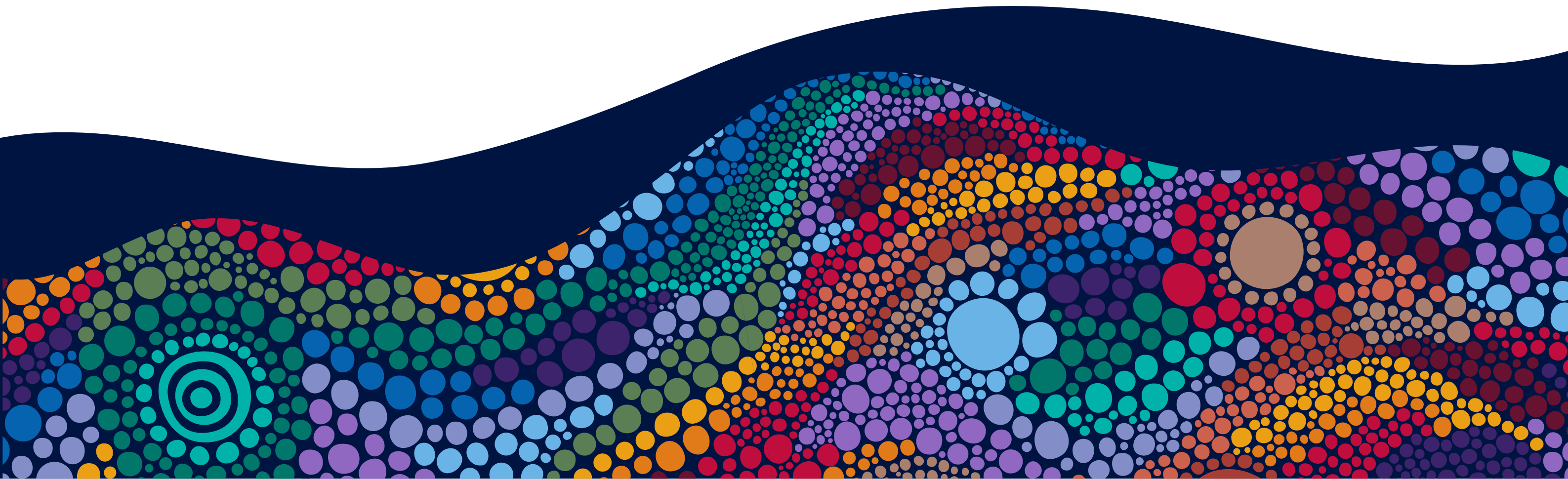
NACCHO
National Aboriginal Community
Controlled Health Organisation

Inquiry into the management of client privacy in the Australian public sector

Submission to the Joint Committee of Public Accounts and Audit

May 2026



About NACCHO

NACCHO is the national peak body representing 148 Aboriginal Community Controlled Health Organisations (ACCHOs). We also assist a number of other community-controlled organisations.

The first Aboriginal medical service was established at Redfern in 1971 as a response to the urgent need to provide decent, accessible health services for the largely medically uninsured Aboriginal population of Redfern. The mainstream was not working. So it was, that over fifty years ago, Aboriginal people took control and designed and delivered their own model of health care. Similar Aboriginal medical services quickly sprung up around the country. In 1974, a national representative body was formed to represent these Aboriginal medical services at the national level. This has grown into what NACCHO is today. All this predated Medibank in 1975.

NACCHO liaises with its membership, and the eight state/territory affiliates, governments, and other organisations on Aboriginal and Torres Strait Islander health and wellbeing policy and planning issues and advocacy relating to health service delivery, health information, research, public health, health financing and health programs.

ACCHOs range from large multi-functional services employing several medical practitioners and providing a wide range of services, to small services which rely on Aboriginal health practitioners and/or nurses to provide the bulk of primary health care services. Our 148 members provide services from about 550 clinics. Our sector provides over 3.1 million episodes of care per year for over 410,000 people across Australia, which includes about one million episodes of care in very remote regions.

ACCHOs contribute to improving Aboriginal and Torres Strait Islander health and wellbeing through the provision of comprehensive primary health care, and by integrating and coordinating care and services. Many provide home and site visits; medical, public health and health promotion services; allied health; nursing services; assistance with making appointments and transport; help accessing childcare or dealing with the justice system; drug and alcohol services; and help with income support. Our services build ongoing relationships to give continuity of care so that chronic conditions are managed, and preventative health care is targeted. Through local engagement and a proven service delivery model, our clients ‘stick’. Clearly, the cultural safety in which we provide our services is a key factor of our success.

ACCHOs are also closing the employment gap. Collectively, we employ about 7,000 staff – 54 per cent of whom are Aboriginal or Torres Strait Islanders – which makes us the third largest employer of Aboriginal or Torres Strait people in the country.

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Recommendations

NACCHO recommends:

1. Any interventions to address client privacy in the Australian Public Sector align with the National Agreement and its four Priority Reform Areas.
2. An audit of personal data being collected across the government, including advice on whether this collection of personal data is necessary to service delivery.
3. The DEX data collection focuses on service-level information, such as the number of people accessing each program. Individual-level identifiable personal information, such as names, should not be collected.
4. Each government agency publishes clear and precise information on the data flow of their data collections, detailing their governance and intended secondary applications.
5. Mandated Indigenous Data Sovereignty and Indigenous Data Governance Training, run by reputable organisations such as Maiam nayri Wingara, for public servants working in data roles.
6. Government Data Custodians are provided training on:
    - their commitments under Priority Reform 4 of the National Agreement
    - what is considered appropriate privacy management when providing Aboriginal and Torres Strait Islander organisations data.
7. Continued commitment to ensuring IHIs are correct, and able to be matched by service providers. This includes built in steps to ensure data quality of IHIs and additional support for vulnerable populations who have known issues with IHI matching, such as Aboriginal and Torres Strait Islander people.
8. A communication and information campaign to explain IHIs to the general public, including tailored materials for Aboriginal and Torres Strait Islander people.
9. Increased transparency on the use of large linked government data sets – including the privacy and ethics requirements on organisations authorised to access such data.
10. An audit of client privacy and intellectual property in the context of government use of AI.
11. No externally hosted AI is used by government.

Acknowledgements

NACCHO welcomes the opportunity to provide a submission to the Joint Committee of Public Accounts and Audit. NACCHO supports the submissions to this consultation made by NACCHO Members and Affiliates.

National Agreement on Closing the Gap

Advocating for and securing the National Agreement on Closing the Gap was an historically significant act of Aboriginal and Torres Strait Islander self-determination. The National Agreement is evidence of a new era of engagement by and with Aboriginal and Torres Strait Islander people. It commits Australia to a new direction and is a pledge from all governments to fundamentally change the way they work with Aboriginal and Torres Strait Islander communities and organisations – to support self-determination and build the capacity of the community-control sector.

This Government's first Closing the Gap Implementation Plan commits to achieving Closing the Gap targets *through implementation of the Priority Reforms*. This represents a shift away from focussing on the Targets, towards the structural changes that the Priority Reforms require, and which are more likely to achieve meaningful outcomes for our people in the long term.

The reforms and targets outlined in the National Agreement seek to overcome the inequality experienced by Aboriginal and Torres Strait Islander people, and achieve life outcomes equal to all Australians. Governments at all levels have committed to the implementation of the National Agreement's four Priority Reform Areas, which offer a roadmap to meaningfully impact structural drivers of poor health and social outcomes for Aboriginal and Torres Strait Islander people:

Priority Reform Area 1 – Formal partnerships and shared decision-making

This Priority Reform commits to building and strengthening structures that empower Aboriginal and Torres Strait Islander people to share decision-making authority with governments, and to accelerate policy making that centres Aboriginal and Torres Strait Islander voices.

Priority Reform Area 2 – Building the community-controlled sector

Recognising that community-controlled services achieve better outcomes, employ more Aboriginal and Torres Strait Islander people and are often preferred over mainstream services, this Priority Reform commits to building Aboriginal and Torres Strait Islander community-controlled sectors to deliver services to support Closing the Gap.

Priority Reform Area 3 – Transformation of mainstream institutions

This Priority Reform commits to systemic and structural transformation of government organisations to identify and eliminate racism, embed and practice cultural safety, deliver services in partnership with Aboriginal and Torres Strait Islander people, support truth telling about agencies' history with Aboriginal and Torres Strait Islander people, and engage fully and transparently with Aboriginal and Torres Strait Islander people when programs are being changed.

Priority Reform Area 4 – Sharing data and information to support decision making

This Priority Reform commits to shared access to regional data and information to inform local-decision making and support achievement of the first three Priority Reforms. This Priority Reform supports principles of Indigenous Data Sovereignty.

Despite some progress, the need for fundamental systemic reform remains evident. In its first review of the National Agreement on Closing the Gap, the Productivity Commission found that governments are not adequately delivering on their commitments. Despite support for the Priority Reforms and some good practice, progress has been slow, uncoordinated, and piecemeal.

The Commission noted that to enable better outcomes, governments need to relinquish some control, share decision making and acknowledge that Aboriginal and Torres Strait Islander people know what is best for their communities. Aboriginal Community Controlled Organisations must be treated as critical partners rather than passive funding recipients, and trusted to design, deliver and measure government services in ways that are culturally safe and meaningful for their communities.

> ‘Too many government agencies are implementing versions of shared decision-making that involve consulting with Aboriginal and Torres Strait Islander people on a pre-determined solution, rather than collaborating on the problem and co-designing a solution’[1]

NACCHO recommends any interventions to address client privacy in the Australian Public Sector align with the National Agreement and its four Priority Reform Areas.

Introduction

While Aboriginal and Torres Strait Islander people were only counted in the Census from 1971,[2] records about Aboriginal and Torres Strait Islander people have been collected since colonisation began.[3] The National Health and Medical Research Council, a Government agency, has noted that Aboriginal and Torres Strait Islander people are the most researched people in the world.[4]

Privacy needs to be considered across the data cycle – from data collection, to data governance and finally, use of data. When conceptualising data and privacy, qualitative data needs to be included as well as quantitative.

Data collection

NACCHO understands the importance of collecting data for advocacy, to inform funding and service delivery and in monitoring and evaluation, among other reasons. However, government needs to assess whether all the data that is being collected is necessary.

During consultation carried out for previous submissions, we heard from our sector that many services were required to submit personal information about participants in order to receive playgroup funding from the Department of Social Services, to be put on their Data Exchange (DEX).

Collection of identifiable information (particularly names) in order to secure DSS funding for playgroup programs is a barrier for engagement for families. Due to historical and current government policies,[5] many Aboriginal and Torres Strait Islander people hold a healthy distrust of the government agenda.[6] Parents are concerned about the potential for government to link DEX data with MyGov and Centrelink payments – to potentially be used to deny access to further funding supports, childcare rebates or early learning childhood supports.

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[1] Productivity Commission, Review of the National Agreement on Closing the Gap, Study Report, Canberra, 7 Feb 2024 https://www.pc.gov.au/inquiries/completed/closing-the-gap-review/report.

[2] National Museum of Australia, Defining Moments: First Nations people counted in Census, 15 March 2024, https://www.nma.gov.au/defining-moments/resources/first-nations-peoples-census.

[3] National Archives of Australia, Records about First Australians, https://www.naa.gov.au/explore-collection/first-australians/records-about-first-australians.

[4] National Health and Medical Research Council, Ethical guidelines for research with Aboriginal and Torres Strait Islander peoples, https://www.nhmrc.gov.au/research-policy/ethics/ethical-guidelines-research-aboriginal-and-torres-strait-islander-peoples.

[5] Australian Human Rights Commission, The history of Aboriginal and Torres Strait Islander peoples advocating for the right to be heard, August 2023, https://humanrights.gov.au/know-your-rights/rights-of-individuals/aboriginal-and-torres-strait-islander-peoples-rights/articles-aboriginal-and-torres-strait-islander-peoples/history-aboriginal-and-torres-strait.

[6] Aurora Milroy, Indigenous Values for the Australian Public Service and a New Relationship of Trust, University of Oxford, July 2019, https://integrity.bsg.ox.ac.uk/article/indigenous-values-australian-public-service-and-new-relationship-trust.

There are also concerns that DEX data will be used to prevent people from accessing DSS programs on top of other supports such as Thriving Kids. The Minister for Health, Disability and Ageing has noted that some children are being "over-serviced" by government programs.[7] This suggests a mutually exclusive approach to family supports – that is, either DSS programs, NDIS-funded supports or Thriving Kids-related support. However, we know that due to the ongoing impacts of colonisation, Aboriginal and Torres Strait Islander people have more complex health and social support needs.[8] Families of Aboriginal and Torres Strait Islander children enrolled in the Thriving Kids Initiative may also be accessing children and family support services through DSS programs. The potential for data to be used to deny eligibility for multiple programs is alarming.

There are further concerns that enrollment and participation in parenting support programs, counselling or relationship services could result in children being removed.[9] This fear is not unfounded - Aboriginal and Torres Strait Islander children continue to be disproportionately removed from their families, even for reasons such as fleeing domestic violence.[10]

In addition, the expectation for ACCHOs to collect data on, for example, playgroup participants is disproportionately burdensome considering they are drop in, casual services. The requirement for playgroups to provide data appears to not consider the processes at the point of origin – there is no existing point of data capture for people attending these services.

NACCHO recommends an audit of personal data being collected across the government, including advice on whether this collection of personal data is necessary to service delivery.

NACCHO recommends the DEX data collection focuses on service-level information, such as the number of people accessing each program. Individual-level identifiable personal information, such as names, should not be collected.

Data governance

Priority Reform 4 of the National Agreement is to have shared access to data and information at a regional level – in order to support Aboriginal and Torres Strait Islander communities and organisations. Key to the implementation of this reform is the involvement of Aboriginal and Torres Strait Islander people, through partnership and collaboration.

Indigenous Data Sovereignty (IDS) and Indigenous Data Governance (IDG) frameworks have allowed Aboriginal and Torres Strait Islander people to assert control on how data about them is used, by who and under what conditions. Aboriginal and Torres Strait Islander organisations, particularly Maiam nayri Wingara, provide a blueprint of what is needed to enact IDS and IDG, and now provide training for organisations to ensure their data governance is approproate.[11] The Framework for Governance of Indigneous data[12] provides a roadmap for government agencies to implement key data governace processes.

Careful governance of Indigenous data is particularly important as more government data is being linked in large cross-agency data sets. For example, DEX data is included in the Person Level Integrated Data Asset (PLIDA) – a large government linked data project held by the Australian Bureau of Statistics. Through PLIDA, DEX data can be linked to DSS data on government payment (e.g. Age Pension and JobSeeker) recipients,

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[7] Mark Butler, Speech from Minister Butler, National Press Club – 20 August 2025, https://www.health.gov.au/ministers/the-hon-mark-butler-mp/media/speech-from-minister-butler-national-press-club-20-august-2025?language=en.

[8] AIHW, Australia's Health: Health and wellbeing of First Nations people, July 2024, https://www.aihw.gov.au/reports/australias-health/indigenous-health-and-wellbeing.

[9] Australian Institute of Aboriginal and Torres Strait Islander Studies, The Stolen Generations, https://aiatsis.gov.au/explore/stolen-generations.

[10] Human Rights Watch, Australia: Disproportionate Removal of Aboriginal Children, March 2025, https://www.hrw.org/news/2025/03/26/australia-disproportionate-removal-aboriginal-children.

[11] Maiam nayri Wingara, Training and Education, https://www.maiamnayriwingara.org/training-and-education.

[12] National Indigenous Australians Agency, Framework for Governance of Indigenous Data, 30 May 2024, https://www.niaa.gov.au/resource-centre/framework-governance-indigenous-data.

tax office data and NDIS data.[13] PLIDA is already being used in a number of government and non-government research projects, as well as by private institutions[14] – without the informed consent or permission of the people being researched.

It is unclear how, or whether, DEX and PLIDA enact principles of Indigenous Data Governance and Indigenous Data Sovereignty. The PLIDA Board has no identified Aboriginal and Torres Strait Islander representation,[15] and there are no evident plans to share PLIDA data or DEX data back to Aboriginal and Torres Strait Islander communities. It is also unclear how DEX is adhering to the National Indigenous Australians Agency's Framework for Governance of Indigenous Data, or even who would be responsible for it, given the multiple government agencies involved. This lack of oversight and transparency is concerning.

NACCHO recommends each government agency publishes clear and precise information on the data flow of their data collections, detailing their governance and intended secondary applications.

NACCHO recommends mandated Indigenous Data Sovereignty and Indigenous Data Governance Training, run by reputable organisations such as Maiam nayri Wingara, for public servants working in data roles.

Data use

The *Auditor-General Report No. 12 of 2025–26: Managing the Privacy of Client Information in Services Australia* – which is part of the terms of reference for this inquiry – notes that Services Australia has a high-risk privacy profile.

"Within the context of its high-risk privacy environment, its arrangements for managing privacy fall short of its risk profile and emerging risks."[16]

While this is true, experience from the Aboriginal community controlled sector is that privacy management practices such as the Five Safes Framework[17] are used to block their access to data. Conversations regarding privacy and use of data are often curtailed to data use within the Australian Public Service (APS), and organisations external to the APS are not included. As such, privacy can come at the cost of our visibilty of the data and right to informed decision-making.

This is in contradiction of government commitments under Priority Reform 4 of the National Agreement on Closing the Gap.

NACCHO recommends government Data Custodians are provided training on:

- their commitments under Priority Reform 4 of the National Agreement
- what is considered appropriate privacy management when providing Aboriginal and Torres Strait Islander organisations data.

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[13] Australian Bureau of Statistics (ABS), PLIDA data and legislation, https://www.abs.gov.au/about/data-services/data-integration/integrated-data/person-level-integrated-data-asset-plida/plida-data-and-legislation.

[14] ABS, Person Level Integrated Data Asset (PLIDA), https://www.abs.gov.au/about/data-services/data-integration/integrated-data/person-level-integrated-data-asset-plida.

[15] ABS, PLIDA Board, https://www.abs.gov.au/about/data-services/data-integration/integrated-data/person-level-integrated-data-asset-plida/plida-board.

[16] Australian National Audit Office, Auditor-General Report No. 12 2025-26, https://www.anao.gov.au/work/performance-audit/managing-the-privacy-of-client-information-services-australia.

[17] ABS, Five Safes framework, 8 November 2021, https://www.abs.gov.au/about/data-services/data-confidentiality-guide/five-safes-framework.

Digital identifiers

The APS has increasingly been moving towards individualised digital identifiers. This began with the failed ‘Australia Card’ proposal in the mid-1980s. This Australia Card was meant to amalgamate government identification systems to assist in identifying tax avoidance, health and welfare fraud. The idea faced intense backlash and legal issue. After 2 years, was abandoned.[18]

More recently, the My Health Record system faced backlash from those worried about medical privacy, and the security of government-held information.[19] As of early 2019, over 2.5 million people had opted out of the system.[20]

Each person’s My Health Record is linked to their Individual Healthcare Identifier (IHI) number – which are used by health professionals to ensure they are accessing and uploading to the correct record.[21] Unlike a Medicare card number, which can change as a person may transition off the family card they grew up on, or create a new family card, IHIs are meant to follow a person across their life.[22] However, feedback from our sector is that many clients have missing IHIs, the majority of which comes from mismatch between patient names and dates of birth held by ACCHOs and those held by Services Australia. There has been ongoing work on remedying these issues for over a decade.

The Regulatory Reform Omnibus bill, which passed in November 2025, among other things enabled the wider use of IHIs. Changes will:

- Enhance the national Healthcare Provider Directory, to facilitate the exchange of health information across jurisdictions and different care settings.[23]
- Authorise the use of healthcare identifiers in emerging health technology solutions such as wearable devices and monitors.[24]
- Increate the ability for IHIs to be disclosed to health technology providers, employers and insurers, subcontractors, and (with permission) research institutes.[25]

NACCHO is particularly concerned with the facilitation of IHI disclosure to external organisations such as health technology providers, employers and insurers. While IHIs alone do not hold health information, this sharing of personal identifiers is the first step towards potentially enabling further sharig in the future. It is concerning that these changes happened with little to no consultation or scrutiny.

While having a unique digital identifier is positive in terms of continuity of care, there are increasing concerns that linked government digital IDs will be used for punitive actions – for example, taking away payments, or adjusting Medicare levies/rebates. It is unclear how the risk to individuals’ privacy is being managed by government.

NACCHO recommends continued commitment to ensuring IHIs are correct, and able to be matched by service providers. This includes built in steps to ensure data quality of IHIs and additional support for

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[18] Davies, S., Campaign Against the Australia Card, Australian Privacy Foundation, February 2004, https://privacy.org.au/about/history/davies0402/.

[19] Kwan, B., Stay or go? My Health Record opt-out met with fierce debate, SBS News, 16 July 2018, https://www.sbs.com.au/news/article/stay-or-go-my-health-record-opt-out-met-with-fierce-debate/rg7vnyyfy.

[20] Knaus, C., More than 2.5 million people have opted out of My Health Record, The Guardian, 20 February 2019, https://www.theguardian.com/australia-news/2019/feb/20/more-than-25-million-people-have-opted-out-of-my-health-record.

[21] Services Australia, Who we chare your IHI with, 19 December 2024, https://www.servicesaustralia.gov.au/who-we-share-your-individual-healthcare-identifier-number-with?context=22591.

[22] Department of Health, Disability and Ageing, Healthcare Identifiers and the Healthcare Identifiers Service, 5 December 2025, https://www.health.gov.au/topics/health-technologies-and-digital-health/about/healthcare-identifiers.

[23] Department of Health, Disability and Ageing, Healthcare Identifiers and the Healthcare Identifiers Service, 5 December 2025, https://www.health.gov.au/topics/health-technologies-and-digital-health/about/healthcare-identifiers.

[24] Department of Health, Disability and Ageing, Healthcare Identifiers and the Healthcare Identifiers Service, 5 December 2025, https://www.health.gov.au/topics/health-technologies-and-digital-health/about/healthcare-identifiers.

[25] Dimes Letters, K., and Moriarty, H., Digital health reforms: the Regulatory Reform Omnibus Act, Minter Ellison, 4 February 2026, https://www.minterellison.com/articles/digital-health-reforms-the-regulatory-reform-omnibus-act.

vulnerable populations who have known issues with IHI matching, such as Aboriginal and Torres Strait Islander people.

NACCHO recommends a communication and information campaign to explain IHIs to the general public, including tailored materials for Aboriginal and Torres Strait Islander people.

Secondary use

With the increased number of large, multi-agency linked data sets, APS data is increasingly being used for secondary purposes, by government and researchers. PLIDA has many research projects whereby organisations outside of government are using different administrative data sets, for example:

- The Relationship Between Health, Work, and Inequality: Evidence from Linked Administrative Data – University of New South Wales
- Mental health help-seeking behaviour among CALD women – Monash University
- Reducing health inequalities for priority populations – University of Melbourne.[26]

This is not to say these are not important and valid research. However, the subject matter is sensitive and participants whose data is included have never consented. It is unclear how government has visibility over privacy practices within universities. In these instances, it is additionally important that privacy is protected. Unfortunately, it is unclear whether the projects have considered privacy impacts, or have even sought approval from Aboriginal and Torres Strait Islander research ethics committees.

NACCHO recommends increased transparency on the use of large linked government data sets – including the privacy and ethics requirements on organisations authorised to access such data.

Artificial intelligence

Government agencies are increasingly using artificial intelligence (AI). Government AI systems are not required to be internally hosted.[27] This may have serious privacy and security impacts. If, for example, submissions to a consultation are summarised using externally hosted AI, it is unclear who would own this intellectual property, and if the submission’s content would be used by the AI to inform the creation of new content in the future.

AI also having client data being misinterpreted. AI analysis and summaries routinely exclude important background information and nuance. AI may misrepresent case studies, or, in the worst case, AI distortion may generate incorrect conclusions. AI models are programmed to condense information and focus on regularly repeated material. In practice this process further marginalises minority voices and overlooks new or innovative ideas.

NACCHO notes its concerns about the use of AI in the creation and distortion of cultural content. In the words of leading Indigenous cultural and intellectual property lawyer Dr Terri Janke: “AI systems are often built without Indigenous participation or consent, using and appropriating their images, art, and knowledge with no attribution or benefit-sharing.”[28]

NACCHO recommends an audit of client privacy and intellectual property in the context of government use of AI.

NACCHO recommends no externally hosted AI is used by government.

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[26] ABS, Data integration project register, updated 27 March 2026, https://www.abs.gov.au/about/data-services/data-integration/data-integration-project-register.

[27] Digital Transformation Agency, Australian Government AI technical standard, Version 1, August 2025, https://www.digital.gov.au/sites/default/files/documents/2025-08/Australian%20Government%20AI%20technical%20standard.pdf.

[28] Terri Janke and Company: Lawyers and Consultants, AI Got No Dreaming: Defending Indigenous Rights in the Digital Age, https://www.terrijanke.com.au/post/ai-got-no-dreaming-defending-indigenous-rights-in-the-digital-age .