

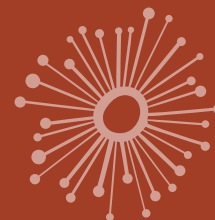
HEALTHY NORTH COAST **ABORIGINAL HEALTH PARTNERSHIP**

Indigenous Data Sovereignty & Governance Protocol

June 2026



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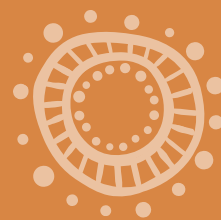
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ACKNOWLEDGEMENTS



We acknowledge and pay respects to Aboriginal and Torres Strait Islander peoples as the Traditional Custodians of the lands and waters across the Healthy North Coast region, including Bundjalung, Githabal, Yaegl, Gumbaynggirr, Dunghutti and Birpai Countries, and to Elders past and present.

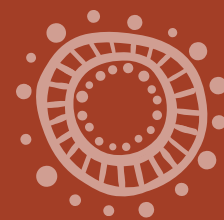
Our respect is extended to the deep and enduring Cultural and spiritual connections that Aboriginal and Torres Strait Islander peoples hold with lands, waters, skies, and Community. We recognise the strength and leadership of Aboriginal and Torres Strait Islander Communities in guiding this work.

Gratitude is extended to Aboriginal Community Controlled Organisations, Community leaders, practitioners, and Healthy North Coast staff who contributed time, knowledge, and stories to the development of this protocol. The generosity and leadership shared throughout this process ensure this work upholds and reflects Aboriginal and Torres Strait Islander values, priorities, and aspirations for self-determination.

Acknowledgement is given to Aboriginal and Torres Strait Islander peoples whose wisdom and resilience continue to contribute to strong, healthy futures for Communities across the region.



ABOUT THE ARTIST



Frances Belle Parker is a proud Yaegl woman, mother and artist from Maclean in Northern New South Wales.

She is deeply inspired by her Mother's land (Yaegl Country) and the Island in the Clarence River that her Mother grew up on, Ulgundahi Island. Frances has been a practising artist for the last 25 years coming to prominence after winning the Blake Prize in 2000 making her the youngest ever winner and the first Indigenous recipient in the prize's history.

'I am inspired by the Yaegl landscape and those stories which were shared with me and passed down from our old people. It is my responsibility to document these stories and to map our landscape. In doing so I am making a valuable resource for my children and all of the younger Yaegl mob.'

Artwork Statement - Guided by Country (Digital artwork, 2025)



Guided by Country honours the principle of Indigenous Data Sovereignty, the right of Aboriginal communities to govern, own, and control the knowledge, stories, and cultural expressions represented in this work. Ownership of these cultural elements remains with the communities to whom they belong.

The piece pays tribute to the lands and Aboriginal communities from Tweed Heads to Port Macquarie, capturing the richness of Country, including its coastal waters, rivers, forests, and mountains. Each element reflects the enduring strength, care, and cultural continuity of the peoples who have

protected these places for generations.

At the heart of the artwork are seven figures that not only depict the partnership, they also reflect the seven guiding principles of Strength, Collaboration, Unity, Sharing, Trust, Reciprocity, and Integrity, they each symbolise the foundations of our partnership and our commitment to walking together with respect and mutual learning.

The work also embodies core principles for engaging with Aboriginal communities: self-determination, cultural rights, amplifying Aboriginal voices, and transparency. These are expressed through various elements including pathways, symbols, layers of sky and land that symbolise connections to community, as well as spiritual figures that invite trust and connection.

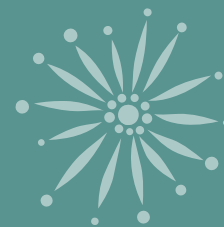
Guided by Country stands as a visual affirmation of our shared commitment to Aboriginal health, education, and cultural strength, inviting viewers to reflect and continue the journey of partnership.

Frances Belle Parker

CONTEMPORARY AUSTRALIAN
ABORIGINAL ARTIST

francesbelleparker.com.au

PREAMBLE



Story of How We Got Here

Aboriginal and Torres Strait Islander peoples have always held knowledge systems that protect, guide, and strengthen Communities, families, and Country. Data on Aboriginal and Torres Strait Islander Communities holds these stories and knowledge, and must be cared for with the same respect as any other Cultural asset.

For too long, data on Aboriginal and Torres Strait Islander Communities have been collected, interpreted, and used without consent, often reinforcing deficit narratives and colonial structures. Communities have called for change, seeking to reclaim control over how data is collected, stored, shared, and used to guide decisions that affect their lives.

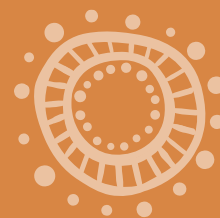
The Healthy North Coast Aboriginal Health Partnership recognise that Indigenous Data Sovereignty and Governance are essential to self-determination, better health outcomes, and the well-being of Communities. Together, we are committed to moving beyond compliance-based approaches to data and towards practices that uphold the rights, priorities, and aspirations of Aboriginal and Torres Strait Islander peoples.

This commitment has grown through conversations, learning together, and reflecting on what true partnership means. It has been strengthened by Community leaders, boards, and practitioners who have guided discussions on how IDS&G should look and feel within the Healthy North Coast region. It is informed by global frameworks and national commitments, including the United Nations Declaration on the Rights of Indigenous Peoples, the CARE Principles, and Priority Reform Four of the National Agreement on Closing the Gap.

This protocol captures what we have heard, learned, and committed to. It marks a practical step towards ensuring that data governance is led by Aboriginal and Torres Strait Islander peoples, is grounded in Cultural responsiveness, and supports Communities to share, protect, and use data to tell stories, advocate for priorities, and determine futures.



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BACKGROUND & INTRODUCTION

This section provides the context for why this protocol was developed and the journey that led to its creation.



About this document

This document outlines the protocol for managing Aboriginal and Torres Strait Islander data and information within the Healthy North Coast (HNC) Aboriginal Health Partnership. It has been developed through a collaborative process, drawing on the insights and contributions of Aboriginal Community Controlled Health Organisations (ACCHOs), Aboriginal Community leaders, practitioners, and HNC.

The protocol is guided by the principles of Indigenous Data Sovereignty and Governance (IDS&G), aiming to establish clear expectations and guidelines for data and information practices that support Aboriginal self-determination in all aspects of data governance and use.

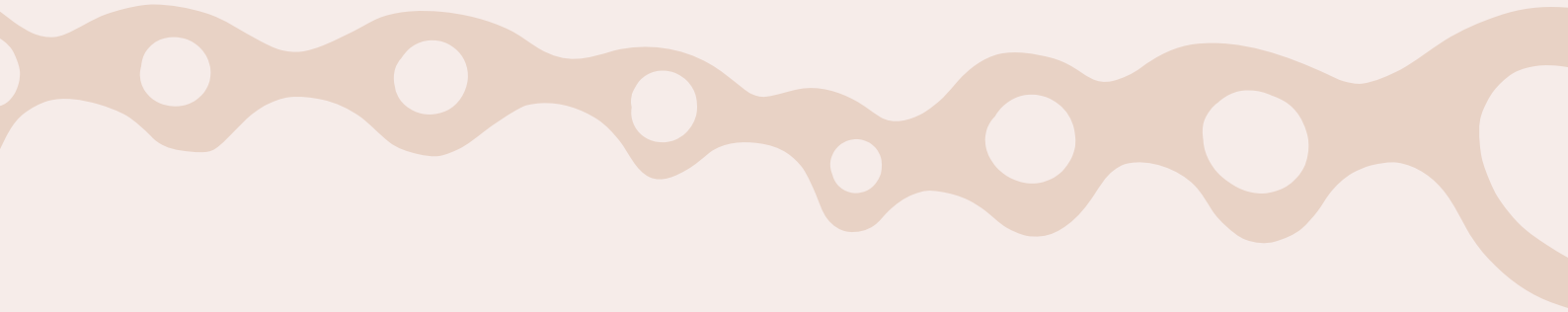
This document is intended to be a living protocol, reviewed and adapted as the HNC Aboriginal Health Partnership's work progresses and collective understanding of IDS&G deepens across the HNC region.

About this Project

This project strengthens IDS&G across the HNC region, ensuring data and information practices uphold the rights, Cultural values, and aspirations of Aboriginal Communities. It has been developed through a series of workshops and co-design sessions with ACCHOs and HNC, reflecting shared priorities for Culturally grounded, Community-led data governance.

About Healthy North Coast

HNC is a regional primary health network, an Australian government-funded organisation working to improve health and wellbeing outcomes for people across the North Coast of NSW. Guided by its vision of Healthy People in North Coast Communities, HNC recognises that Aboriginal and Torres Strait Islander peoples hold the knowledge and solutions to drive positive change for Community health and wellbeing. HNC is committed to partnering with ACCHOs to ensure primary health care is Community-led, Culturally safe, and strengths-based.



About the HNC Aboriginal Health Partnership Agreement

In October 2023, HNC and the six ACCHOs across the region signed a landmark Partnership Agreement, known as the Healthy North Coast Aboriginal Health Partnership. This agreement reaffirms a shared commitment to improving health outcomes for Aboriginal Communities through self-determination, partnership, and shared decision-making in primary health care. It recognises the expertise and leadership of ACCHOs in delivering Culturally safe services and acknowledges the critical role of data and information in informing decisions aligned with Community priorities.

Core Partners

This protocol has been developed in partnership with all members of the HNC Aboriginal Health Partnership, which at the time consisted of HNC and participating ACCHOs across the region, including

- Bulgarr Ngaru Medical Aboriginal Corporation
- Durri Aboriginal Corporation Medical Service
- Werin Aboriginal Corporation
- Bullinah Aboriginal Health Service
- Galambila Aboriginal Health Service
- Rekindling the Spirit

All partners work together to ensure that data governance upholds the rights of Aboriginal and Torres Strait Islander peoples while supporting better health and wellbeing outcomes for Communities across the North Coast.

About This Protocol

This protocol guides HNC's IDS&G work, which was developed in partnership with participating ACCHOs and Community partners. It reflects collective commitments to uphold IDS&G, ensuring data and information are collected, interpreted, and shared in ways determined by Aboriginal Communities.

This protocol is a living document, evolving as the HNC Aboriginal Health Partnership matures and as the understanding and practice of IDS&G deepen across the HNC region. Version 1 endorsed in June 2026.

PROJECT APPROACH



This protocol was developed through a multi-phased, collaborative, and iterative process, prioritising the perspectives, lived experience, and active participation of Aboriginal and Torres Strait Islander stakeholders across the North Coast. The methodology ensured the protocol is grounded in IDS&G principles while being practical and relevant to the HNC Aboriginal Health Partnership context.

Phase 1: Establishing Strong Foundations for Sovereignty

Phase 1 focused on creating a shared understanding of IDS&G principles across the HNC Aboriginal Health Partnership and recognising historical and current concerns around data.

- Facilitated initial workshops and discussions with ACCHOs, health leaders, and Aboriginal Community representatives across the North Coast.
- Explored the meaning of data sovereignty in the HNC Aboriginal Health Partnership context, clarifying that data sovereignty is about Community control and care for stories, information, and knowledge, not simply data sharing.
- Discussed past and current experiences of data misuse and the “weaponisation of data” that have contributed to mistrust and disengagement.
- Centred self-determination, Aboriginal leadership, and Community control in data collection, analysis, interpretation, governance, and advocacy.
- Established a shared language and understanding of key concepts such as “data sovereignty,” “data governance,” “self-determination,” and “story as data” to ensure clarity across partners.
- Identified HNC Aboriginal Health Partnerships opportunity to model reparative practice in IDS&G within the regional health ecosystem.



Phase 2: Understanding the Current Landscape and Assessing Readiness

Phase 2 assessed the current landscape, systems, and readiness of the HNC Aboriginal Health Partnership to implement IDS&G principles in practice.

- Mapped current data governance practices and data flows within HNC, ACCHSs, and broader service networks, including existing data sharing agreements, data handling practices, and system limitations.
- Identified systemic challenges and power imbalances, including the disproportionate control and access to data by mainstream services compared to ACCOs and Community.
- Evaluated technical capacity, infrastructure, and workforce capability within HNC and ACCHSs to manage, interpret, and utilise data effectively.
- Assessed organisational and governance readiness, including the willingness and commitment of partners to centre IDS&G, address structural barriers, and uphold First Nations-led governance.
- Used readiness self-assessment rubrics during Workshop 2 to identify where ACCHSs and HNC currently sit along an early–developing–leading spectrum, noting a collective aspiration to move towards leading practice.

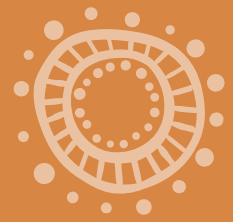
Phase 3: Protocol Development and Implementation Planning

Phase 3 involved co-designing the HNC Aboriginal Health Partnership IDS&G Protocol, ensuring its principles and governance arrangements are actionable, sustainable, and Community-driven.

- Facilitated Workshop 3 to co-design IDS&G principles using the OCCAAARS framework, contextualising each principle to the HNC Aboriginal Health partnership. Defined governance structures, confirming the HNC Aboriginal Health Partnership as the Indigenous data governance body to oversee protocol implementation and decision-making.
- Clarified roles and responsibilities for data custodianship, access, interpretation, use, and sharing, centring Aboriginal-controlled, shared decision-making, and transparency.
- Established mechanisms for Community accountability, informed consent, Culturally responsive data management, and ‘do no harm’ principles in all data work.
- Identified pilot projects to operationalise the protocol (e.g., nKPI triangulation projects), recognising the importance of starting small to test and refine processes collaboratively.
- Developed strategies to strengthen capacity building, data literacy, and shared language across partners, supporting sustainable and scalable implementation over time.

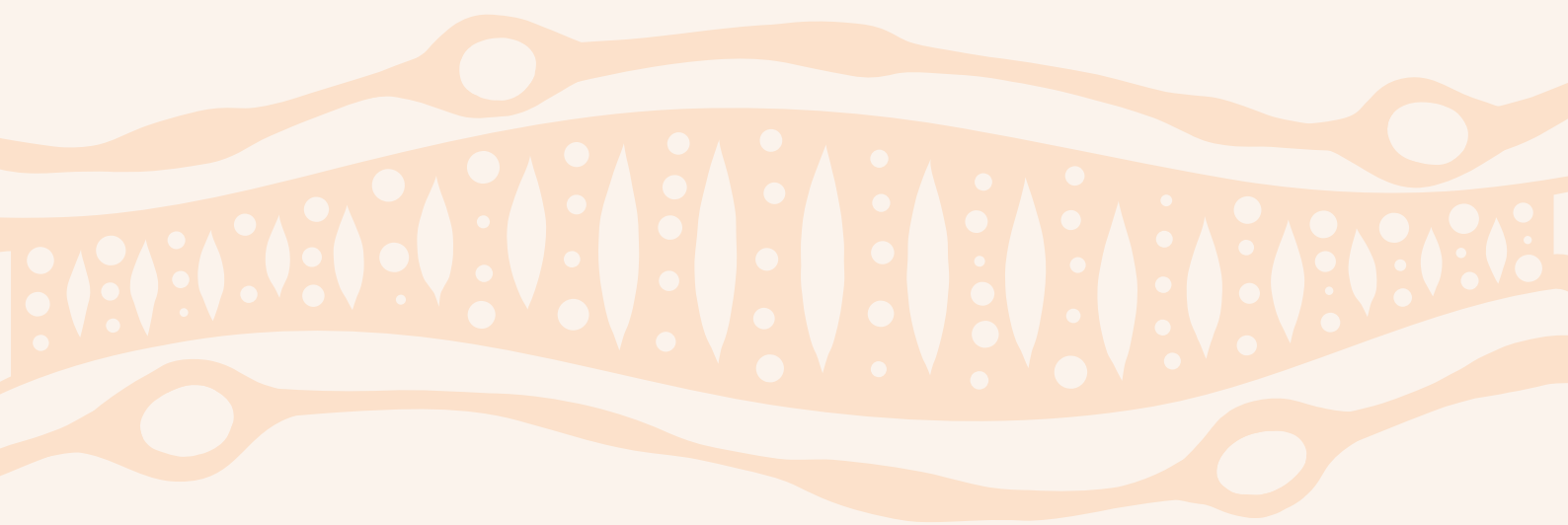
ESTABLISHING STRONG FOUNDATIONS FOR SOVEREIGNTY

This section outlines the foundational concepts, frameworks, and definitions that underpin HNC's commitment to IDS&G. It explains why IDS&G is essential for HNC and its partners and the principles guiding how IDS&G will be realised in practice across the region.



Indigenous Data Sovereignty: A Global Perspective

IDS is gaining momentum worldwide, driven by Aboriginal and Torres Strait Islander peoples' rights to reclaim ownership and control over their data. It challenges historical practices where data on Aboriginal Communities has been collected, used, and disseminated without meaningful consent, perpetuating harm and reinforcing colonial power dynamics. IDS&G asserts the need for Aboriginal Communities to govern data to ensure it is used in Culturally appropriate, ethical, and beneficial ways.



The Importance of Indigenous Data Sovereignty in Health

IDS is of paramount importance within the healthcare context. The significant health disparities experienced by Aboriginal Communities underscore the necessity of gathering health data that is not only accurate and relevant but also Culturally sensitive. Aboriginal Communities possess unique insights into their health priorities and are best positioned to develop effective strategies for addressing them. Therefore, adopting IDS principles is crucial to ensure that health data collection, analysis, and use align with Aboriginal perspectives, priorities, and aspirations.

A scoping review indicates that while IDS&G is increasingly recognised across various sectors, its implementation within the health sector is still in the early stages. This is reflected in the limited literature and established frameworks that specifically operationalise IDS&G in healthcare settings. Nonetheless, the review affirms a strong recognition of the importance of IDS&G and a growing commitment to support self-determination for Aboriginal Communities, particularly in alignment with the Australian Government's Priority Reform Four of the National Agreement on Closing the Gap, which emphasises shared access to data and information at the regional level for Aboriginal Communities.

Global frameworks such as the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) and principles like CARE (Collective Benefit, Authority to Control, Responsibility, Ethics) provide essential foundational standards for IDS&G. However, the practical application of these frameworks within the health sector requires further development.

Aboriginal Communities have consistently demonstrated leadership in designing and governing their health data despite these challenges. The reviewed frameworks underscore the importance of Community-led governance structures that prioritise Cultural knowledge, respect Indigenous worldviews, and ensure that data is collected, analysed, and used to enhance Community well-being. This emphasis on Community-led data governance is echoed across numerous frameworks and initiatives within the Australian context, including those advanced by organisations such as the Lowitja Institute, the Maiam Nayri Wingara Collective, the Agency for Clinical Innovation (ACI), and the Cancer Institute.

Embedding IDS&G within complex health systems presents considerable challenges. Many health institutions often operate with entrenched data governance structures and policies that may conflict with Aboriginal Communities' rights to self-determination. Overcoming these obstacles necessitates sustained efforts to relinquish control over health data and ensure that Aboriginal voices are central to decision-making processes. Increasing transparency and accessibility of data for Aboriginal Communities is crucial.

The HNC Aboriginal Health Partnership recognises the inherent complexities of working with diverse, independent organisations and the need for negotiated, Community-led approaches to data governance. Refining data governance frameworks to fully integrate IDS&G principles, processes, and practices is a key consideration for the HNC Aboriginal Health Partnership.

A central challenge in embedding IDS&G within the health sector lies in ensuring that data is handled in a manner that respects Aboriginal privacy and confidentiality. HNC's commitment to strong privacy and security protocols, including informed consent, Culturally responsive data practices, and secure data handling systems, will be critical to ensuring IDS&G is enacted meaningfully within regional health governance.



The Importance of IDS&G for the North Coast

Aboriginal partners across HNC foresee that embedding IDS&G will fundamentally reshape policy, governance, and Community resilience for the long term. By putting decision-making back in the hands of Community-controlled sectors, IDS&G will fuel self-determined pathways and nurture lasting Community growth. IDS&G holds the power to shift policy directions, ensuring they reflect Community priorities, enhance Cultural safety, and transform systems to better respond to Aboriginal perspectives. The long-term vision shared by partners is for Communities to harness data to achieve tangible improvements, particularly in health and well-being.

For the HNC Aboriginal Health Partnership, IDS&G is foundational. It guarantees that Aboriginal Communities have control over data and are supported to uphold rights to self-determination. Partners have raised critical concerns about governance, ethical considerations, and privacy in relation to Aboriginal health data, particularly within smaller Communities. In response, the HNC Aboriginal Health Partnership is committed to developing and implementing IDS&G across its programs and data practices.

By embracing IDS&G principles, the HNC Aboriginal Health Partnership has the potential to set new benchmarks in health data sovereignty and governance, aligning with global frameworks such as UNDRIP, the CARE Principles, and the Maïam Nayri Wingara collective, all of which emphasise Community control over data. While integrating IDS&G within existing health infrastructure presents challenges, the increasing recognition of IDS&G signifies a positive shift towards health systems that respect the rights and self-determination of Aboriginal Communities.

The implementation of IDS&G within the HNC Aboriginal Health Partnership will require investment in Aboriginal leadership, targeted training, and knowledge-sharing to build local capacity for data governance and self-determination. Through workshops, mentoring, and leadership pathways, the HNC Aboriginal Health Partnership will support Aboriginal Communities to govern and safeguard data well into the future.

Partners have identified that IDS&G for the HNC Aboriginal Health Partnership must:

- Prioritise Aboriginal leadership in data collection, analysis, and governance, ensuring data benefits Community.
- Establish Aboriginal ownership of data platforms and infrastructure to protect privacy and build trust.
- Address over-research without tangible change, promoting data-driven decisions aligned with Community values and priorities.
- Empower Communities to share narratives, control services, and achieve outcomes reflecting strengths and aspirations.

By establishing Aboriginal governance and integrating Culturally informed Understanding, Monitoring, Evaluation, and Learning (UMEL) practices, the HNC Aboriginal Health Partnership will protect Indigenous data and amplify Aboriginal voices, cultivating trust, accountability, and shared responsibility.

Partners identified several enablers critical for effective IDS&G:

- Building IDS&G expertise through training and leadership opportunities.
- Embedding Aboriginal governance across systems and structures.
- Developing Data Sharing Agreements and mapping data-sharing opportunities aligned with IDS&G.
- Supporting Community control through inclusive conversations about data use, ownership, and benefit.

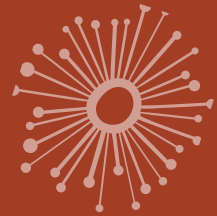
Challenges include:

- Historical misuse of data contributes to Community mistrust.
- Cultural safety practices of non-Aboriginal organisations
- Data practices driven by government priorities are misaligned with Community needs.
- Resource constraints and limited dedicated IDS&G workforce capacity.
- Bureaucratic processes within health systems can undermine Community governance.
- The diverse needs of Communities require flexible, tailored approaches.

This protocol guides the HNC Aboriginal Health Partnership towards sustainable, systemic practices that uphold Aboriginal self-determination within health data governance. By embracing systemic change and First Nations-led governance, the HNC Aboriginal Health Partnership can lead the transformation of regional health data systems to ensure IDS is respected and championed across the health sector.



ESTABLISHING READINESS OF PARTNERS TO REALISE IDS&G FOR HNC ABORIGINAL HEALTH PARTNERSHIP



This section outlines how HNC and ACCHOs partners assessed the readiness to embed IDS&G across the HNC Aboriginal Health Partnership. It explains the structured approach used to reflect on strengths, identify opportunities for growth, and understand the challenges and enablers for progressing IDS&G in a way that is Culturally responsive and led by Aboriginal Communities.

Understanding Readiness for IDS&G

Understanding the current readiness levels of all participating organisations is essential to effectively embedding IDS&G within HNC and its partnerships. This enables a clear, staged approach to strengthening IDS&G, ensuring governance practices are robust, ethical, and aligned with the aspirations of Aboriginal Communities across the region.

The Readiness Rubric

To support this process, each organisation used the Readiness Rubric developed by Kowa to support organisations in understanding how ready they are to support progress towards IDS. This structured tool enables organisations to assess the current stage of readiness across eight domains of IDS&G as defined within the OCCAAARS Framework:

- Ownership
- Control
- Custodianship
- Access
- Accountability
- Amplifying Community Voice
- Relevance and Reciprocity
- Sustainably Self-Determining Practices

Through reflective questioning and scoring, organisations identified whether they were at an early, developing, or leading stage in each domain. This allowed them to highlight strengths, recognise gaps, and prioritise actions to advance IDS&G in a Culturally responsive, strengths-based manner.

Readiness Insights

The readiness assessment process identified variation across organisations, reflecting different histories, capacities, and governance contexts. Partner voices highlighted both the strengths already in place and the challenges that need to be addressed.

PARTNER STORY: OUR BOARD

In Coffs Harbour, on Gumbaynggirr Country, partners gathered around the readiness rubric. The conversation turned to how governance was already working within ACCHOs. One CEO leaned back in his chair, speaking with quiet conviction about his own organisation: ***“Our boards already protect Community data through their decisions.”***

Then another CEO added, ***“That’s right. Every request, every report, has to go through them. It’s not written in some policy manual, but it’s practice. It’s governance in action.”***

From across the table, someone else reflected, ***“That accountability is to our own mob first. We can’t just sign off data to government or funders without checking how it sits with Community.”***

Nods circled the room. These weren’t abstract points; they were lived practices. Long before anyone drafted a protocol, boards have been acting as the guardians of Community knowledge. The conversation reminded everyone that IDS&G is not something being imported from elsewhere. It is already alive on the North Coast, held in the decisions of Community representatives who carry the trust of their people.

PARTNER STORY: TIRED OF TICK-BOXES

That afternoon the conversation turned from strengths to frustrations. One CEO leaned forward on the table, his voice carrying both weariness and sharpness: ***“We’re tired of government priorities driving data collection, while our own needs aren’t recognised.”***

Across the room, another CEO let out a sigh and shook her head. ***“We spend hours filling in forms, ticking boxes for KPIs no one here asked for. And what happens to the data that matters to us? It goes nowhere. It’s invisible.”***

A third leaned in, clasping her hands tightly as she spoke: ***“Our staff burn out doing reports for Canberra, while the stories about connection, about wellbeing, about what’s really happening for families, they never even get collected.”***

The words hung heavy. A murmur of agreement moved through the partners. Someone summed it up plainly: ***“We’re feeding their machine, not ours.”***

The frustration wasn’t anger for its own sake; it was clarity. The system, as it stood, was upside down. If sovereignty was to mean anything, the partners agreed, it had to turn the priorities back around: data collected for Community first, and only then for the funders.

Insights from the Readiness Assessment

Strengths: Strong Aboriginal governance already exists through ACCHO boards, which are protecting Community data and ensuring accountability to mob.

Opportunities for Growth: Partners identified the need to document and formalise existing IDS&G practices, build staff capability in data management, and develop policies that embed reciprocity and Cultural protocols. As one participant put it: “We are already leading in some areas of IDS&G – but it’s not always written down or formalised.”

Challenges: Fragmented data systems, under-resourcing, and funder-driven reporting continue to undermine sovereignty.

Capacity-Building Opportunities: The readiness process itself was seen as valuable, strengthening shared understanding of IDS&G and enabling boards, staff, and Community members to identify actions for continuous improvement. Participants noted that “early stage” self-assessments often reflected high internal standards rather than a lack of progress. Many practices already align with IDS&G principles, even if not yet formalised.

ABORIGINAL DATA SOVEREIGNTY AND GOVERNANCE FOR HNC

The establishment of this protocol has involved deep dialogue, reflection, and collaborative design with HNC partners to determine what it means to realise IDS&G in practice across the HNC region. This section sets out the practical conditions, expectations, and principles for implementation, ensuring that IDS&G is not just a concept but a lived, operational reality within all programs, data practices, and partnerships under this collective.



Governance, Ethics, and Accountability: Empowering Aboriginal Leadership

Aboriginal leadership must guide all data-related decisions within this HNC Aboriginal Health Partnership, ensuring decisions are made by those directly connected to and accountable to Community. This principle is grounded in both the commitments of the HNC Aboriginal Health Partnership and the foundational values of IDS&G.

Current mechanisms in place include:

- Each ACCHO holds authority over data decisions related to their own service, with explicit consent sought for each request, recognising that data sharing is context-dependent and should be underpinned by clear purpose, trust, and mutual benefit.
- A shared executive role (Director, Aboriginal Health Partnerships) embedded within HNC, jointly supervised by the ACCHOs and HNC, ensuring direct accountability and ongoing engagement with each ACCHO's CEO.
- Quarterly face-to-face HNC Aboriginal Health Partnership meetings provide a formal governance forum to review progress on work priorities and collectively address issues related to the HNC Aboriginal Health Partnership Agreement, including data governance.
- A signed HNC Aboriginal Health Partnership Agreement that affirms joint decision-making, transparency, and shared responsibility in alignment with Priority Reform One of the National Agreement on Closing the Gap (CTG), HNC Aboriginal Partners.

To strengthen governance and ensure data decisions remain led by Aboriginal Communities, the HNC Aboriginal Health Partnership will:

- Establish more formalised governance mechanisms, such as terms of reference for data sharing and decision-making processes, including escalation and authorisation pathways.
- Continue to strengthen the interim Data Sharing Agreement (DSA) to ensure it remains Culturally responsive, flexible to diverse governance structures, and supports evolving trust relationships across the HNC Aboriginal Health Partnership.
- Co-design decision-making criteria for future data requests (e.g. funders, government, researchers), so that partners can determine when and how data may be shared beyond individual services.

- Consider AH&MRC participation, where appropriate, to enhance ethical oversight and sector alignment.
- Uphold “do no harm” as a core principle, ensuring that all governance processes protect Community, Cultural integrity, and self-determination.

These evolving governance mechanisms will be co-developed and documented transparently, ensuring the HNC Aboriginal Health Partnership’s data-related decisions are informed by Community values, accountable to Aboriginal stakeholders, and embedded within enduring, Culturally grounded governance structures.

Supporting ACCHOs and Empowering Data Management

Data sovereignty is inseparable from Community well-being, advocacy, and control. ACCHOs partners identified the need to:

- Develop clear policies to protect data on Aboriginal Communities from misuse and external pressures tied to funding.
- Co-create reports and analyses with ACCHOs to ensure data is relevant, meaningful, and grounded in the local context.
- Build data literacy and governance capacity within ACCHOs to support informed, empowered decision-making.

Building Governance Confidence and Capability

ACCHOs partners emphasised that IDS&G must be embedded through practical, Culturally responsive governance structures that uphold Community leadership and protect data on Aboriginal Communities. Key priorities identified include:

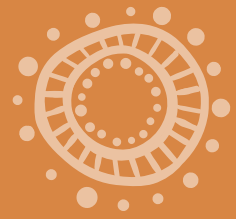
- Strengthening board capability and confidence to lead IDS&G, including providing plain-language resources, briefings, and tailored learning opportunities.
- Supporting boards and staff to interpret and use data in ways that reflect Cultural priorities and guide service delivery.
- Developing Culturally responsive data-sharing agreements that protect Community stories and align with local protocols.
- Ensuring that data is returned to Community in accessible, meaningful formats to support local decision-making.
- Building internal data literacy and governance skills within ACCHOs, ensuring staff and boards can confidently engage with and lead IDS&G practices.

Resourcing Sustainable IDS&G

Embedding IDS&G across the HNC Aboriginal Health Partnership requires dedicated, sustained investment to:

- Support Aboriginal-led governance structures and ensure Community voices guide data-related decisions.
- Allocate resources within each partner organisation to enable participation in IDS&G activities, including staff time, travel, and capacity to engage in governance processes.
- Facilitate training opportunities, tools, and tailored support to build data literacy and governance capability across the HNC Aboriginal Health Partnership.
- Enable practical, Culturally meaningful ways to return data to Community, ensuring it can be used to guide service priorities and support Community-led decision-making.

EMBEDDING INDIGENOUS DATA SOVEREIGNTY: THE OCCAAARS FRAMEWORK FOR HNC

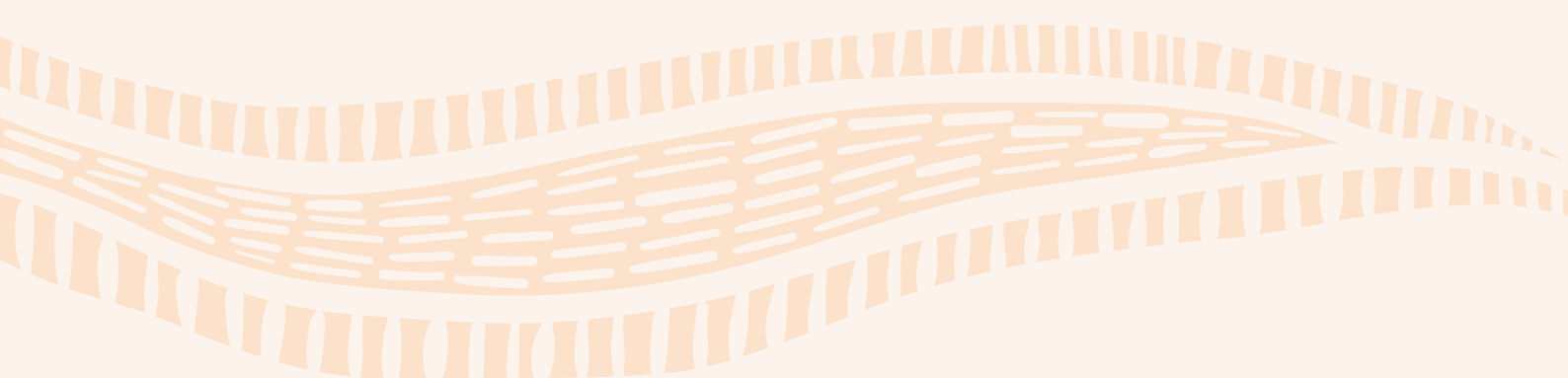


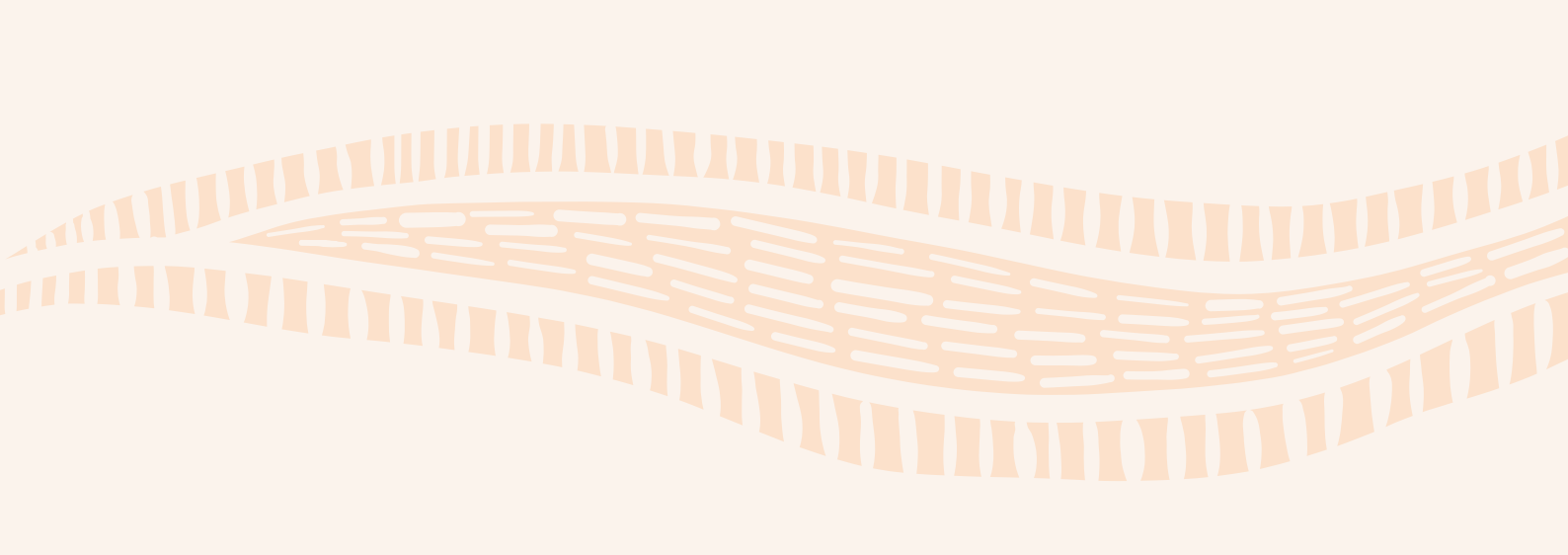
This section outlines how the HNC Aboriginal Health Partnership will practically embed IDS&G across the work, guided by the OCCAAARS Framework. This ensures that IDS&G principles are lived within governance structures, data practices, and everyday decision-making across the HNC Aboriginal Health Partnership.

Using the OCCAAARS Framework (Ownership, Control, Custodianship, Access, Accountability, Amplify Community Voice, Relevant & Reciprocal, Sustainably Self-Determining), developed by Dr Skye Trudgett and grounded in national and international literature and Aboriginal Community practice, participants collaboratively explored what these principles mean in practice for the HNC region.

ACCHOs leaders, board members, and HNC team members reflected on historical experiences of data misuse, the ongoing impacts of deficit narratives, and the structural challenges of working with government data systems that often conflict with Community self-determination. These discussions were framed not only as risk mitigation but as pathways for reclaiming data as a tool for advocacy, healing, and Community-led service transformation. ***“As one Workshop 3 participant explained: ‘Data must be understood as Community stories, not just numbers.’”***

Partners emphasised that data must be understood as Community stories, not just numbers, requiring governance and decision-making processes that respect, protect, and use these stories to benefit Aboriginal Communities.





Understanding the OCCAAARS Framework

The OCCAAARS Framework supports the practical translation of data sovereignty concepts into tangible action. During the workshop, partners agreed on the following shared understandings:

- **Ownership:** Aboriginal Communities and their ACCHOs are the rightful owners of data about people, lands, and services. Ownership is collective, with boards holding governance responsibility as elected representatives of Communities.
- **Control:** Aboriginal organisations must decide how data is collected, analysed, used, and shared. This includes determining priorities for what data is gathered and ensuring consent processes align with Cultural protocols.
- **Custodianship:** While data can be securely held by agreed custodians, such as ACCHOs themselves or, where appropriate, trusted custodians, custodianship does not negate ownership or control by Community. Custodianship involves the responsibility to protect and care for data according to Cultural values.
- **Access:** Community and ACCHOs should have timely, practical access to data in formats that support advocacy, planning, and storytelling.
- **Accountability to First Nations:** Governance structures must prioritise accountability to Community through transparency, clear decision-making, and ongoing reporting back in Culturally appropriate ways.
- **Amplifying Community Voice:** Data must reflect Community realities and strengths, not just government priorities. Data should be used to advocate for Community needs, highlight strengths, and challenge deficit-based narratives.
- **Relevant & Reciprocal:** Data collection and use should meet Community-defined priorities, and Community must see tangible benefits from contributing data. Ensure the use of readiness tools and Community engagement aligns data collection with Community-defined priorities, ensuring data collection results in benefits for Community.
- **Sustainably Self-Determining:** Governance frameworks must outlast individual leaders and funding cycles, ensuring that Aboriginal-led decision-making continues across generations.

Collective Insights and Practical Expectations

PARTNER STORY – MORE THAN NUMBERS

By the time the partners came together again for Workshop 3, the tone had shifted. On beautiful Gumbaynggirr Country again, there was less of the heaviness from earlier sessions and more of a sense of possibility.

One of the CEOs spoke up first, steady and clear: “Our priority is that data helps our Communities, not just the funders.” The room went quiet for a moment, the words hanging in the air. People leaned in.

Another leader followed, a small smile flickering as she recalled a win: “When we’ve done it right, data has been more than compliance. We’ve used it to prove impact, to secure funding, to show what we already knew, that our services are working.”

Another voice, softer but resolute: “But we’ve also seen the other side. We’ve seen the weaponisation of data, used against our Communities, not for them.”

The room fell silent again. No one needed to explain further; everyone had lived examples in their minds. For a long moment, there was only the weight of those stories. Then the energy shifted again. Heads nodded and murmured agreement. It was a turning point in the conversation: data wasn’t just about harm, nor just about numbers. It was about stories, about power, about ensuring that from here forward, the Partnership would only use data in ways that lifted up Communities rather than tore them down.

To embed IDS&G in practice, partners agreed that several conditions must be created:

- **Cultural Safety First:** Governance must align with Cultural protocols. Concepts of privacy and confidentiality often differ in Aboriginal contexts and must be respected.
- **Shared Decision-Making:** Data sharing, reporting, and interpretation must be collaborative and guided by ACCHOs and the Community.
- **Clear Governance Pathways:** An Aboriginal-led governance group within the HNC Aboriginal Health Partnership should oversee all decisions about data use.
- **Practical Tools and Resources:** Data must be returned in accessible formats, such as visuals, plain-language summaries, and Community-friendly reporting.
- **Resource Allocation:** Funding must support governance infrastructure, board participation, and staff capacity to engage in data governance.
- **Co-Creation, Not Extraction:** Reports and analyses should be co-created with ACCHOs to ensure context and accuracy.

Respecting Clients and the Data They Share

Aboriginal and Torres Strait Islander clients and patients trust ACCHOs when they share stories and information. ACCHOs acknowledge that this data is not just technical information but holds Cultural, personal, and Community significance.

They commit to:

- Ensuring Culturally responsive, clear, and ongoing consent processes for collecting and using individual client data. ***“As highlighted in Workshop 1: ‘Consent isn’t just a form – it’s an ongoing conversation led by Community.’”***
- Being transparent with clients about how data is stored, protected, and used to support individual and Community well-being.
- Supporting clients to access, understand, and use their own data where appropriate.
- Ensuring that individual data rights align with Community governance structures and Cultural protocols.
- Using client data only in ways that are consistent with the “do no harm” principle and the aspirations of Aboriginal and Torres Strait Islander Communities for self-determination.

Upholding Privacy, ICIP, and IDS&G Together

- Participants reflected on the need to align privacy law, ICIP rights, and IDS&G to protect Aboriginal people, knowledge, and Cultural heritage:
- Privacy laws provide minimum standards, but Cultural protocols often exceed these, requiring Community-led consent processes.
- CIP rights ensure that Cultural knowledge and expressions are respected and protected.
- IDS&G ensures that Aboriginal Communities lead data governance across all processes.

The partners agreed that clear, Culturally responsive consent processes, data-sharing agreements reflecting Community control, and transparency in data use will be foundational to respecting these rights within the HNC Aboriginal Health Partnership agreement.

PARTNER STORY: BRINGING PRINCIPLES TO LIFE

In the final session, the OCCAAARS framework was laid out. It could have felt like theory, but the room quickly turned it into something else.

One participant leaned forward, pointing at the first principle: ***“Ownership means our boards have to say, ‘This is ours.’ We can’t leave it vague — it has to be written into every agreement.”***

Across the table, another voice came in: ***“Control is about who gets to say yes or no. Our boards should authorise what’s collected and why. That way it’s not someone else’s decision.”***

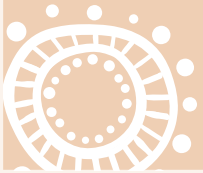
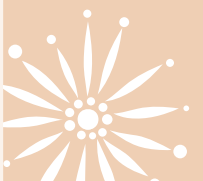
A third added, tapping the paper: ***“Custodianship isn’t just about storage. Holding places for data must respect our Cultural ways. We don’t just drop it into a system — it has to be cared for properly.”***

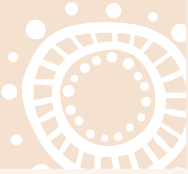
There were murmurs of agreement. Someone else spoke up: ***“And if we give data, we expect to see benefit back. That’s reciprocity. That’s respect.”***

The yarn kept weaving, each principle sparking another story or reflection. By the end, OCCAAARS was no longer a set of abstract letters on a page. It had become a lived map of practice for the North Coast — shaped by the voices in the room, carried by the weight of

Making OCCAAARS real within the HNC Aboriginal Health Partnership

During the sessions, partners identified definitions, shared understandings, and practical mechanisms to operationalise each OCCAAARS principle in the HNC Aboriginal Health Partnership context. The following reflections, drawn directly from Workshop 3, include partner voices to anchor each principle in lived experiences.

Principle	Definition & Shared Understanding	Practical Mechanisms
Ownership 	Aboriginal Communities are the rightful owners of their data and stories. Data is a Community asset and must be treated with respect. <i>“Data about our people belongs to our people. That’s the starting point.”</i>	All agreements and processes explicitly state Community ownership, with ACCHOs defining data inclusion, sharing conditions, and access pathways.
Control 	Aboriginal Communities determine how data is collected, analysed, interpreted, and used. <i>“We should decide what’s collected, how it’s analysed, and what it’s used for.”</i>	ACCHOs’ boards and the Indigenous-led governance group approve and oversee data collection processes, using Community-led program logic models to define purpose.
Custodianship 	Aboriginal organisations steward and protect data, respecting Cultural protocols and trust. <i>“Holding places for data must respect our Cultural ways.”</i>	Use Culturally appropriate terms (e.g., “holding places”), apply traditional knowledge labels, and establish Culturally responsive data management practices.
Access 	Community can access data in meaningful, practical, and timely ways. <i>“Community needs timely and practical access – not locked away.”</i>	Develop visual, plain-language reporting tools and summaries for Community use. Embed Aboriginal data analysts within ACCHOs and HNC where feasible, to support interpretation and application.
Accountability to First Nations 	Governance structures are transparent and responsible to Community. <i>“You need to bring it back to Community – we decide if it’s being used the right way.”</i>	Incorporate “do no harm” principles, provide regular feedback loops, return data to Community in accessible formats, and use shared dashboards with ACCHOs for ongoing reporting.

Principle	Definition & Shared Understanding	Practical Mechanisms
Amplifying Community Voice 	Data reflects and elevates Community priorities, stories, and strengths. <i>“Our stories and strengths need to be visible, not buried under statistics.”</i>	Co-design reporting templates with ACCHOs partners, embed Community stories alongside quantitative data, and ensure Community voice guides advocacy messaging.
Relevant and Reciprocal 	Data collection and use align with Community priorities and return value to contributors. <i>“If we give data, we expect to see benefit back.”</i>	Use readiness tools to align data collection with Community-defined priorities. Prioritise reciprocal reporting and practical application of data insights for local decision-making.
Sustainably Self-Determining 	Governance enables enduring, Culturally grounded decision-making led by Aboriginal Communities. <i>“Governance must outlast individuals – it has to be set up for future generations.”</i>	Establish and maintain an Aboriginal-led Data Governance Group within the HNC Aboriginal Health Partnership with clear terms of reference, succession planning, and transparent authorisation pathways.

By embedding the OCCAAARS Framework into its everyday practices and governance structures, the HNC Aboriginal Health Partnership will transform data governance from a compliance process into a Community-led practice that upholds the rights, priorities, and aspirations of Aboriginal Communities.

This work has been shaped by deep reflection, dialogue, and shared learning across the HNC Aboriginal Health Partnership, centring self-determination, Cultural responsiveness, and respect for data as stories, not just numbers. It has affirmed that IDS&G must be practical, protective, and empowering, enabling Communities to guide how data is collected, interpreted, and used to improve health and well-being.

To ensure these principles are not only understood but lived, the HNC Aboriginal Health Partnership have committed to the following practical redefined principles that will guide the work every day and across every project, decision, and partnership. These principles support Aboriginal and Torres Strait Islander self-determination in all aspects of data governance and use.

Our Commitments in Practice

These principles translate our commitments into clear, everyday actions for how the HNC Aboriginal Health Partnership will embed IDS&G across all work.

Community Ownership of Data

What: We recognise that data on Aboriginal Communities belongs to those Communities, and we will protect and uphold this ownership.

How: We will ensure all data agreements explicitly state Community ownership, with ACCHOs defining what data is included, how it is shared, and who can access it.

Community Decision-Making and Control

What: Aboriginal and Torres Strait Islander peoples will lead decisions on what data is collected, how it is interpreted, and how it is used.

How: We will seek authorisation and input from ACCHO boards for data projects, using Community-led program logic to define purpose, consent, and data use.

Holding Places for Data

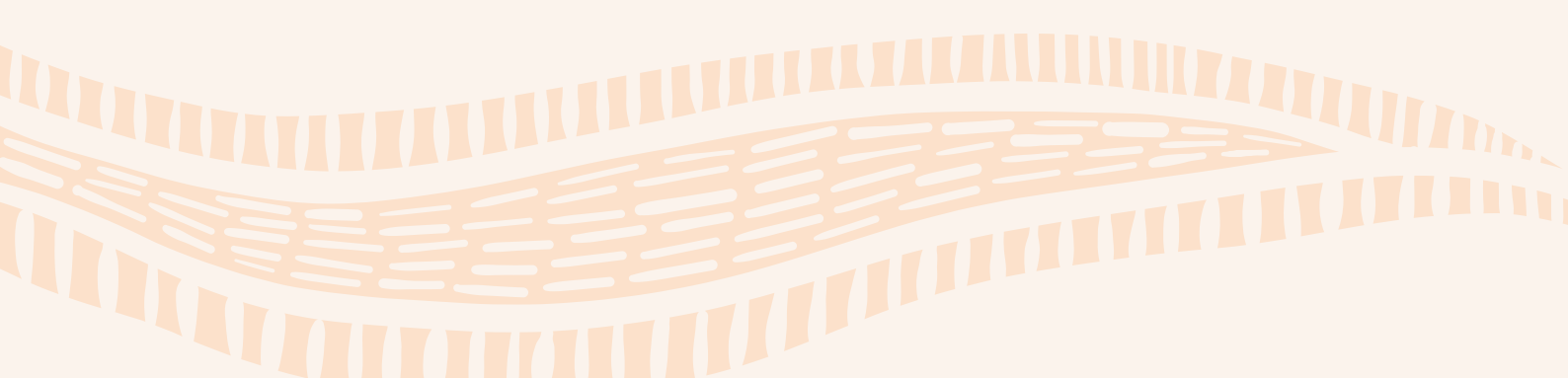
What: We will care for and protect data as a Cultural asset, reflecting Cultural protocols and trust.

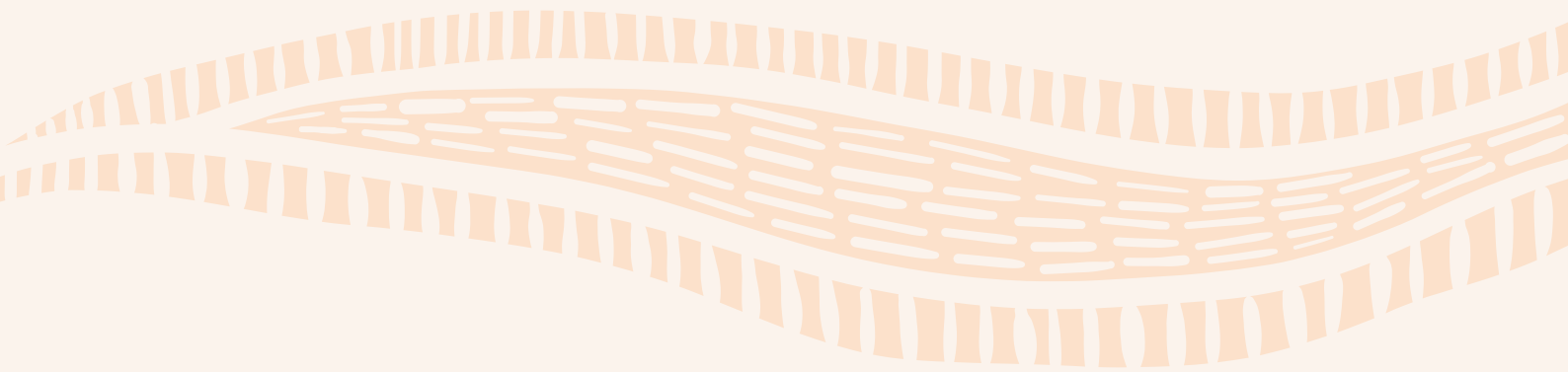
How: We will use secure, Culturally responsive data systems (e.g., “holding places”) that respect Traditional Knowledge labels and ensure Community control over storage and access.

Accessing Data in Meaningful Ways

What: Data will be returned to Communities in accessible, practical formats to support local decision-making and storytelling.

How: We will provide plain-language reports, visuals, and opportunities for boards and Community members to yarn about what the data shows and means.





Accountability Back to Community

What: We will report back to Communities about how data is used, ensuring transparency and alignment with Community priorities.

How: We will establish regular feedback loops and use shared dashboards with ACCHOs, returning data in Culturally meaningful ways to support ongoing governance.

Data as a Tool to Share Community Voice

What: Data will be used to tell stories that reflect Community realities and strengths, supporting advocacy and planning.

How: We will co-design reporting templates with ACCHOs, embed Community stories alongside data, and ensure Community voices guide service delivery.

Relevant Data that Gives Back

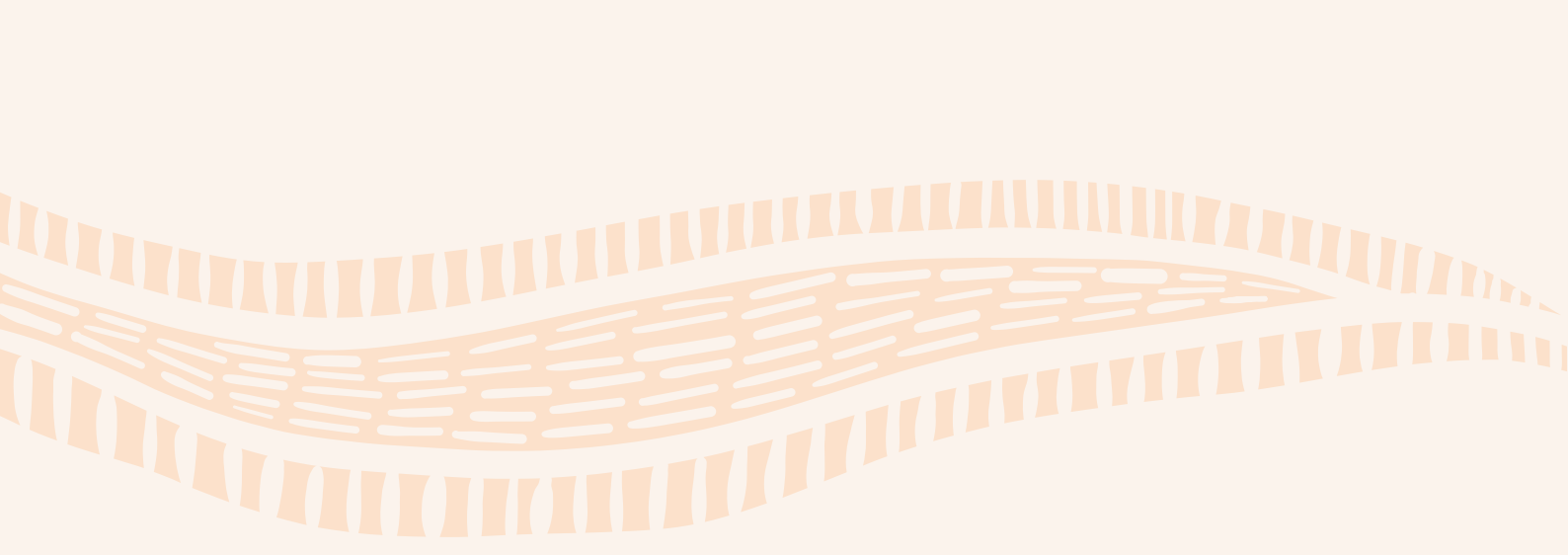
What: Data collection and use will align with Community priorities and deliver benefits to Communities.

How: We will engage with Communities to define data priorities and ensure reporting and insights are used for local planning, advocacy, and resource allocation.

Upholding Self-Determination for the Future

What: We will maintain governance structures that ensure Aboriginal and Torres Strait Islander leadership continues across generations.

How: We will establish and resource Aboriginal-led data governance groups within the HNC Aboriginal Health Partnership, with clear terms of reference, succession planning, and decision-making pathways.



Sustaining IDS&G in HNC

To ensure IDS&G is not a one-off initiative but an enduring shift in how data governance operates, HNC partners identified the need for long-term investment in systems, relationships, and capacity. This includes:

- Embed principles in everyday practice, including non-clinical and corporate governance.
- This means ensuring that IDS&G is reflected in staff position descriptions, internal policies and procedures, governance training for boards and leadership, and that IDS&G is included as a standard consideration in program design and data projects.
- Provide ongoing training across the HNC and ACCHOs teams.
- This could include workshops on data ethics and Cultural safety, peer learning opportunities between ACCHOs, and mentoring for emerging Aboriginal data stewards or analysts.
- Secure dedicated funding to support governance structures and capacity-building.
- Partners noted the importance of resourcing ACCHOs to participate in governance activities, lead data analysis and reporting, and support local coordination roles.
- Monitor and review the protocol regularly with ACCHOs' input to adapt as Community needs and contexts evolve.
- This review process could be built into existing HNC Aboriginal Health Partnership meetings or through annual IDS&G review yarnings led by the HNC Aboriginal Health Partnership members.
- Start with priority projects (e.g., regional needs assessments and evaluation pilots) to demonstrate and refine IDS&G practices in action.

Early projects should be selected collaboratively, prioritising those where data use is most visible to Community and where joint data interpretation and reporting can build trust and shared capability.

PARTNER STORY: LEARNING TO WALK BEFORE RUNNING

As the project drew to a close and approached the practical question of **“what next?”**, the energy shifted again. The partners leaned into the hard part: how to make IDS&G real without overwhelming already stretched organisations.

One participant broke the silence first, with a kind of plain-spoken wisdom: **“Don’t over-engineer it. Start small. Pilot it. Learn together.”**

Another picked up the idea immediately: **“We don’t have to build a whole new system straight away. We could use something we already know, like the nKPI data, and test it against our own indicators. See how the governance works in practice, then refine it before we scale.”**

The comments drew nods around the room. A CEO added with a wry smile: **“It’s better to walk first, get it right, than to run and fall flat.”**

There was laughter, but it carried truth. The partners knew too well how often new initiatives tried to sprint, only to collapse under their own weight. Here, the mood was different: steady, grounded, careful.

The story of implementation wasn’t about rushing to perfection. It was about building confidence step by step — starting with projects small enough to learn from, but significant enough to matter. By moving slowly and deliberately, the Partnership was setting itself up for the long haul, ensuring IDS&G would not just launch, but last.