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AUSTRALIA

Indigenous Data Sovereignty in Australia

Professor James Ward
University of Queensland

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Acknowledgement of Country

I acknowledges the Traditional Owners of Tardnayanga, the Kaurna People and their custodianship of the lands on which we meet.

I pay my 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.

Digital reproduction of *Consolidate* by proud Kalkadoon artist Sid Domic.

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Data and Indigenous peoples

- Historically data has been used to control, count, restrict movements, identify, and to manage First Nations peoples in Australia
- Data is power, can tell compelling stories, and equally can do harm
- In contemporary Australia most data is held in institutions, and not with communities where data is derived from
- The Indigenous data sovereignty movement is one of the foundational movements for “health data justice”
- IDS Supported by the UN DRIP and CTG Priority reform number 4

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Defining Indigenous Data?

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Information or knowledge in any format, inclusive of statistics that is about Indigenous people and that impacts Indigenous lives at the collective and/or individual level

Our Resources

environments, land, history, geographical information, titles and water information

About Us

demographic, social, legal, health, education use of services including our own data

From Us

traditional cultural, archives oral literature ancestral knowledge and community stories.

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Indigenous Data Sovereignty

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“Indigenous Data Sovereignty is the right of Indigenous peoples to govern the collection, ownership and application of data about Indigenous communities, peoples, lands, and resources.

4. <u>Priority Reform 4 NACTG Shared access to data and information at a regional level</u>

- This reform focuses on improving and sharing access to data and information so that communities can make informed decisions. It involves providing data to Aboriginal and Torres Strait Islander people, not just collecting it.

Indigenous Data Sovereignty

- IDS had its origins in 2004
- Indigenous groups in CANZUS countries have led the way
- Leading Australian work in IDS is the Maim Nayri Wingara collaboration

Why IDS and why IDG is essential?

Addressing the Indigenous data paradox – i.e., Too much of the wrong type of data and too little data of the right sort.

IDS aims to address what is all too often is done with Indigenous data what is termed by Prof Maggie Walter the 5D data- Differences, Disparity, Disadvantage, Dysfunctional and Deprivation.

IDS aims to overcome 5 categories of Indigenous data failure = BADDR Data- Blaming, Aggregate, Decontextualized, Deficit data, Restricted Access.

Miam Nayri Wingara IDS Principles

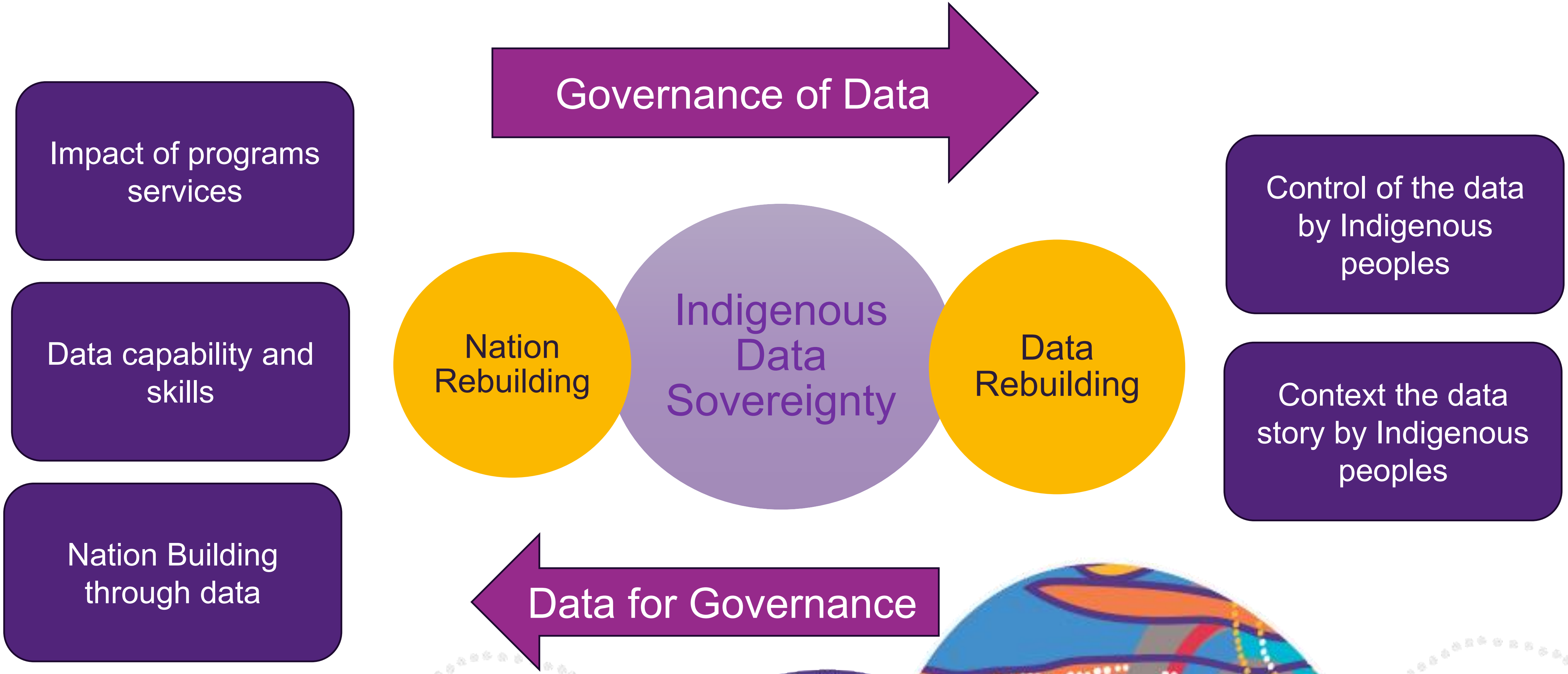
1. Exercise control of the data ecosystem including creation, development, stewardship, analysis, dissemination and infrastructure.
2. Data that is contextual and disaggregated.
3. Data that is relevant and empowers sustainable self-determination and effective self-governance.
4. Data structures that are accountable to Indigenous peoples and First Nations.
5. Data that is protective and respects our individual and collective interests

SOURCE: Walter, M. Lovett R., Bodkin Andrews, G. & Lee, V. (2018) *Indigenous Data Sovereignty Communique* Miaim nayri Wingara Data Sovereignty Group and the Australian Indigenous Governance Institute

Sensitive issues for us re data

- Data that is collected but not analysed
- Big data that is predicated on majority populations
- Data collected without Indigenous input to governance
- Language is important when discussing Indigenous people
    - STIs without context -structural systemic
    - STIs in children
    - IDU without context
    - HIV cases -low numbers, local context
    - Data and issues that can lead to child removal

Data Governance in Indigenous Communities



Governance of Data

Impact of programs services

Data capability and skills

Nation Building through data

Nation Rebuilding

Indigenous Data Sovereignty

Data Rebuilding

Control of the data by Indigenous peoples

Context the data story by Indigenous peoples

Data for Governance

SOURCE: Adapted from Russo Carroll et al, 2019, Indigenous Data Governance: Strategies from the United Stat Native Nations. Data Sci J

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ATLAS

Indigenous Primary Care and Surveillance Network

- Nationally there is a gap in testing data
- We have positives through notifiable diseases but not negatives
- 2016 established ATLAS comprising 90 Indigenous Primary Health Care services to understand testing and management of STIs and BBVs

SESSION 13E Riverbank Room Tomorrow 4-530pm

Establishment of a sentinel surveillance network for sexually transmissible infections and blood borne viruses in Aboriginal primary care services across Australia: the ATLAS project

Clare Bradley ✉, Belinda Hengel, Katy Crawford, Salenna Elliott, Basil Donovan, Donna B. Mak, Barbara Nattabi, David Johnson, Rebecca Guy, Christopher K. Fairley, Handan Wand, James Ward & and the Centre of Research Excellence in Aboriginal Sexual Health investigator group

ATLAS Surveillance and Research Network

96 clinics nationally

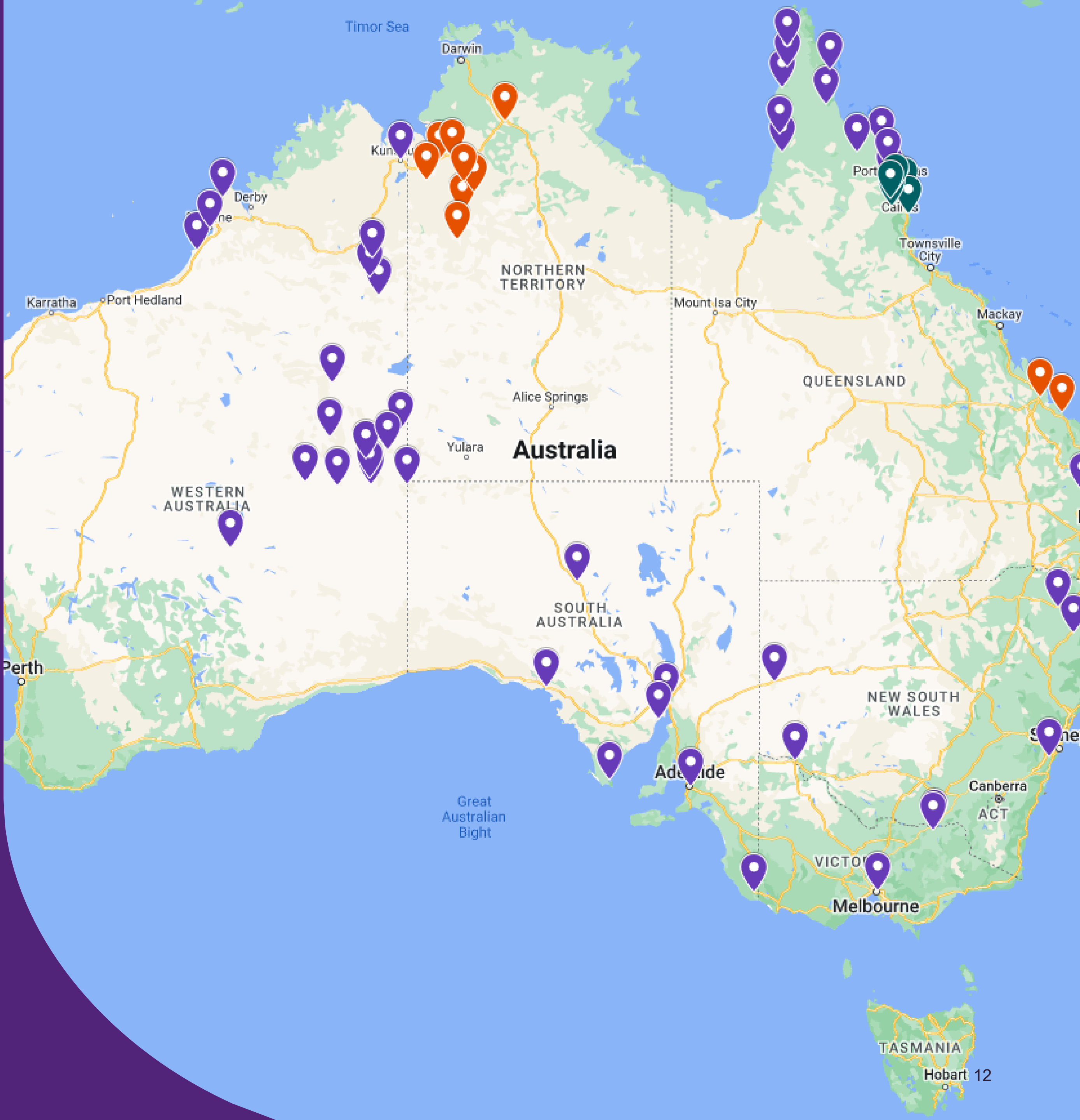
STIs and BBVs (soon to expand to VPDs)

Regular (weekly) automated, deidentified, individual, clinical data extracted from electronic medical record (EMRs)

ATLAS functions are:

- *Surveillance*
- *CQI*
- *Research*
- *Capacity building*

Each ACCHS has access to a dashboard containing own data



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Governance of ATLAS

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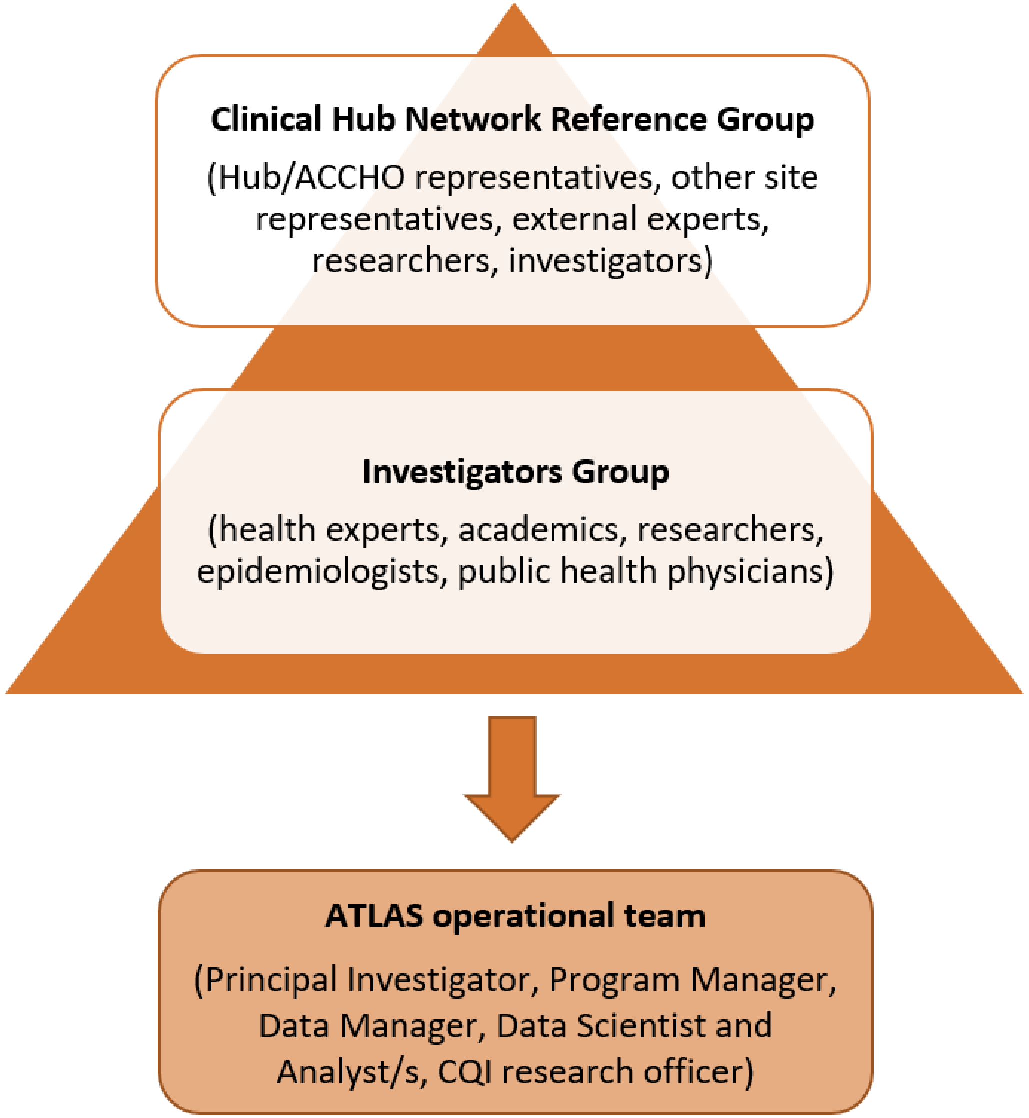
ATLAS has a strong focus on **Indigenous data sovereignty**, **Community involvement** and **governance arrangement led by communities**.

The primary governance group for ATLAS is the Clinical Hub Network Reference Group.

-- provide Indigenous governance expertise, review research proposals & ensure the ATLAS program adheres to Aboriginal and Torres Strait Islander health research principles



Clinical Hub Network Reference Group

(Hub/ACCHO representatives, other site representatives, external experts, researchers, investigators)

Investigators Group

(health experts, academics, researchers, epidemiologists, public health physicians)

ATLAS operational team

(Principal Investigator, Program Manager, Data Manager, Data Scientist and Analyst/s, CQI research officer)

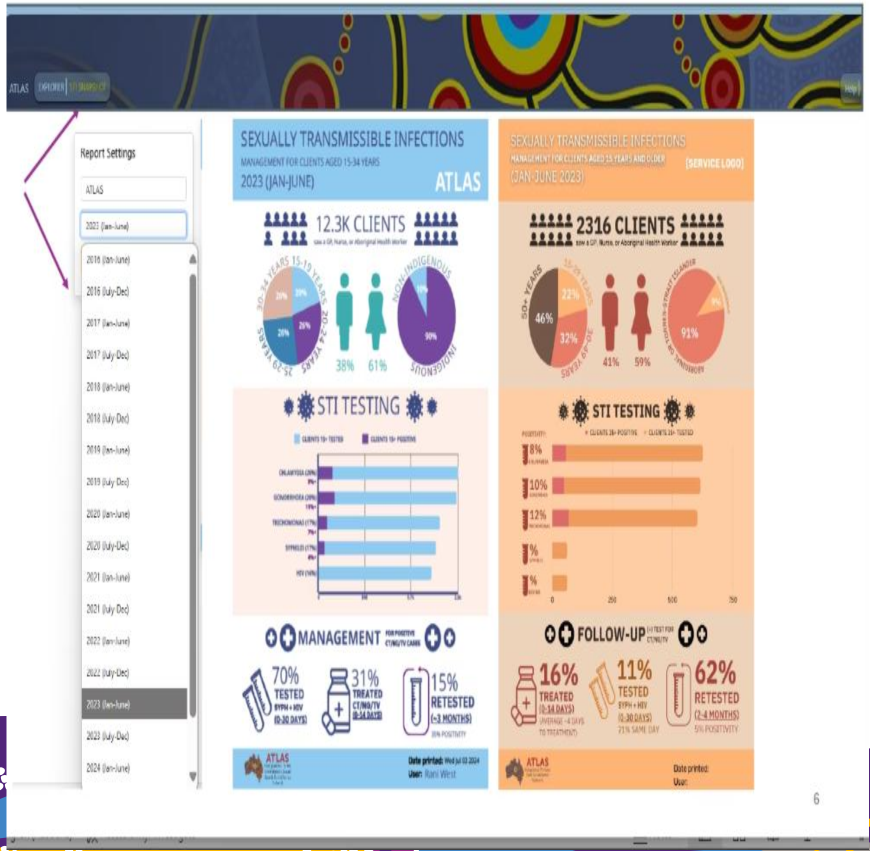
ATLAS data relates only to clinical guidelines

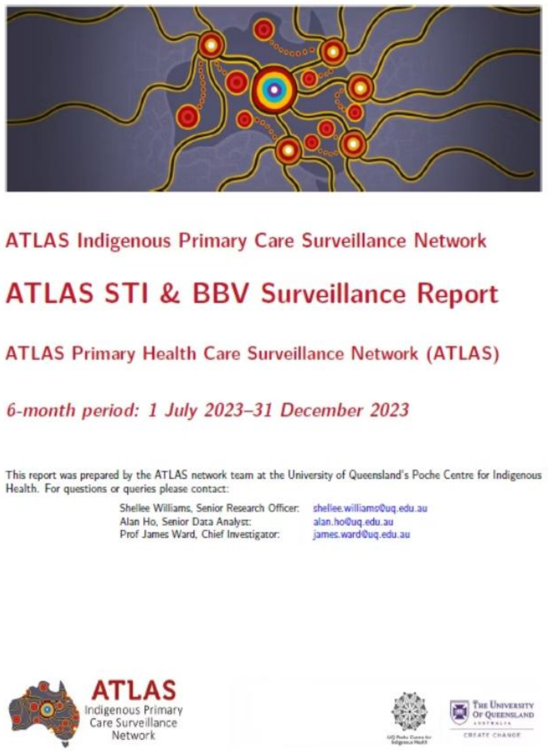
Health service dashboards and reports

6 BBV measures

STI Performance Measures

1. STI Testing Rate
2. STI Testing Coverage
3. STI Test Positivity
4. Completeness of STI Testing
5. STI Treatment Interval
6. STI Retesting Rate
7. STI Repeat Positivity Rate





ATLAS Indigenous Primary Care Surveillance Network

ATLAS STI & BBV Surveillance Report

ATLAS Primary Health Care Surveillance Network (ATLAS)

6-month period: 1 July 2023–31 December 2023

This report was prepared by the ATLAS network team at the University of Queensland's Poche Centre for Indigenous Health. For questions or queries please contact:

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Care Surveillance
Network

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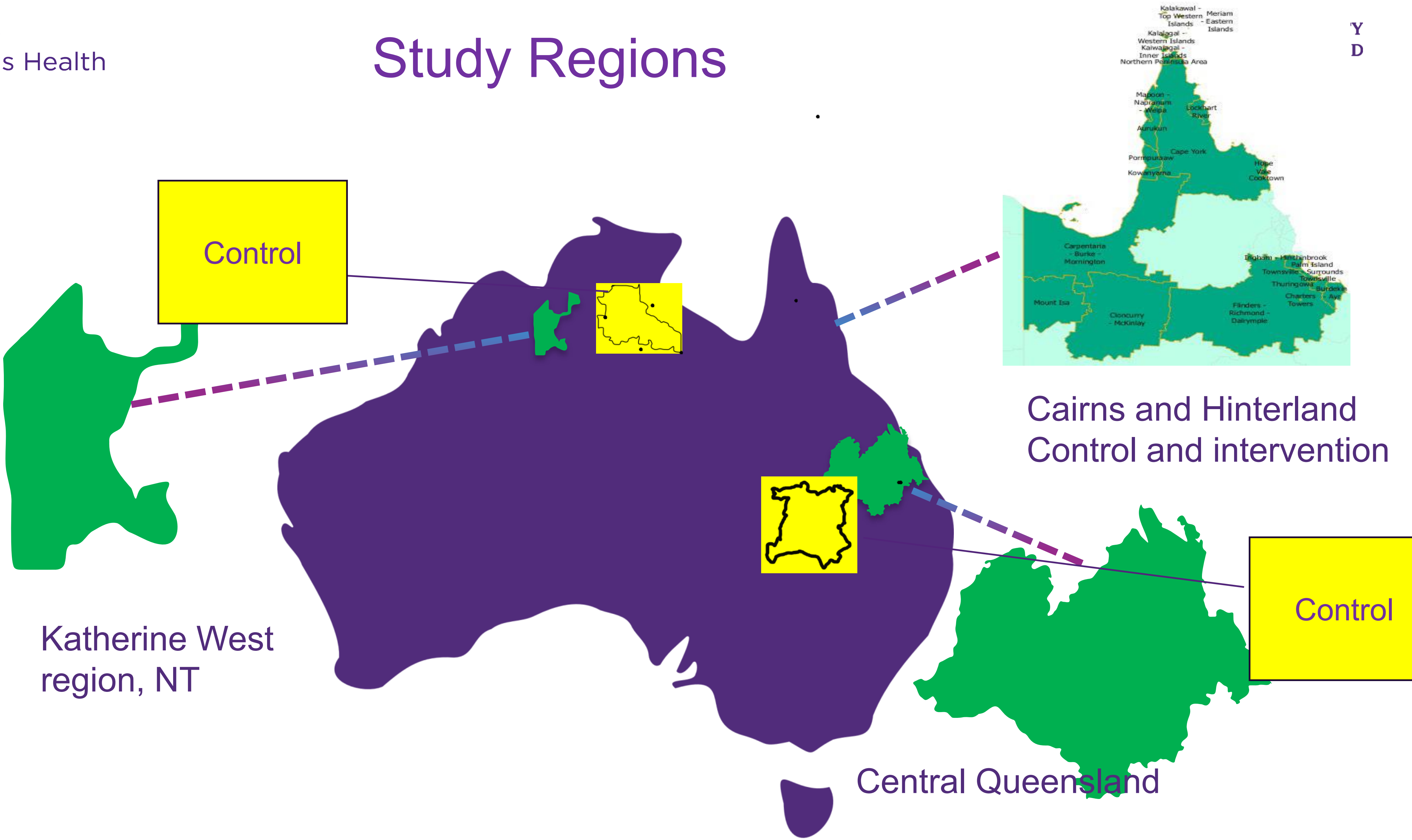
Study Regions



Control

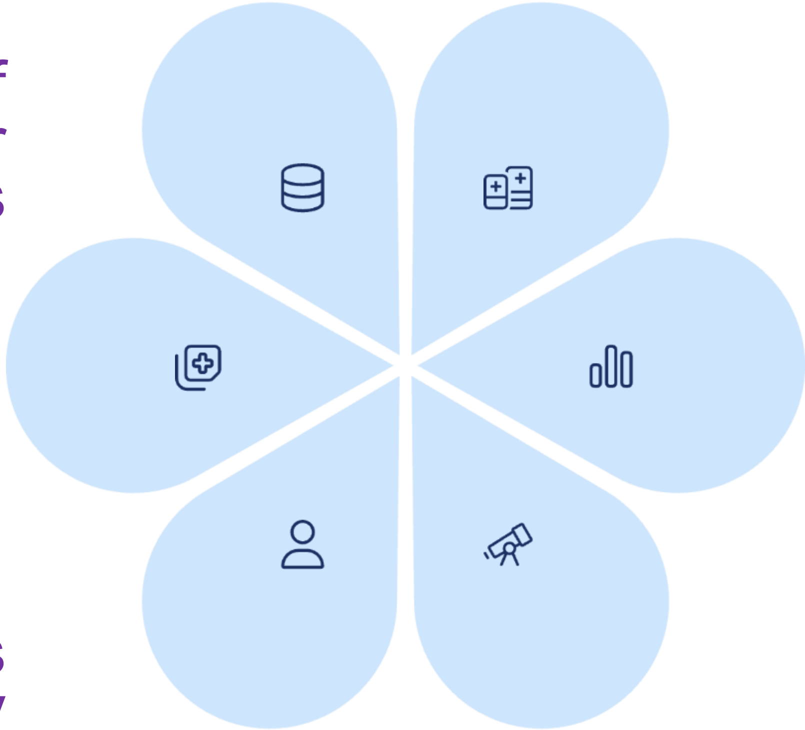
Katherine West region, NT

Cairns and Hinterland
Control and intervention

Control

Central Queensland

Epidemic appraisal + collating determinants and local mapping to Inform Intervention



SDOH Data

Social determinants of health indicators for communities

Hospital STI Outcomes

Complications and sequelae of untreated infections

Behavioral

Interviews and focus groups mobility relationships, access t care

Health Service Data

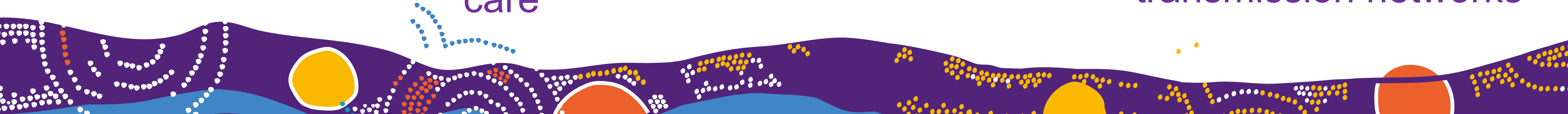
Testing rates, treatment times, and service delivery metrics

Notifiable Diseases Data

Regional and population-specific STI notification trends

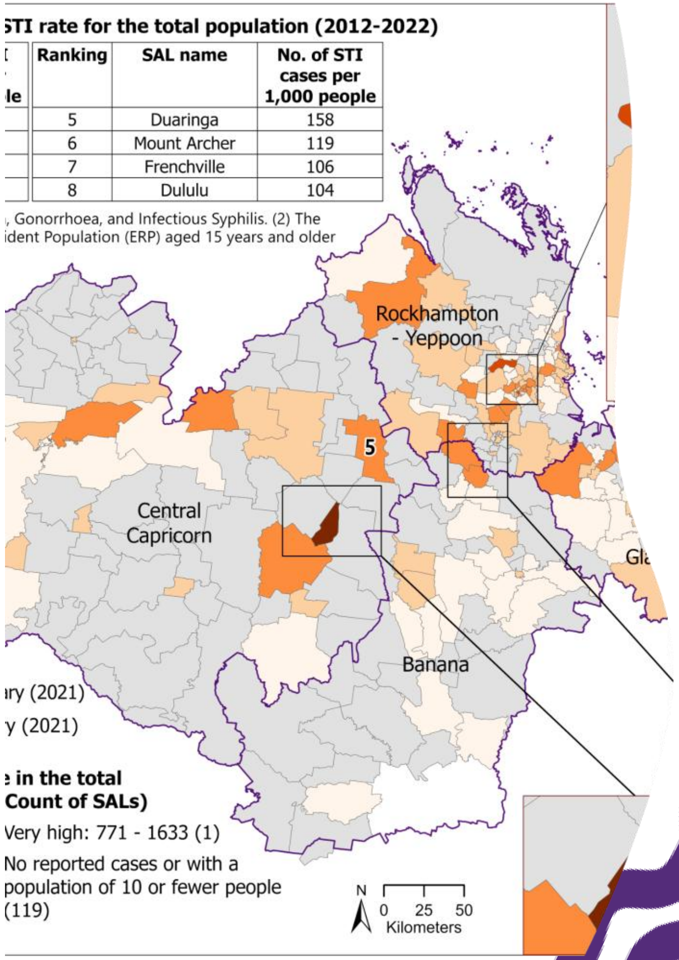
Genomics Data

NG/Syphilis strain characterization and transmission networks



Mapped most of this data at the local level within each region to inform interventions

To help shape interventions
Guide potency
Right areas
Right populations
Provided to community engagement groups for interpretation and local contextual information



TI rate for the total population (2012-2022)

Ranking	SAL name	No. of STI cases per 1,000 people
5	Duaringa	158
6	Mount Archer	119
7	Frenchville	106
8	Dululu	104

, Gonorrhoea, and Infectious Syphilis. (2) The
ident Population (ERP) aged 15 years and older

ry (2021)
y (2021)

in the total
Count of SALs)
Very high: 771 - 1633 (1)
No reported cases or with a population of 10 or fewer people (119)

Our Multilevel Intervention Framework

Community level (access)
- Nudges
- Regional Health promotion campaign

Health Services (management)
- Staff training
  Clinician nudges
- CQI/ATLAS
- Targets
- Point of care

Structural
- Men’s clinics
- Condoms
- Men B Vax
- Model of care- longer clinic hours

Study Outcomes

Primary Outcomes:

Decrease in STI prevalence

CT/NG, Syphilis, TV (NT only) by intervention sites

- Region and community level, Aboriginal status
- Age groups: 15-19, 20-24, 25-29
- Reproductive age group (15-44) for females

Secondary Outcomes:

- STI Cascade of Care regionally and at health service level

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Secondary Outcome: Improved testing and management STI Cascade of Care at each health service (n=18) and at a regional level (x 3)

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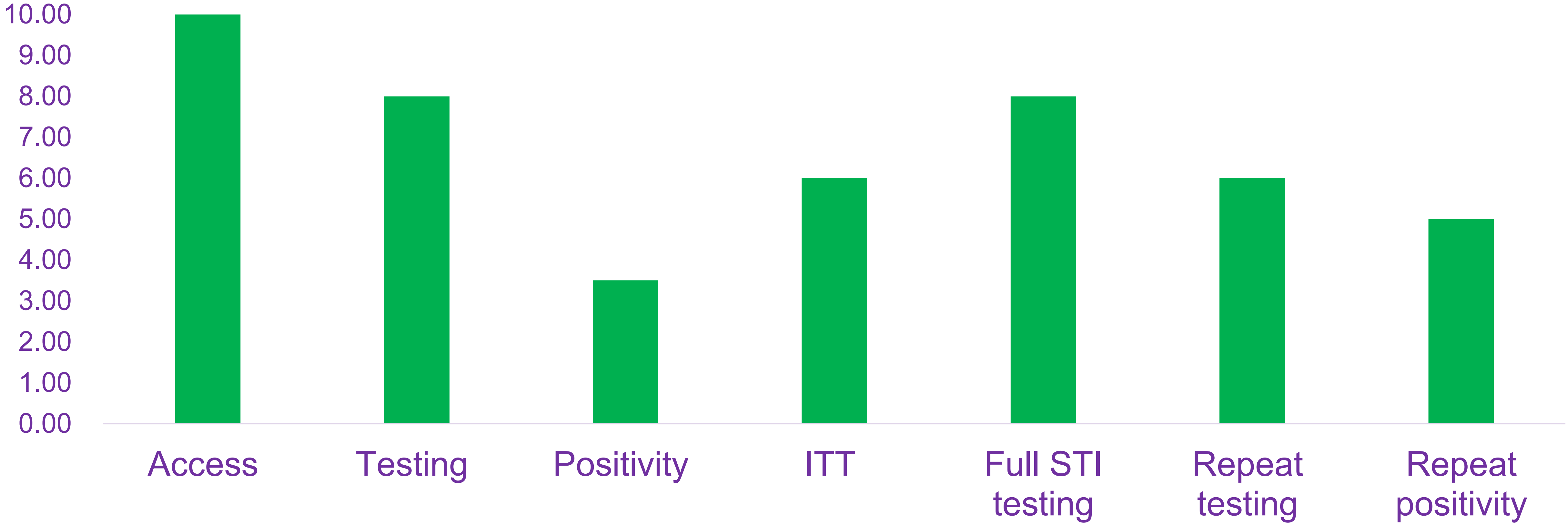

*ITT= Interval time to treatment

How IDS might be enacted with National HIV data

- In alignment with a shift in the future of Indigenous Sovereignty including truth telling healing and Treaty
- Possession of Data could sit in a yet to be established research data commons with Indigenous Data Governance
- Enables communities particularly affected communities to shape data that is beneficial for communities that is encompassing of relationality
- Enables spaces for build capacity for community-led, localised HIV research that is rooted in ceremony, kinship, and Indigenous sovereignty

Examples of how Indigenous HIV data could benefit if IDS and IDG is realised

- Shift in research centring trauma to an intersectional framework that centres, joy and wellness
- A shift in truth telling to move forward with strategies and policies
- A shift that pushes against colonisation, its systems and structures
- A shift in peers and communities as support mechanisms
- A shift toward thrivance, then survivance, as opposed to counts of illness, disease and mortality.

In summary

- IDS and IDG are paramount to achieving better outcomes for Indigenous peoples globally
- Achieving IDS and IDG will take courage, disrupting systems that were never about us, it means relinquishing power by those who have power in data , it means trusting, it means better outcomes for mob if our aspirations are achieved.
- In the meantime and even once achieved, there will be room for trusted allies.
- Finally there should be proper consideration for a research data commons established with IG within ACDC