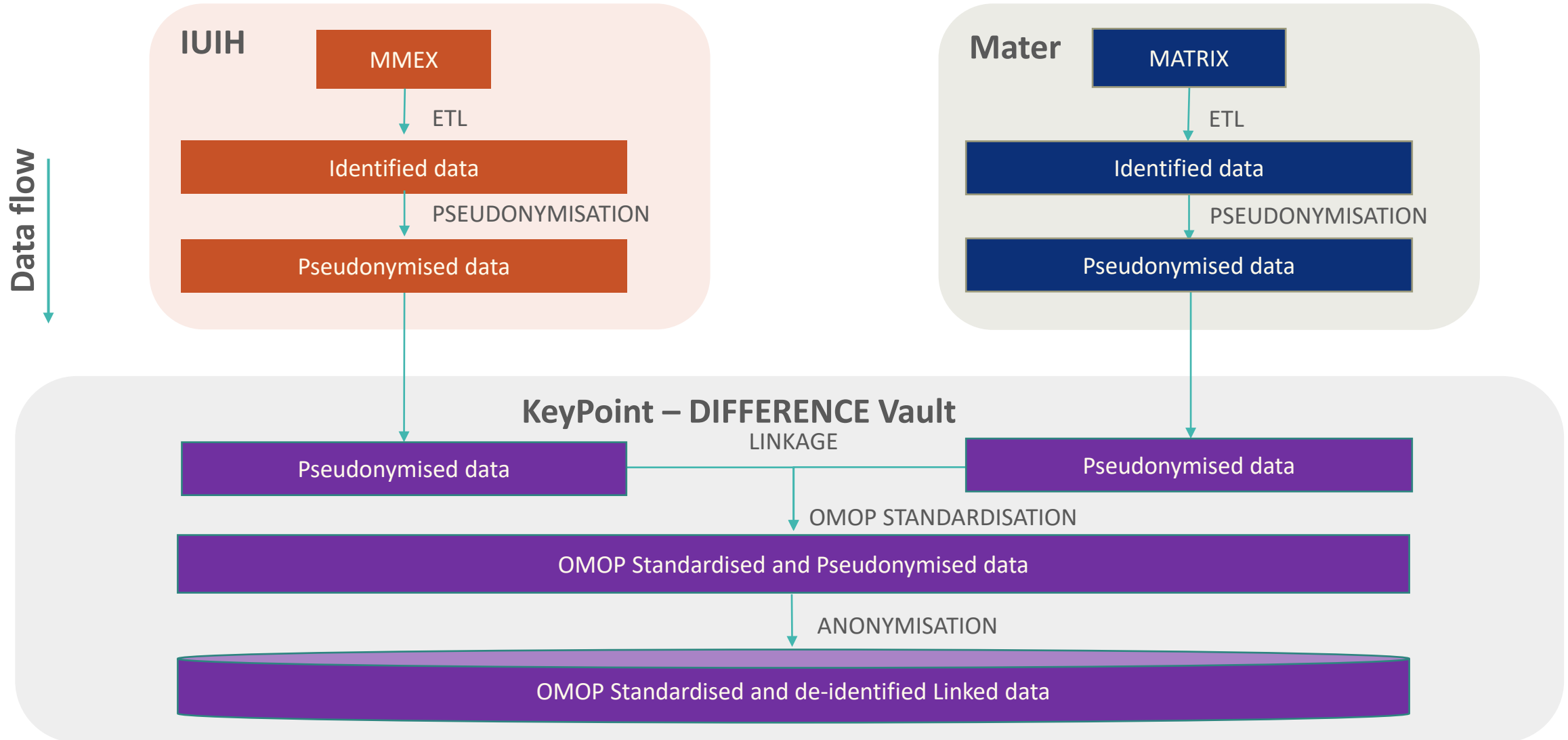
KeyPoint



KeyPoint in Action



Data Linkage within KeyPoint

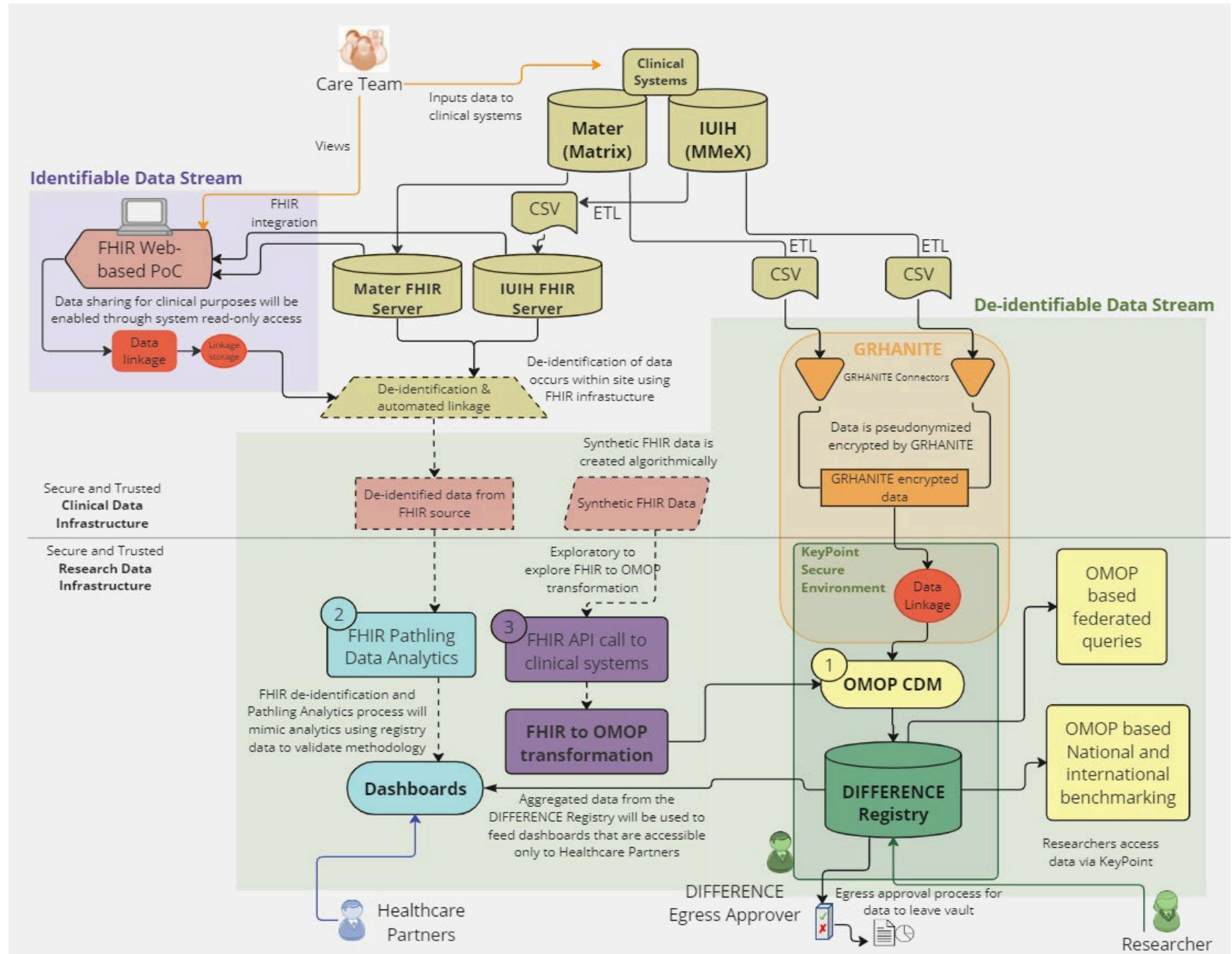


Data Flows

These workflows will deliver:

(i) real-time exchange of information for individual identifiable consumers to streamline care, and

(ii) the development of de-identified data and analytics to enable sophisticated, precision medicine using AI and ML techniques – with decision-making driven by women, families and community



Indigenous Data Sovereignty and Data Governance – from Principles to Practice

*“**Indigenous Data Sovereignty** is the right of Aboriginal and Torres Strait Islander peoples, communities and organisations to maintain, control, protect, develop, and use data as it relates to us. Indigenous Data Sovereignty describes how the rights of Indigenous peoples, our experiences, values and understanding are developed and reflected in any data and information gathered about us, our communities and our knowledges. Indigenous Data Sovereignty is practiced through Indigenous data governance”.*

Indigenous Data Governance - *the enactment and oversight of an accountability framework to ensure the right of Indigenous peoples to exercise self-determination and autonomously decide what, how and why Indigenous information or knowledge are collected, accessed, stored, shared and used, reflecting and led by Indigenous priorities, values and worldviews.*

Definition from “Indigenous Data Governance and Sovereignty | RESEARCH PATHWAYS: INFORMATION SHEET SERIES” Lowitja Institute (p.2).
Lowitja Institute also referencing: Maïam nayuri Wingara Indigenous Data Sovereignty Network & Australian Indigenous Governance Institute 2018, Indigenous Data Sovereignty, Briefing Paper; 7. Griffiths K.E., Johnston M., Bowman-Derrick S. 2021, Indigenous Data Sovereignty: Readiness Assessment and Evaluation Toolkit, Lowitja Institute, Melbourne.



Indigenous Data Sovereignty and Data Governance – from Principles to Practice

- Indigenous-led decision-making at all stages of project design and implementation
- Data owners = BiOC women and families → driving what data is used and how
- Role of the IUIH Network Data and Research Governance Committee
- Parallel community engagement project providing guidance on information custodianship and decision-making principles
- Technology to support enactment of principles
- Iterative learning and development



DIFFERENCE Expected Outcomes

Utilising cutting edge informatics and technology to deliver better outcomes for First Nations women, babies and families:

- 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
- Develop processes for de-identified data for precision medicine using AI and ML techniques



DIFFERENCE Expected Outcomes (cont.)

- Throughout all stages of the project – design, develop, implement, test and re-design systems and processes which secure the translation of Indigenous Data Governance and Data Sovereignty principles into practice
- Redesigning healthcare through integrating digital workflows
- Considering scaling and translation of systems into other settings – including expanding BiOC partnerships across SEQ
- And ultimately – contributing to ongoing improvement in health and well-being outcomes for mothers, babies and their families

