

A framework for operationalising Aboriginal and Torres Strait Islander data sovereignty in Australia: Results of a systematic literature review of published studies

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Summary

Background Racial health disparities are only likely to be meaningfully improved by tailoring public health and clinical interventions to the specific needs of Indigenous people and their communities. Accurate tailoring relies on the availability of high-quality Indigenous-specific data. The potential benefits of increased availability of Indigenous data need to be balanced by efforts to ensure those data are collected and used appropriately. This paper identifies characteristics of Indigenous Data Sovereignty (IDS) principles and considers a framework for operationalisation.

Methods A PRISMA compliant search of the literature was undertaken, using methods detailed in the Cochrane Collaboration Handbook on Systematic Reviews of Health Promotion and Public Health Interventions (1). The search strategy comprised two steps: a search of 11 scientific electronic databases and five grey literature sources. The search was limited by date of publication (1 January 2000 to 1 December 2021). The following keywords and subject heading terms were used: (exp Aboriginal and Torres Strait Islander or Aborigin* or Torres Strait Island* or, Oceanic ancestry group) and (exp research or biomedical research or population surveillance or translational medical research or, research design) and (exp data or datasets or data collection or data management or health surveys or information dissemination or, intellectual property) and (exp self-determination or ownership or control or access or possession or OCAP or sovereignty or, ethics) and, (exp Australia). IDS principles: (i) ownership; (ii) control; (iii) accessibility; (iv) custodianship; (v) accountability to Indigenous people; (vi) amplify Community voice; (vii) relevant and reciprocal; and (viii) sustainably self-determining. Using standard data extraction forms, we examined relevant Australian studies to identify key characteristics and frequency with which they cited IDS principles. These findings were consolidated into an operationalisation framework.

Findings 34 relevant Australian published studies were identified. The most frequently cited IDS principles were Accountability to Aboriginal and Torres Strait Islander peoples and sustainably self-determining. The least frequently cited principle was Access. A framework to operationalise IDS principles is proposed that is both standardised internationally and able to be tailored to the diverse contexts of Indigenous peoples.

Interpretation IDS is emergent in Australia and there is a clear need to establish an agreed set of International IDS principles and a framework for their operationalisation and contextualisation across diverse Indigenous communities and contexts.

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Research in Context

Evidence before this study

A PRISMA compliant search of the English language literature, published between 1 January 2000 and 1 December 2021, was undertaken in two steps. First, a search of 11 scientific electronic databases (AIATSIS, APA-ATSIS, APAIS-Health, CINAHL, EBM Review CDS, Embase, Emcare, Global Health, Medline, PAIS and, PsychINFO). Second, a search of five grey literature databases (Health Infonet, Lowitja Institute, Australian Government Productivity, Austlit & APO Online). The keywords and subject heading terms used were: (exp Indigenous or Aborigin* or Torres Strait Island* or Oceanic ancestry group) and (exp research or biomedical research or population surveillance or translational medical research or research design) and (exp data or datasets or data collection or data management or health surveys or information dissemination or intellectual property) and (exp self-determination or ownership or control or access or possession or OCAP or sovereignty or ethics) and (exp Australia). Thirty-four studies were identified for analysis.

Added value of this study

Previous studies have rightly advocated for a wider range, and improved quality, of Indigenous data to help reduce the existing health and socio-economic inequalities between Indigenous and non-Indigenous people globally. This study highlights the need to ensure these expanded Indigenous data are protected from misuse. Given Indigenous Data Sovereignty (IDS) is an emerging mechanism to protect Indigenous data, examining the current use of IDS principles and how these principles might be operationalised in practice is a timely contribution to inform future deliberations of IDS by Indigenous experts.

Implications of all the available evidence

Some principles of IDS are cited much more frequently than others which either means there needs to be greater focus on all IDS principles in the published research literature, or that it would be useful for IDS experts to review the ongoing relevance of the least frequently cited IDS principles. A framework to help operationalise the IDS principles would be helpful in activating IDS. Such a framework needs to be both standardised internationally and able to be tailored to the needs and specific circumstances of different Nations, Indigenous communities, and Indigenous service providers.

Introduction

There is clear evidence of practically meaningful health and socio-economic disparities between Indigenous¹ and non-Indigenous populations globally: a systematic

review by *The Lancet-Lowitja Institute Global Collaboration* identified a range of indicators that were all poorer for Indigenous populations: life expectancy, infant mortality, maternal mortality, low and high birthweight, child malnutrition, child and adult obesity, educational attainment, and economic status. That review recommended that governments develop targeted policy responses that are informed by, and evaluated with, higher quality Indigenous data. Although there is an obvious need for high quality, Indigenous-specific data, it is also critical to ensure that those data are collected and used appropriately, especially given the increased utilisation of administrative data for monitoring and research purposes, and the emerging ability to routinely link across different databases.

National statistical systems commonly fail to recognise the human rights and worldviews of Indigenous peoples through the generation and primacy of data which is inherently biased and not reflective of Indigenous worldviews, experiences, or priorities. Such data which are generated about Indigenous peoples is then protected within a Western system of privacy and licencing law, rendering the realisation of collective ownership and self-governance, impossible.⁴ Furthermore, these data resources are commonly used by researchers, Government departments and statistical agencies in conducting analyses and decision making, which play a subtle yet significant role in influencing broader societal conceptualisations of Indigenous peoples, communities, lands, resources, and Culture.⁵ This exploitation, misinterpretation and misuse of Indigenous data is commonplace, there are many examples of Indigenous peoples being blamed for experiencing inequities, rather than acknowledging that many outcomes are in fact the result of longstanding and ongoing social, cultural and racial injustices.^{2,3,6–15} Such examples from academics and Indigenous leaders have established a growing recognition of the need to protect against the misuse of data generally has given rise to the concept of data sovereignty, defined as the need to ensure information is managed according to “...the laws, practices and customs of the nation-state in which it is located.¹⁶” Indigenous Data Sovereignty (IDS) requires Indigenous data to be similarly managed. As for nation states, IDS is not a single concept but could vary depending on the practices and customs of different Indigenous communities and Indigenous controlled services. This means that attempts to operationalise IDS need to be sufficiently flexible to allow for different data management practices.

The development of key IDS concepts has been informed by three sets of principles published from Canada, New Zealand and Australia (the United States of America’s IDS Network is currently developing its own principles), and two landmark workshops convened in Australia (2015 in Canberra and 2017 in Melbourne). One set of principles is Canada’s Ownership,

¹ Within this paper, the term ‘Indigenous’ is used to refer to First Peoples globally, including Aboriginal peoples and Torres Strait Islander Australians.

Control, Access and Possession (OCAP) paradigm.¹⁷ A second set is New Zealand's *Aotearoa-Te Mana Raraunga* principles, which comprise Whanaungatanga and Whakapapa (a focus on the primacy of the relationship between people, the natural world and the spiritual powers of the natural world), Rangatiratanga (a focus on self-determination), Kotahitanga (a focus on collective vision), Manaakitanga (a focus on basic rights) and Kaitiakitanga (a focus on stewardship and sustainability of culture).¹⁸ A third set is Australia's *Maiam nayri Wingara (MnW)* principles, which emerged from a process of mapping the principles from OCAP, *Aotearoa-Te Mana Raraunga* and the United Nations Declaration on the Rights of Indigenous Peoples. These principles assert the right of Torres Strait Islander people to: control their own data ecosystem; access their own data in different formats; collect and analyse data in a way that is self-determining and sustainable; define the relevance of data to their own concerns; ensure advantageous reciprocity in the use of their data; promote accountability in the use of their data; and guarantee that the use of their data is protective of their individual and collective interests.¹⁹ The 2017 Melbourne workshop also identified amplification of community voice as central to IDS.²⁰

In addition to the articulation of these IDS principles, Indigenous networks have been established since 2013 specifically to promote IDS. These networks include the International IDS Interest Group (established by the European Commission, and the United States (US) and Australian governments), the US IDS Network, British Columbia's Indigenous Data Governance Initiative in Canada, the Te Mana Raraunga Maori Data Sovereignty Network in New Zealand and the MnW Indigenous Data Sovereignty Collective in Australia. IDS is practiced through Indigenous Data Governance (IDG), which asserts First Nation's interests in relation to data by: determining when, how and why our data are gathered, analysed, accessed, and used; and ensuring Indigenous data reflects First Nation's defined priorities, values, culture, worldviews, and diversity. IDS and IDG address the recognised connection between Indigenous development agendas and data as a resource. So whilst there is strong recognition of the need to protect against the misuse of data in the general sense, deeper conceptualisation and implementation is required to ensure that the concepts of IDS and IDG move beyond theory and into practice through the operationalisation and use of Indigenous data in line with the principles of self-determination and the rights of Indigenous peoples.^{1–3,41}

Having established IDS principles and appropriate networks to promote their real-world application, it is timely to critically examine the current use of IDS principles and explore how they might be operationalised to optimise their pragmatic value to IDS experts, services, communities, and individuals. Although the design of

an internationally relevant framework would be highly useful for providing a mechanism to standardise the operationalisation of IDS across countries, the practical application of IDS principles will have to be country-specific because, just like the IDS principles themselves, they will inevitably have to be applied through the national, community and individual-level structures that exist in different countries, such as the country-specific treaties or agreements between governments and their Indigenous people.

Consequently, this systematic review has three aims: to identify published Australian IDS-relevant studies; to describe the key characteristics of the identified papers and identify the frequency with which they cite the existing IDS principles; and to draft a framework for how IDS principles might be operationalised that is both able to be standardised internationally and adapted to the specific circumstances of Australia and other countries.

Method

Ethics approval and consent

Ethics approval was provided by the Aboriginal Health and Medical Research Council (1405/18) and the Central Australian Human Research Ethics Committee (CA-18–3145).

Search strategy

A PRISMA compliant search of the literature was undertaken, using methods detailed in the Cochrane Collaboration Handbook on Systematic Reviews of Health Promotion and Public Health Interventions.¹ The search strategy comprised two steps: a search of 11 scientific electronic databases (AIATSIS, APA-ATSIS, APAIS-Health, CINAHL, EBM Review CDS, Embase, Emcare, Global Health, Medline, PAIS and, PsychINFO); and five grey literature sources (APO Online, Austlit, Australian Government's Productivity Commission, HealthInfonet and, Lowitja Institute). The search was limited by date of publication (One January 2000 to One December 2021). The following keywords and subject heading terms were used: (exp Aboriginal and Torres Strait Islander or Aborigin* or Torres Strait Island* or, Oceanic ancestry group) and (exp research or biomedical research or population surveillance or translational medical research or, research design) and (exp data or datasets or data collection or data management or health surveys or information dissemination or, intellectual property) and (exp self-determination or ownership or control or access or possession or OCAP or sovereignty or, ethics) and, (exp Australia). As summarised in [Figure 1](#), the search of the electronic and grey literature databases identified 6592 unique studies after removing 1508 duplicates.

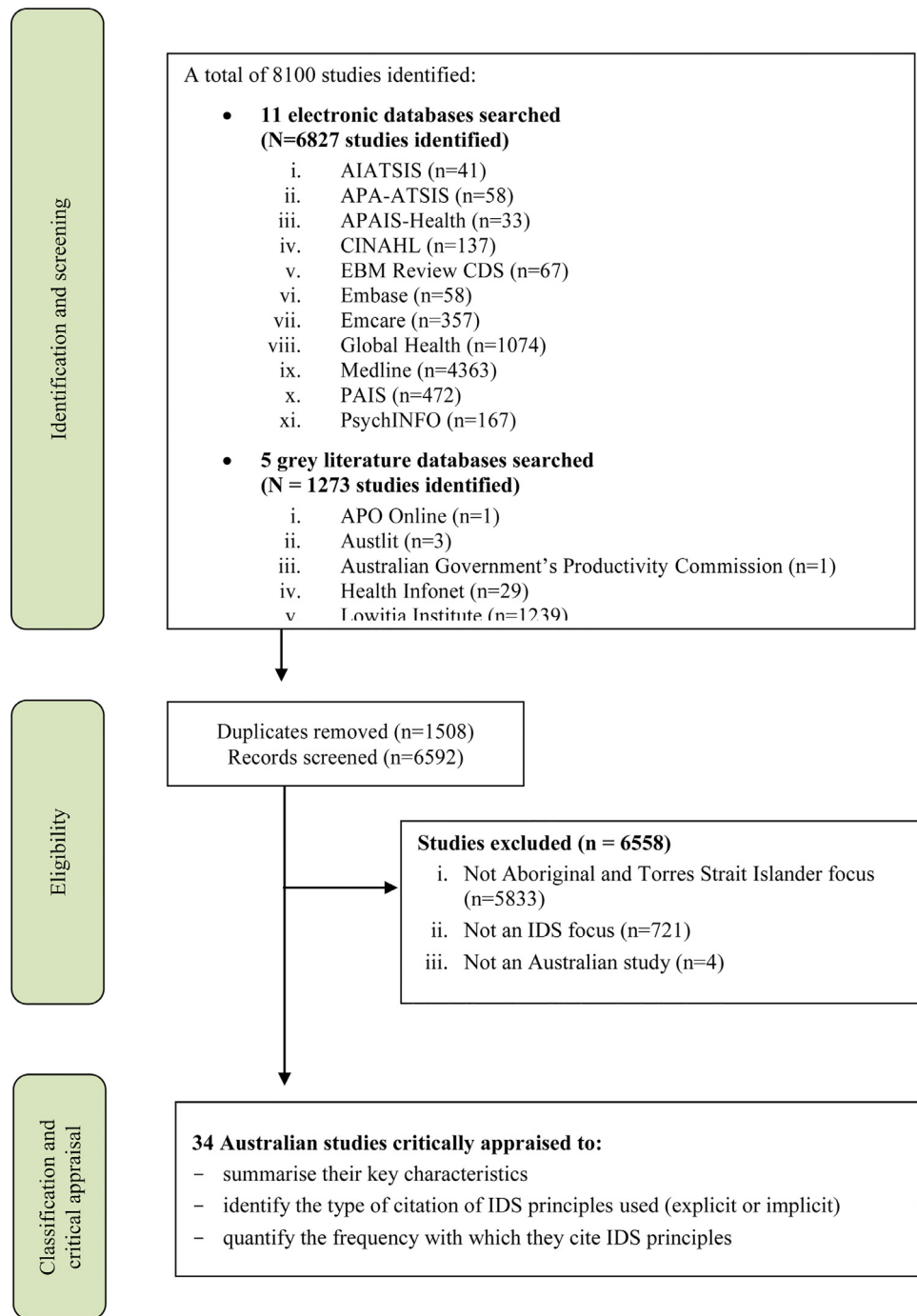


Figure 1. PRISMA flowchart summarising the identification and classification of articles.

Application of the exclusion criteria

The titles of these 6592 unique studies were manually reviewed by the lead author, or their abstract was examined if the title was insufficiently informative, to assess their relevance against three exclusion criteria: i) not an Aboriginal and Torres Strait Islander focus (n = 721

studies excluded); ii) not an IDS focus (n = 5833 studies excluded); and, iii) not an Australian study (n = 4 studies excluded). 6558 studies were excluded, leaving 34 studies for in-depth appraisal. An independent review of papers for relevance was conducted by an unnamed author, the reviewer examined the coded reference

IDS principles by source				Eight synthesised principles
Canada	New Zealand	Australia	IDS Symposium	
Ownership				1. Ownership
Control		Control of the data ecosystem		2. Control
Accessibility	Manaakitanga (basic rights)	Availability and accessibility		3. Accessibility
Possession	Kaitiakitanga (stewardship & sustainability)	Accountability		4. Custodianship
	Whanaungatanga and Whakapapa (relationships) Kotahitanga (collective vision)	Protect individual and collective vision	Amplify the voice of the community	5. Accountability to Indigenous 6. Amplify the voice of the community
	Rangatiratanga (self-determination)	Relevant and reciprocal Sustainable self-determination		7. Relevant and reciprocal 8. Sustainably self-determining

Table 1: Synthesis of eight Indigenous Data Sovereignty (IDS) principles from Canada, New Zealand, Australia and the 2017 IDS symposium.
^aNote that the Canadian principle of possession is adapted to custodianship in this review to attempt to capture a greater sense of the responsibility that should be attributed to holding or using Indigenous data.

library of excluded studies, a minimum of 10% of each exclusion criteria was reviewed. There were no instances of discordance.

Synthesis of international IDS principles for literature appraisal

As summarised in Table 1, eight principles arose from synthesising the published principles from Australia, New Zealand, Canada and discourse from the 2017 Indigenous IDS Symposium.^{17,18,21} In this review, the authors used these synthesised principles to identify the extent to which they are discussed in the Australian IDS literature. The two IDS principles identified most frequently were accessibility of Indigenous data and ensuring Indigenous data are used to amplify the voice of Indigenous people and, communities ($n=$ three of these four sources each). The next three most common IDS principles ($n = 2$ sources each) were control, custodianship, and self-determination. The least cited IDS principles ($n = 1$ source each) were ownership, accountability and, the extent to which the data are relevant and reciprocal.

Classification and critical appraisal of studies

The full-text version of the 34 IDS-relevant studies were critically examined by the lead author. First, their key characteristics were summarised (first author, year published, study type, aims, methods, summary of results and the specific type of IDS principle cited, either explicitly or implicitly). Study type was determined using categories adapted from previous reviews by the authors²²

²⁴: (i) *reviews*, defined as any type of literature review (e.g., narrative, systematic) that aims to collate or synthesise the content of published papers on IDS; (ii) *descriptive*, defined as descriptions of attitudes to IDS or IDS guidelines, issues related to the management of Indigenous data, or the application of one or more IDS principles; (iii) *evaluation*, defined as examinations of the process or outcomes of implementing IDS principles using formal qualitative or quantitative evaluation methods; or (iv) *opinion*, defined as proposals, comments or discussions of IDS principles. To include all papers discussing their emerging field, no assessment of quality assessment was made, and all papers were included. This analysis was replicated by a blinded coder (Author Three), there were no instances of discordance.

Second, the frequency with which studies cited any of the eight IDS principles was quantified. As shown in Table 1, the eight synthesised IDS principles are: (i) ownership - the explicit ownership of data by First Peoples and/or organisations; (ii) control- where Indigenous peoples lead, hold power and are in control; Cultural values, principles, approaches, and methods prevail. It does not exclude the involvement of Others, but only as far as usefulness. Involvement of Others is by invitation only.; (iii) access- Indigenous people are able to find and obtain disaggregated and relevant data about themselves as individuals, community and cohorts levels.; (iv) custodianship- Refers to the concept of holding and stewarding data in its raw form, as well as the narrative. Custodianship holds significant responsibility for chartering the data along its intended path, with its intended spirit and within its intended place.; (v) accountability to Indigenous peoples- refers

to the data, in and of itself, as well as the data users to answer to First Peoples, take responsibility for data use and outcomes, and provide explanation to Indigenous peoples. This may include the data structures, the use and nesting of data within the public domain and the continued use of data in research, policy and social domains.; (vi) amplify the voice of the community- refers to the requirement for data to represent upwards and outwards, the voice and experience of Community, the determined needs of Community and the contextualised analysis of data by Community.; (vii) relevant and reciprocal- Relevant refers to useful data which supports Community to make good decisions and reciprocal refers to the data structures, metadata, and data itself providing a platform for giving back to Community. Data collected for Community good and Community need; not just for data's sake or Government determined stake.; and (viii) sustainably self-determining- refers to the continued use and operationalisation of data, metadata, data structures, resources and interests which affect self-determination beyond their immediate intent.

Third, the lead author identified the frequency with which each of these eight IDS principles were explicitly or implicitly cited in the 34 IDS-relevant studies. The author considered the discourse used to describe processes and/or experiences detailed within each paper, the above descriptions were applied to determine if the paper discussed the principles and their related applicability explicitly, then a judgement was determined as explicit. In the instance that papers reflected the descriptions noted in the latter without explicitly naming the principle, then the paper was determined to implicitly discuss the principle. This analysis was replicated by a blinded coder (Author Four) to test the reliability with which the IDS principles were identified in each study and classified as implicit or explicit. The rate of agreement between coders was 80% for explicitly cited, and 53% for implicitly cited, IDS principles. Disagreements were resolved by discussion between the two coders, resulting in an agreed final estimate for the frequency with which the IDS principles were cited.

Role of funding sources

The funding source had no role in the design of the study, execution of research, analyses, interpretation of data, or decision to submit results.

Results

Key characteristics of studies

The key characteristics of the 34 studies identified for analysis are summarised in [Table 2](#).

The prevalence of IDS discourse in Australia. The number of IDS publications is increasing over time: eight

times the number of IDS studies ($n = 30$) were published in the most recent ten years of this review period (January 2011 to December 2021) compared to the previous ten years (January 2000 to December 2010).

Study type, aims, methods and key results. Studies were either descriptive ($n = 20$ studies, 59%) or opinion pieces ($n = 14$, 41% studies). Their aims articulate best practice techniques for Indigenous research in relation to a range of IDS issues, including data collection and analysis, data interpretation, relationship building, confidentiality, informed consent, community participation and cross-cultural considerations. The methods in all studies were appropriate for the study aims: all qualitative studies used standard methodological techniques, such as semi-structured interviews²⁵ and analysis of case studies,^{26,27} or described processes, such as the development of guidelines for the management of Aboriginal health information.²⁸ Seven papers explored methods in the context of Indigenous-led research^{26,3}: although results were specific to each study, the methods used in both studies focused on multiple aspect of IDS, including the collection, utilisation, interpretation, appropriate storage and effective governance of Indigenous data.

Frequency with which IDS principles are explicitly or implicitly cited. [Table 2](#) also identifies whether studies made explicit or implicit reference to IDS principles and specifies the IDS principles that each study referenced. The frequency with which IDS principles are explicitly or implicitly cited is summarised in [Table 3](#), which shows three broad groups: relatively frequent citations, defined as at least 80% citation rate (control, accountable to Aboriginal and Torres Strait Islander peoples and, sustainably self-determining); relatively moderate citations, defined as 60–79% citation rate (ownership, access, custodianship and amplifying community voice and relevant and, reciprocal); and relatively infrequent citations, defined as 59–0% citation rate (nil). [Table 3](#) also identifies that for all the IDS principles, the number of explicit citations was easily greater than the number of implicit citations. The variance between explicit and implicit citations was greatest for principles with relatively moderate citations.

Operationalising IDS

55% percent ($n = 152$) of explicit citations of IDS principles are provided by five authors (Walter, Prehn, Lovett, Maher and Kukutai) who are leaders within the current movement toward IDS and IDG. The remainder of citations are within academic publication (as opposed to grey literature); this suggests that the movement of IDS and IDG from expert theoretical notion to practical community or place based implementation may need to be

Source #	Year	1st Author	Study type	Aims	Brief description of methods	Summary of results	Indigenous Data Sovereignty principles explicitly or implicitly cited
1	2016	Young	Descriptive	To describe the attitudes and beliefs of health professionals working in Aboriginal Community Controlled Health Services (ACCHS) towards the access, usage, and potential value of routinely obtained clinical and research data. To propose establishing an Indigenous data voice.	Face-to-face, semi-structured interviews were conducted with 35 health professionals from 2 urban and 1 regional ACCHS in New South Wales (NSW). Expository opinion piece (a balanced analysis of issues).	<p>Key messages:</p> <ul style="list-style-type: none"> • Six major themes were identified: <ol style="list-style-type: none"> i. occupational engagement ii. trust and assurance iii. motivation and empowerment iv. building research capacity v. optimising service provision vi. and enhancing usability. • A set of principles is required to govern Indigenous data processes and practices to protect ownership and control over the sort of data that are collected and the use of those data. <p>Key messages:</p> <ul style="list-style-type: none"> • The project produced the NSW Aboriginal Health Information Guidelines, covering the collection, ownership, storage, security, release, usage, interpretation, privacy, confidentiality and reporting of Aboriginal data. The guidelines underpinned a 1998 Memorandum of Understanding between NSW Health and the AH&MRC. 	<p>Explicit:</p> <ul style="list-style-type: none"> • Ownership • Control • Sustainably self-determining • Relevant and reciprocal <p>Implicit:</p> <ul style="list-style-type: none"> • Accountability <p>Explicit:</p> <ul style="list-style-type: none"> • Ownership • Control • Ownership • Control • Self-determining <p>Explicit:</p> <ul style="list-style-type: none"> • Ownership • Control • Accessibility • Relevant and reciprocal
2	2018	Walter	Opinion				
3	2000	Todd	Descriptive	To describe the development of guidelines for the management of Aboriginal health information in NSW. The purpose of the guidelines is to promote the ethical management of Aboriginal health information, with appropriate consideration for cultural factors.	Collaborative development of guidelines by the NSW Aboriginal Health Partnership, comprising NSW Health and the NSW Aboriginal Health and Medical Research Council (AH&MRC). A comprehensive consultation process facilitated input from a wide range of groups.	<p>Key messages:</p> <ul style="list-style-type: none"> • In taking ownership for developing the "Knowing our Community" household survey in Broome (remote Western Australia), the Yawuru set a precedent for the acquisition and use of Indigenous data by using survey data in a Geographic Information System to inform their decisions about community development in the post-native title determination era. <p>Key messages:</p> <ul style="list-style-type: none"> • An effective governance framework to protect Indigenous knowledge would specify processes for accessing and sharing benefits of data and knowledge and would be governed by an Indigenous led authority. 	<p>Implicit:</p> <ul style="list-style-type: none"> • Ownership • Control • Access • Custodianship • Self-determining • Accountability • Amplifying community voice • Relevant and reciprocal
4	2014	Taylor	Descriptive	To describe the background events leading to the Yawuru Native Title Holder's Aboriginal Corporation to secure information for its own needs as an act of self-determination and essential governance.	Case study.		
5	2016	Sexton	Opinion	To examine the experience of developing a governance framework to protect Indigenous knowledge.	One-on-one interview with Professor Natalie Stolanoff.		

Table 2 (Continued)

Source #	Year	1st Author	Study type	Aims	Brief description of methods	Summary of results	Indigenous Data Sovereignty principles explicitly or implicitly cited
6	2001	ViHealth Koori Health Research Community Development Unit Koch	Descriptive	To examine issues of community control of Koori health research, including Indigenous researchers' experiences and methods.	A hypothetical case study was used in a community workshop to identify the potential harms and benefits of a research proposal.	<p>Key messages:</p> <ul style="list-style-type: none"> This study highlighted the importance to IDS of confidentiality, informed consent, community participation mechanisms and Indigenous data ownership. <p>Key messages:</p> <ul style="list-style-type: none"> Understanding ethical practices in collecting Indigenous data. Importance of control of access to the data and to published works based on the data. 	<p>Implicit:</p> <ul style="list-style-type: none"> Ownership Relevant and reciprocal Accountability Sustainably self-determining Control <p>Implicit:</p> <ul style="list-style-type: none"> Ownership Control Access Custodianship
7	2010	Foster	Descriptive	To identify ethical dilemmas in the proper management of research collections of Indigenous cultural materials, concentrating upon the use of such material for Native Title purposes.	A review of draft AIATSIS Guidelines for Ethical Research in Indigenous studies and case studies of issues that may arise when requests are made for Indigenous data.	<p>Key messages:</p> <ul style="list-style-type: none"> An adapted model of conducting Indigenous research is needed to inform Indigenous and non-Indigenous researchers about IDS-relevant processes. 	<p>Implicit:</p> <ul style="list-style-type: none"> Ownership Control Access Custodianship Self-determining Accountability Amplifying community voice Relevant and reciprocal
8	2006	Dunne	Descriptive	To highlight the research practices used by a research team.	A case study of a research project focusing on Indigenous mental health issues.	<p>Key messages:</p> <ul style="list-style-type: none"> Researchers who focus on consulting and negotiating the terms of their project with the community, including the issues of collaboration, informed consent, and ownership of data, are more likely to achieve research that is both ethical and relevant to the community. Essential components for research are development of rapport, informed consent, and ownership of data. 	<p>Implicit:</p> <ul style="list-style-type: none"> Ownership Control Custodianship Self-determining Accountability Amplifying Community voice Relevant and reciprocal
9	2000	Kukutai	Descriptive	A collection of descriptions of various aspects of an IDS ecosystem.	Multiple case studies.	<p>Key messages:</p> <ul style="list-style-type: none"> UNDRIP provides a necessary but insufficient foundation for the realisation of Indigenous rights and interests in data. IDS discussions are considered preliminary and there remains a clear need to refine definitions, concepts, and theory, and develop frameworks for their routine application. 	<p>Explicit:</p> <ul style="list-style-type: none"> Ownership Control Access Custodianship Self-determining Accountability Amplifying community voice Relevant and reciprocal

Table 2 (Continued)

Source #	Year	1st Author	Study type	Aims	Brief description of methods	Summary of results	Indigenous Data Sovereignty principles explicitly or implicitly cited
11	2018	Andrews	Opinion	Examine the issue of census volatility from within the Indigenous community and get people to openly provide their perspectives on census engagement and census utility as an expression of Indigenous data sovereignty.	Interviews with Indigenous people in Victoria.	<p>Key messages:</p> <ul style="list-style-type: none"> The census as a social instrument needs to be viewed as a dynamic interplay between the state and Indigenous people. Indigenous community awareness of their role in the census process needs to be further explored. Views of Indigenous people on IDS and data governance are likely to become more prevalent. <p>Key messages:</p> <ul style="list-style-type: none"> The health promotion community needs to engage in conversations about strong data governance development, and developing robust partnerships with data scientists, statisticians and epidemiologists who are focused on health equity. The capacity for data scientists and statisticians to consider the lives of the populations most impacted by health disparities needs to be built. There is a need for health promoters to engage with data in new and innovative ways that respond to, and are respectful of, community needs. Governments could more effectively ensure avoidable health disparities are clearly identified and addressed. 	<p>Implicit:</p> <ul style="list-style-type: none"> Ownership Control Custodianship Self-determining <p>Explicit:</p> <ul style="list-style-type: none"> Access Accountability Amplifying community voice Relevant and reciprocal <p>Implicit:</p> <ul style="list-style-type: none"> Control Self-determining Accountability Amplifying community voice Relevant and reciprocal
12	2020	Griffiths	Opinion	Discussion and consideration of the current data ecosystem. Identify key challenges in the measurement of health disparities in rural and remote regions, and data quality, specifically in relation to Indigenous people.	Opinion piece.	<p>Key messages:</p> <ul style="list-style-type: none"> There is a current lack of population-level data that adequately represents the experiences of Indigenous people. The Mayi Kuwayi Study will contribute to filling key evidence gaps, including quantifying the contribution of cultural factors to wellbeing, alongside standard elements of health and risk <p>Key messages:</p> <ul style="list-style-type: none"> There is an opportunity to embed IDS, or at a minimum IDG, within the CTG framework. Opportunities should be sought to embed IDS and/or IDG into routine practice to enhance control of data by Indigenous Peoples for the benefit of Indigenous Peoples and communities. 	<p>Implicit:</p> <ul style="list-style-type: none"> Ownership Control Access Custodianship Self-determining Accountability Amplifying community voice Relevant and reciprocal <p>Explicit:</p> <ul style="list-style-type: none"> Ownership Control Access Custodianship Self-determining Accountability Amplifying community voice Relevant and reciprocal
13	2018	Jones	Descriptive	To present a protocol for the Our Cultures Count, Mayi Kuwayi Study (a national longitudinal study of Indigenous wellbeing).	A baseline survey that was developed through extensive community consultation, and includes items on: cultural practice and expression, sociodemographic factors, health and wellbeing, health behaviours, experiences and environments, and family support and connection.	<p>Key messages:</p> <ul style="list-style-type: none"> Case study of embedding IDS and IDG principles into CTG policy. 	<p>Implicit:</p> <ul style="list-style-type: none"> Ownership Control Access Custodianship Self-determining Accountability Amplifying community voice Relevant and reciprocal <p>Explicit:</p> <ul style="list-style-type: none"> Ownership Control Access Custodianship Self-determining Accountability Amplifying community voice Relevant and reciprocal
14	2020	Lovett	Descriptive	Discussion about IDS and Closing the Gap (CTG) policy, and guidance for incorporating IDS and Indigenous Data Governance (IDG) into future policy.	Case study of embedding IDS and IDG principles into CTG policy.	<p>Key messages:</p> <ul style="list-style-type: none"> Case study of embedding IDS and IDG principles into CTG policy. 	<p>Implicit:</p> <ul style="list-style-type: none"> Ownership Control Access Custodianship Self-determining Accountability Amplifying community voice Relevant and reciprocal <p>Explicit:</p> <ul style="list-style-type: none"> Ownership Control Access Custodianship Self-determining Accountability Amplifying community voice Relevant and reciprocal

Table 2 (Continued)

Source #	Year	1st Author	Study type	Aims	Brief description of methods	Summary of results	Indigenous Data Sovereignty principles explicitly or implicitly cited
15	2019	Lovett	Opinion	To provide clarity concerning the definitions of IDS and Indigenous data governance; provide an overview of the historical context in which IDS has emerged; and provide examples of IDS and IDG across the spectrum of community, policy and practice.	Perspectives from Indigenous scholars across Australia, Aotearoa, and North America to explain historical and emergent IDS and/or IDG practices.	<p>Key messages:</p> <ul style="list-style-type: none"> • IDS may be applicable to the group level (iwi/tribe/mob/Māori), not just the nation-state level. • Data governance is authority over its design, ownership, access and use. • The intent of IDS focused groups (eg. Te Mana Rauanga in New Zealand and Maiamayri Wingara in Australia) is to advocate for the right of Indigenous peoples to the protection and use of their data (informed by UNDRIP). 	<p>Explicit:</p> <ul style="list-style-type: none"> • Ownership • Control • Access • Custodianship • Self-determining • Accountability • Amplifying community voice • Relevant and reciprocal
16	2019	Prehn	Descriptive	Exploration about how Indigenous Community Research Officers (ICROs) may be conducive to fostering and developing IDS and, subsequently, the improvement of community health and wellbeing.	Case study.	<p>Key messages:</p> <ul style="list-style-type: none"> • Emerging research suggests ICROs enable higher levels of participant retention and assist in more accurate data 'sense-making', both of which are strongly aligned with the goals and principles of IDS. 	<p>Explicit:</p> <ul style="list-style-type: none"> • Self-determining • Accountability • Amplifying community voice
17	2020	Walker	Opinion	Discuss the consequences of Open Data and Big Data for IDS, and approaches to mediate risks while providing pathways to collective benefits.	Opinion Piece.	<p>Key messages:</p> <ul style="list-style-type: none"> • Neither existing data infrastructure nor the emerging Open and Big Data infrastructure recognise Indigenous agency, worldviews, or their specific data needs. • Although there are potential benefits of open/big data, Indigenous people will not share equally in these benefits without the application of IDS principles. 	<p>Explicit:</p> <ul style="list-style-type: none"> • Ownership • Control • Access • Custodianship • Self-determining • Accountability • Amplifying community voice • Relevant and reciprocal
18	2019	Walker and Suina	Opinion	An exploration of the potential of using Indigenous quantitative methodologies in practice.	Case study.	<p>Key messages:</p> <ul style="list-style-type: none"> • The absence of a systematic Indigenous presence from data production has resulted in an overwhelming statistical narrative of deficit for dispossessed Indigenous peoples globally. • There is a need to disturb Western logics of statistical data and apply Indigenous methodologies and/or interpretations of data analyses. 	<p>Explicit:</p> <ul style="list-style-type: none"> • Ownership • Control • Access • Custodianship • Self-determining • Accountability • Amplifying community voice

Table 2 (Continued)

Source #	Year	1st Author	Study type	Aims	Brief description of methods	Summary of results	Indigenous Data Sovereignty principles explicitly or implicitly cited
19	2018	Wilks	Descriptive	To examine the type and nature of Indigenous specific data required or sought in the higher education sector.	Case studies of researchers' experiences	<p>Key messages:</p> <ul style="list-style-type: none"> • Call for a rigorous inquiry that must involve Indigenous educators, researchers, evaluators and communities to bring into effect their aspirations for IDS, including stewardship, ownership and realising the cultural benefits of data. • Collaboration between key stakeholders (eg. governments, researchers, organisations) is needed to reach a consensus on a decolonised IDS framework. • Prioritise Indigenous data needs, protect the integrity of their data, support their leadership in IDS, be accountable to Indigenous people and communities, and recognise Indigenous Rights in relation to data (PIIAR). <p>Key messages:</p> <ul style="list-style-type: none"> • Call for a revision of ethical protocols and standards to be more inclusive for bioethics • Collaboration between key stakeholders is needed to reach a consensus on a decolonised IDS framework • Prioritise Indigenous worldviews and decision-making in bioethics 	<p>Explicit:</p> <ul style="list-style-type: none"> • Ownership • Control • Access • Custodianship • Self-determining • Accountability • Relevant and reciprocal
20	2021	Anderson	Opinion	Discussion of the consequence of white privilege and research approaches on bioethics	Case studies of genome research practices	<p>Key messages:</p> <ul style="list-style-type: none"> • Call for a revision of ethical protocols and standards to be more inclusive for bioethics • Collaboration between key stakeholders is needed to reach a consensus on a decolonised IDS framework • Prioritise Indigenous worldviews and decision-making in bioethics 	<p>Explicit:</p> <ul style="list-style-type: none"> • Control • Self-determining • Access <p>Implicit:</p> <ul style="list-style-type: none"> • Accountability • Relevant and reciprocal
21	2020	Bourke	Descriptive	To present the approach to developing the first national survey to measure this relationship, designed and owned by Indigenous Australians — the Mayi Kuwayu National Study of Aboriginal and Torres Strait Islander Wellbeing.	Observations of focus groups	<p>Key messages:</p> <ul style="list-style-type: none"> • Indigenous leadership and ownership enhances meaningful data from MK study. • MK empowers Indigenous Australian communities and decolonising the wider Indigenous health narrative 	<p>Explicit:</p> <ul style="list-style-type: none"> • Ownership • Control • Accountability • Amplifying community voice • Relevant and reciprocal • Access
22	2021	Krakouer	Descriptive	To present findings from a scoping review of predictive risk modelling for Indigenous Australians	Scoping Review	<p>Key messages:</p> <ul style="list-style-type: none"> • Participatory model development, transparency and Indigenous data sovereignty are crucial to ensure the development of fair and unbiased PRMs in Australian child protection systems. • Inclusion of Indigenous Australians in future tool development is needed before PRM's are used with Indigenous Australians 	<p>Implicit:</p> <ul style="list-style-type: none"> • Self-determining <p>Explicit:</p> <ul style="list-style-type: none"> • Ownership • Control • Access • Custodianship • Accountability • Relevant and reciprocal <p>Implicit:</p> <ul style="list-style-type: none"> • Self-determining • Amplifying community voice

Table 2 (Continued)

Source #	Year	1st Author	Study type	Aims	Brief description of methods	Summary of results	Indigenous Data Sovereignty principles explicitly or implicitly cited
23	2020	Lewis	Opinion	A description of one Universities approach to repatriating historical biobank data	Newspaper Article	<p>Key messages:</p> <ul style="list-style-type: none"> The return of biobank samples as part of is a ground-breaking approach Institutions continue to grapple with how to use historical samples ethically in research <p>Key messages:</p> <ul style="list-style-type: none"> Future policy should incorporate IDS and IDG principles 	<p>Explicit:</p> <ul style="list-style-type: none"> Ownership Control Access Custodianship Accountability <p>Implicit:</p> <ul style="list-style-type: none"> Self-determining <p>Explicit:</p> <ul style="list-style-type: none"> Ownership Control Access Custodianship Self-determining Accountability Amplifying community voice Relevant and reciprocal
24	2020	Lovett	Opinion	This chapter examines the intersection of Indigenous Data Sovereignty and Closing the Gap policy in Australia	Critical assessment of the CTG in relation to IDS and Indigenous Data Governance (IDG)	<p>Key messages:</p> <ul style="list-style-type: none"> Indigenous data have been gleaned and assembled into knowledges through the frame of 'settler-colonialism to produce generalisations about Indigenous peoples, which are then expressed as 'wisdom' about Indigenous historical and contemporary lives Rarely acknowledged in the process of knowledge production is the settler-colonial cultural lens that is imbued with concepts such as racial hierarchy, racism and sexism This practice has been particularly prevalent in the context of our demography, health and wellbeing <p>Key messages:</p> <ul style="list-style-type: none"> In-depth interviews with Indigenous knowledge holders will occur in the first instance to inform the search terms and define collective capability from an Indigenous standpoint. The concept may be completely new and not fully established in the literature relating to the Australian evaluation context. 	<p>Explicit:</p> <ul style="list-style-type: none"> Ownership Control Access Custodianship Self-determining Accountability Amplifying community voice Relevant and reciprocal
25	2020	Lovett	Opinion	Critique of the power and knowledge structures of the economic, political, social and cultural resources that are Aboriginal and Torres Strait Islander data.	Challenge presented to the current holders of Aboriginal and Torres Strait Islander data and the colonial 'worldview from which such data are converted into knowledges. To map a new path, we offer solutions that are embedded in the concept of Indigenous Data Sovereignty (IDSov) and Indigenous Data Governance (IDGov).	<p>Key messages:</p> <ul style="list-style-type: none"> In-depth interviews with Indigenous knowledge holders will occur in the first instance to inform the search terms and define collective capability from an Indigenous standpoint. The concept may be completely new and not fully established in the literature relating to the Australian evaluation context. 	<p>Explicit:</p> <ul style="list-style-type: none"> Ownership Control Access Custodianship Self-determining Accountability Amplifying community voice Relevant and reciprocal
26	2021	Maher	Descriptive	Protocol for future research	Describes a protocol for defining collective capability within an Indigenous methodological context and includes the investigator team being driven by Aboriginal researchers.	<p>Key messages:</p> <ul style="list-style-type: none"> In-depth interviews with Indigenous knowledge holders will occur in the first instance to inform the search terms and define collective capability from an Indigenous standpoint. The concept may be completely new and not fully established in the literature relating to the Australian evaluation context. 	<p>Explicit:</p> <ul style="list-style-type: none"> Ownership Control Access Custodianship Self-determining Accountability Amplifying community voice Relevant and reciprocal

Table 2 (Continued)

Source #	Year	1st Author	Study type	Aims	Brief description of methods	Summary of results	Indigenous Data Sovereignty principles explicitly or implicitly cited
27	2021	Robinson	Descriptive	Examination of one case study to construct an offering of a framework for the design and use of CARE-informed data practices, which can be embedded into project design to enable the ethical and responsible use of Indigenous data to improve Indigenous policies and services.	Case study of a project that used data reported by Indigenous ranger groups to capture the multiple benefits of Indigenous land and water management activities.	<p>Key messages:</p> <ul style="list-style-type: none"> Challenges of ensuring that Indigenous data sets are used in a way that protects Indigenous rights to that data and maximises benefits for Indigenous peoples are increasing with advances in open data, big data, and data linkage 	<p>Explicit:</p> <ul style="list-style-type: none"> Control Access Custodianship Self-determining Accountability Amplifying community voice Relevant and reciprocal <p>Implicit</p> <ul style="list-style-type: none"> Ownership Control Self-determining Accountability Amplifying community voice Relevant and reciprocal
28	2020	Schultz	Opinion	A description of the inclusion of Indigenous voices in the development of indicators with critical use, such as SDG's and Close the Gap (CTG)	Provision of an Indigenous developed set of indicators (of sustainable development)	<p>Key messages:</p> <ul style="list-style-type: none"> Consultation with indigenous peoples in the development of the SDGs was limited Although SDGs to improve health, education and employment may reduce disadvantage, the underlying approach to development promoted by the SDGs continues the historic relationships between powerful and poorer communities Outside the SDG processes, indigenous people have developed indicators of development significant for themselves 	<p>Implicit:</p> <ul style="list-style-type: none"> Ownership Control Custodianship Self-determining Accountability Amplifying community voice Relevant and reciprocal
29	2021	Thorpe	Descriptive	The aim of the article is to bring greater visibility to the voice and experiences of Indigenous Australian people who are working to facilitate access to collections in libraries and archives.	Article discusses the dangers of libraries and archives for Indigenous Australian workers by introducing doctoral research on the topic of Indigenous archiving and cultural safety: Examining the role of decolonisation and self-determination in libraries and archives.	<p>Key messages:</p> <ul style="list-style-type: none"> Libraries and archives are troubling spaces for Indigenous Australian people as they are sites of renewal and truth-telling as well as sites of deep tension. 	<p>Implicit:</p> <ul style="list-style-type: none"> Ownership Control Custodianship Self-determining Accountability Amplifying community voice Relevant and reciprocal
30	2020	Thurber	Descriptive	This paper describes and empirically evaluates a set of strategies to support strengths-based quantitative analysis.	A case study about Aboriginal and Torres Strait Islander child wellbeing was used to demonstrate approaches to support strengths-based quantitative analysis, in comparison to the dominant deficit approach of identifying risk factors associated with a negative outcome.	<p>Key messages:</p> <ul style="list-style-type: none"> The application of the strengths-based approach retains the identification of statistically significant exposure-outcome associations seen with the standard deficit approach Strengths-based approaches can enable a more positive story to be told, without altering statistical rigour For Indigenous research, a strengths-based approach better reflects community values and principles, and it is more likely to support positive change than standard pathogenic models 	<p>Implicit:</p> <ul style="list-style-type: none"> Self-determining Accountability Amplifying community voice Relevant and reciprocal

Table 2 (Continued)

Source #	Year	1st Author	Study type	Aims	Brief description of methods	Summary of results	Indigenous Data Sovereignty principles explicitly or implicitly cited
31	2020	Tong	Descriptive	Examination of learnings and experiences of Indigenous peoples within genetic research	Description of research methodology and qualitative analysis of research participant experiences	<p>Key messages:</p> <ul style="list-style-type: none"> Genetic research for Indigenous peoples around the world must uphold rights, participation and respect for the integrity and safeguarding of social, cultural, religious, and spiritual values. These documents provide an important framework for the conduct of genetic research with Indigenous peoples <p>Key messages:</p> <ul style="list-style-type: none"> In the digital age, governments are increasingly dependent on data and data analytics to inform their policies and decision-making Indigenous Peoples have often been the unwilling targets of policy interventions and have had little say over the collection, use and application of data about them, their lands and cultures At the heart of Indigenous Peoples' demands for change are the enduring aspirations of self-determination over their institutions, resources, knowledge and information systems. 	<p>Explicit</p> <ul style="list-style-type: none"> Control Accountability Amplifying the voice Access Self-determining Relevant and reciprocal Ownership <p>Explicit:</p> <ul style="list-style-type: none"> Ownership Control Access Custodianship Self-determining Accountability Amplifying community voice Relevant and reciprocal
32	2021	Walter	Opinion	This book examines how Indigenous Peoples around the world are demanding greater data sovereignty and challenging the ways in which governments have historically used Indigenous data to develop policies and programs.	Collation of accounts of the potential for Indigenous Data Sovereignty to support human flourishing and to protect against the ever-growing threats of data-related risks and harms	<p>Key messages:</p> <ul style="list-style-type: none"> The impact of data is magnified by the emergence of Big Data and the associated impetus to open publicly held data (Open Data). Existing data infrastructure, and the emerging Open Data infrastructure, neither recognise Indigenous agency and worldviews nor consider Indigenous data needs. <p>Key messages:</p> <ul style="list-style-type: none"> Bringing together health and the humanities through the particularity of Indigenous scholarship, a deeper understanding of the human experience of health will be developed alongside a greater understanding of the enablers to building a transdisciplinary collective of Indigenous researchers The potential benefits include a more sustainable, relational, and ethical approach to advancing new knowledge, and health outcomes, for Indigenous people in its fullest sense. 	<p>Explicit:</p> <ul style="list-style-type: none"> Ownership Control Access Custodianship Self-determining Accountability Amplifying community voice Relevant and reciprocal <p>Implicit:</p> <ul style="list-style-type: none"> Control Self-determining Accountability Amplifying community voice Relevant and reciprocal
33	2021	Walter	Opinion	This paper discusses the unforeseen (and likely unseen) consequences of the influence of Open Data and Big Data and discusses how Indigenous Data Sovereignty can mediate risks while providing pathways to collective benefits.	Description of challenges in approach and worldviews which are currently leading discussions around open data	<p>Key messages:</p> <ul style="list-style-type: none"> The impact of data is magnified by the emergence of Big Data and the associated impetus to open publicly held data (Open Data). Existing data infrastructure, and the emerging Open Data infrastructure, neither recognise Indigenous agency and worldviews nor consider Indigenous data needs. <p>Key messages:</p> <ul style="list-style-type: none"> Bringing together health and the humanities through the particularity of Indigenous scholarship, a deeper understanding of the human experience of health will be developed alongside a greater understanding of the enablers to building a transdisciplinary collective of Indigenous researchers The potential benefits include a more sustainable, relational, and ethical approach to advancing new knowledge, and health outcomes, for Indigenous people in its fullest sense. 	<p>Explicit:</p> <ul style="list-style-type: none"> Ownership Control Access Custodianship Self-determining Accountability Amplifying community voice Relevant and reciprocal <p>Implicit:</p> <ul style="list-style-type: none"> Control Self-determining Accountability Amplifying community voice Relevant and reciprocal
34	2021	Watego	Descriptive	This paper outlines the development of Indigenous Health Humanities as a new and innovative field of research building an intellectual collective capable of bridging the knowledge gap that hinders current efforts to close the gap in Indigenous health inequality.	This paper is a story of the emergence of a new field of research from so-called Australia which redefines the parameters by which we understand health and humanity via a foregrounding of Indigenous sovereignty, both locally and globally.	<p>Key messages:</p> <ul style="list-style-type: none"> The impact of data is magnified by the emergence of Big Data and the associated impetus to open publicly held data (Open Data). Existing data infrastructure, and the emerging Open Data infrastructure, neither recognise Indigenous agency and worldviews nor consider Indigenous data needs. <p>Key messages:</p> <ul style="list-style-type: none"> Bringing together health and the humanities through the particularity of Indigenous scholarship, a deeper understanding of the human experience of health will be developed alongside a greater understanding of the enablers to building a transdisciplinary collective of Indigenous researchers The potential benefits include a more sustainable, relational, and ethical approach to advancing new knowledge, and health outcomes, for Indigenous people in its fullest sense. 	<p>Explicit:</p> <ul style="list-style-type: none"> Ownership Control Access Custodianship Self-determining Accountability Amplifying community voice Relevant and reciprocal <p>Implicit:</p> <ul style="list-style-type: none"> Control Self-determining Accountability Amplifying community voice Relevant and reciprocal

Table 2: Key characteristics of studies that explicitly or implicitly referred to indigenous data sovereignty principles (N = 34 studies).

Source #	Year	1st Author	Ownership	Control	Access	Custodianship	Accountable to Aboriginal and Torres Strait Islander Peoples	Amplifying Community voice	Relevant and reciprocal	Sustainably self-determining
1	2016	Young	Y	Y					Y	Y
2	2018	Walter	Y	Y			Y			Y
3	2000	Todd	Y	Y	Y				Y	
4	2014	Taylor	Y	Y	Y	Y		Y		Y
5	2016	Sexton	Y	Y			Y			
6	2001	VicHealth Koori Health Research Community Development Unit	Y			Y			Y	Y
7	2010	Koch	Y	Y	Y	Y				Y
8	2006	Foster	Y	Y	Y		Y		Y	
9	2000	Dunne	Y	Y	Y	Y		Y	Y	Y
10	2016	Kukutai	Y	Y	Y	Y		Y	Y	Y
11	2018	Andrews	Y	Y	Y	Y		Y	Y	Y
12	2020	Griffiths	Y	Y	Y	Y		Y	Y	Y
13	2018	Jones	Y	Y	Y	Y		Y	Y	Y
14	2020	Lovett	Y	Y	Y	Y		Y	Y	Y
15	2019	Lovett	Y	Y	Y	Y		Y	Y	Y
16	2019	Prehn	Y	Y	Y	Y		Y	Y	Y
17	2020	Walter	Y	Y	Y	Y		Y	Y	Y
18	2019	Walter and Suina	Y	Y	Y	Y		Y	Y	Y
19	2018	Wilks	Y	Y	Y	Y		Y	Y	Y
20	2021	Anderson	Y	Y	Y	Y		Y	Y	Y
21	2020	Bourke	Y	Y	Y	Y		Y	Y	Y
22	2021	Krakouer	Y	Y	Y	Y		Y	Y	Y
23	2020	Lewis	Y	Y	Y	Y		Y	Y	Y
24	2020	Lovett	Y	Y	Y	Y		Y	Y	Y
25	2020	Lovett	Y	Y	Y	Y		Y	Y	Y
26	2021	Maher	Y	Y	Y	Y		Y	Y	Y
27	2021	Robinson	Y	Y	Y	Y		Y	Y	Y
28	2020	Schultz	Y	Y	Y	Y		Y	Y	Y
29	2021	Thorpe	Y	Y	Y	Y		Y	Y	Y
30	2020	Thurber	Y	Y	Y	Y		Y	Y	Y
31	2020	Tong	Y	Y	Y	Y		Y	Y	Y
32	2021	Walter	Y	Y	Y	Y		Y	Y	Y

Table 3 (Continued)

Source #	Year	1st Author	Ownership	Control	Access	Custodianship	Accountable to Aboriginal and Torres Strait Islander Peoples	Amplifying Community voice	Relevant and reciprocal	Sustainably self-determining
33	2021	Walter	Y	Y	Y	Y	Y	Y	Y	Y
34	2021	Watego				Y	Y	Y	Y	Y
		Total Implicit	6	7	4	7	11	8	8	12
		Total Explicit	20	22	19	17	20	16	19	19
		Total Mentions	26	29	23	24	31	24	27	31
		Citation Rate:% Mentions Implicit	23%	24%	17%	29%	35%	33%	30%	39%
		Citation Rate:% Mentions Explicit	77%	76%	83%	71%	65%	67%	70%	61%
		Citation Rate: Overall Mention	76%	85%	68%	71%	91%	71%	79%	91%
		Relatively Frequent Citations		x			X			X
		Relatively Moderate Citations	x		X	x		x		
		Relatively Infrequent Citations							x	

Table 3: The frequency with which eight indigenous data sovereignty principles are explicitly or implicitly cited (N = 34 studies).

^aY = Implicitly cited principles of IDS.

^bX = Explicitly cited principles of IDS.

Core components of a proposed IDS framework	Example lead network / group	Indigenous Data Sovereignty principles and their potential application in Australia
<p>1. International agreements (human rights)</p>	<p>Global Indigenous Data Alliance (GIDA) International Indigenous Data Sovereignty Interest Group Maiaam nayri Wingara (MnW)IDS Collective (Australia) British Columbia's Indigenous Data Governance Initiative (Canada) Te Mana Rauunga Maori Data Sovereignty Network (New Zealand)</p>	<p>A primary intent of international agreements is to provide a visible, collective approach to progressing IDS / IDG internationally, such as stipulating the appropriate IDS principles that should apply in any country</p> <ul style="list-style-type: none"> The 8 globally relevant IDS principles synthesised in this review from current literature (summarised in Table 1) are: i) ownership; ii) control; iii) access; iv) custodianship; v) accountability to Aboriginal and Torres Strait Islander; vi) amplify the voice of the community; vii) relevant and reciprocal; and viii) sustainably self-determining. Ensure national Aboriginal and Torres Strait Islander representation in global networks <ul style="list-style-type: none"> Australian example: potentially members of the MnW/IDS Collective represent Australia globally or responsibility is rotated through key Aboriginal and Torres Strait Islander stakeholders
<p>2. National or jurisdictional level agreements (policy, systems)</p>	<p>The primary purposes of national or jurisdictional level agreements could include:</p> <ul style="list-style-type: none"> Stipulating which international IDS principles are appropriate in a specific country or jurisdiction. Australian example: MnW principles. The five IDS principles / rights determined by MnW are: i) Control of the data ecosystem, ii) Availability and accessibility, iii) Accountability, iv) Protect individual and collective vision, v) Relevant and reciprocal, and vi) Sustainable self-determination Aboriginal and Torres Strait Islander/IDG leaders working with governments and policy makers to develop and implement relevant and effective IDS/IDG policies and legislation, and clearly articulating the relationships between government and IDS/IDG agencies. Australian example⁶⁵: Indigenous owned data infrastructure that contains de-identified data from Indigenous administrative datasets for research and policy decision making.— Australian example⁶⁷: Design of policies in accordance with IDS principles. 	<p>The primary purposes of national or jurisdictional level agreements could include:</p> <ul style="list-style-type: none"> Stipulating which international IDS principles are appropriate in a specific country or jurisdiction. Australian example: MnW principles. The five IDS principles / rights determined by MnW are: i) Control of the data ecosystem, ii) Availability and accessibility, iii) Accountability, iv) Protect individual and collective vision, v) Relevant and reciprocal, and vi) Sustainable self-determination Aboriginal and Torres Strait Islander/IDG leaders working with governments and policy makers to develop and implement relevant and effective IDS/IDG policies and legislation, and clearly articulating the relationships between government and IDS/IDG agencies. Australian example⁶⁵: Indigenous owned data infrastructure that contains de-identified data from Indigenous administrative datasets for research and policy decision making.— Australian example⁶⁷: Design of policies in accordance with IDS principles.
	<p>Developing standardised data collection tools and frameworks.</p> <ul style="list-style-type: none"> Australian example⁶⁸: Development of data collection tools and approaches that generate adequate data for policy and decision making. 	<p>Developing standardised data collection tools and frameworks.</p> <ul style="list-style-type: none"> Australian example⁶⁸: Development of data collection tools and approaches that generate adequate data for policy and decision making.
	<p>Acting as a clear mechanism for Aboriginal and Torres Strait Islander people to determine which data about Aboriginal and Torres Strait Islander peoples are held in national or jurisdictional data collections (e.g. population census data), and contribute to the collection, analysis and sense making of those data.</p> <ul style="list-style-type: none"> Australian example⁶⁹: Development of new data items and cultural indicators that are representative and important to Indigenous peoples. Australian example⁷⁰: Indigenous peoples to have skills and role in collection, analysis and sense making of data. 	<p>Acting as a clear mechanism for Aboriginal and Torres Strait Islander people to determine which data about Aboriginal and Torres Strait Islander peoples are held in national or jurisdictional data collections (e.g. population census data), and contribute to the collection, analysis and sense making of those data.</p> <ul style="list-style-type: none"> Australian example⁶⁹: Development of new data items and cultural indicators that are representative and important to Indigenous peoples. Australian example⁷⁰: Indigenous peoples to have skills and role in collection, analysis and sense making of data.
	<p>Highlighting examples of good practice</p> <ul style="list-style-type: none"> Australian example⁷¹: Yawuru Native Title Holder's Aboriginal Corporation's "Knowing our Community" survey. 	<p>Highlighting examples of good practice</p> <ul style="list-style-type: none"> Australian example⁷¹: Yawuru Native Title Holder's Aboriginal Corporation's "Knowing our Community" survey.

Table 4 (Continued)

Indigenous Data Sovereignty principles and their potential application in Australia

Core components of a proposed IDS framework

Example lead network / group	Ownership	Control	Access	Custodianship	Accountable to Aboriginal and Torres Strait Islander Peoples	Amplifying Community voice	Relevant and reciprocal	Sustainably self-determining
N/A	Aboriginal and Torres Strait Islander data are formally owned by local Aboriginal and Torres Strait Islander organisations who provide permission for others to access data ⁴²	Aboriginal and Torres Strait Islander data are held by authorised custodians (in a way that is determined by the owner) and made available for national or jurisdictional purposes on request ⁴²	Data are locally contextual and only accessible through local Aboriginal and Torres Strait Islander organisations ⁴³	Acquisition and application of demographic information for internal planning and community development ²⁶	Researchers need to engage in extensive community consultation, negotiation and collaboration and formal agreement for collection and use of data needs to be obtained ⁴⁴	Yawuru Native Title Holder's Aboriginal Corporation's "Knowing our Community" household survey ²⁶	Place based models of conducting research for other Aboriginal community-controlled organisations and demonstrating best practice and sharing findings with non-Aboriginal orgs/ researcher. ⁴⁵	Aboriginal and Torres Strait Islander peoples to have skills and role in collection, analysis and sense making of data ⁸
N/A	Examples to be shared through MnW collective learnings	Native Title Holders determine what success looks like for them, in their Community and aligned with cultural practice ⁴¹	Staff recruited for data roles with clear view of outcomes and practices/policy implications ²⁵	Examples to be shared through MnW collective learnings	Examples to be shared through MnW collective learnings	Researchers need to engage in extensive community consultation, negotiation and collaboration and formal agreement for collection and use of data needs to be obtained ⁴⁴	Examples to be shared through MnW collective learnings	Examples to be shared through MnW collective learnings

The primary purpose of individual-level agreements is to highlight the right of individuals to make decisions as to if, when and how they provide data and obtain data relevant to their individual context, understanding and experience within societal systems

Table 4: A proposed framework to assist countries to develop Indigenous Data Sovereignty (IDS) agreements and processes that are both standardised internationally and tailored to their circumstances, with examples of its potential application in Australia from studies identified in this literature review.

supported. To that end, the authors have provided a potential conceptual framework to support Indigenous peoples and communities to interrogate and define IDS for themselves and consider how each principle should be enacted within their context. This is a conceptual framework for researching, evaluating, and designing Indigenous programs, initiatives, and organisations. The eight principles adopted within this literature review have been applied to the proposed framework.

Given that the MnW principles for Australian IDS have been developed and this is where the included studies arise from, it is important to note that the IDS principles defined by MnW continue to be recognised and adhered to within the proposed framework as they have been incorporated into the eight above mentioned synthesised principles. Based on the first author's expertise in Indigenous place-based practice, a decision was made to apply the eight principles synthesised in this literature review to the proposed framework as their nuance will likely provide clearer scope during the design and/or evaluation process conducted by Indigenous peoples and communities.

A conceptual framework for operationalising IDS. Table 4 presents a potential framework for operationalising the IDS principles, comprising four core components: (i) international agreements; (ii) national or jurisdictional agreements, (iii) place-based agreements, and (iv) agreements for the individuals who may choose to contribute their data. The central idea of this framework is to create a standardised approach to operationalising IDS at any level.

Enacting and standardising IDS globally (component one). The suggested framework acknowledges Global Indigenous Data Alliance (GIDA, the peak international body advancing Indigenous Data Sovereignty and Governance) as providing leadership in asserting Indigenous Peoples' rights and interests in data, advocating for data for the self-determined wellbeing of Indigenous Peoples and reinforcing the rights to engage in decision-making in accordance with Indigenous values and collective interests. This component focuses on open data and prescribes a globally standardised set of IDG principles. The CARE (eg. Collective Benefit, Authority to Control, Responsibility, and Ethics) Principles²⁹ for IDG are people and purpose-oriented, reflecting the crucial role of data in advancing Indigenous innovation and self-determination and were developed by GIDA in response to the current movement toward open data and open science which does not fully engage with Indigenous Peoples rights and interests. Existing principles within the open data movement (eg. FAIR:

findable, accessible, interoperable, reusable)³⁰ primarily focused on characteristics of data that will facilitate increased data sharing among entities while ignoring power differentials and historical contexts. The emphasis on greater data sharing alone creates a tension for Indigenous Peoples who are also asserting greater control over the application and use of Indigenous data and Indigenous Knowledge for collective benefit. This includes the right to create value from Indigenous data in ways that are grounded in Indigenous worldviews and realise opportunities within the knowledge economy. The CARE principles complement the FAIR principles encouraging open and other data movements to consider both people and purpose in their advocacy and pursuits.

Enacting IDS nationally (component two). The suggested framework acknowledges the role and principles determined by the peak IDS body in Australia, MnW. The MnW Indigenous Data Sovereignty Collective was formed in early 2017 in order to develop Indigenous data sovereignty principles and to identify Indigenous strategic data assets. The intent of MnW is to empower Aboriginal and Torres Strait Islanders to engage in Indigenous Data Sovereignty and to advocate for rights (informed by the United Nations Declaration on the Rights of Indigenous People (UNDRIP)) using data to inform development.

The framework suggests that as the peak IDS body in Australia, MnW may also work with governments and policy makers to develop and implement relevant and effective Indigenous Data Sovereignty and Governance (IDS/G) policies and legislation, and clearly articulate and support the relationships between government and IDS/G agencies. The peak body may also develop standardised data collection tools, frameworks and warehouses; and lead the approach to determining which data about Indigenous people are held in national or jurisdictional data collections (eg. population census data), and contribute to the collection, analysis and sense making of those data.

The peak should also provide leadership and advisory to place-based IDS/IDG efforts as requested.

Enacting place-based IDS (component three). The framework provides core components/principles for place-based communities, organisations and services to define each principle, and co-design an appropriate approach to implementation which adheres to appropriate protocol and cultural practice. Some examples of evidence within this literature review are provided.

Place-based efforts should be informed by Aboriginal and Torres Strait individuals, advocates and advisors

who can support the process of co-design and/or co-creation.

Enacting individual IDS (component four). The framework includes individual level agreements which may be made implicitly or explicitly. This is an important consideration for place-based efforts; and for state and national institutions who should be considering the way individual IDS can be upheld and respected.

Overall, this framework provides the flexibility for different countries and communities/services to give effect to the internationally agreed IDS/G principles in different ways, depending on their unique circumstances. Finally, key studies identified in this systematic review have been mapped onto [Table 4](#) to illustrate how existing IDS knowledge can be applied to this framework, both to highlight how the tailored components of the framework are being operationalised (e.g. the Lovett papers, and the Griffiths and Smith paper for core component two; and the Taylor paper for core component three) and to identify key knowledge gaps in terms of applying Individual level IDS.

Discussion

Global interest in the need to meaningfully protect IDS is growing. The first attempt to define the core components of IDS, Canada's OCAP principles published in 2004,¹⁷ were augmented by New Zealand's *Aotearoa-Te Mana Raraunga* principles in 2016³¹ and Australia's MnW principles in 2018.²¹ An international workshop in 2017 generated an additional IDS principle by consensus and the US is currently formulating its own IDS principles. Findings from this systematic review are highly consistent with this growth in global interest and the establishment of Indigenous IDS networks in Canada, New Zealand, Australia and internationally: the number of IDS publications dramatically increased in the ten years to 2020 (74% of papers were published in the period 2011–2020, relative to the period 2000–2010), and IDS principles are cited explicitly more frequently than implicitly (they were explicitly cited eighty percent more frequently than implicitly cited).

Given this growth in interest in IDS, this review presents a timely synthesis of the existing IDS academic literature. It is understood by the authors that the groundwork in developing IDS principles in multiple countries has come primarily from Indigenous thought leaders, and a key motivation for this systematic review was to capture and synthesise their pioneering work. Specifically, this review has identified three key areas for further development.

First, there is not yet international consensus on a standardised set of core IDS principles. Although this study used 8 principles, these were a synthesis of principles identified in different countries rather than a set of

principles generated through expert consensus. Establishing an agreed set of international IDS principles would represent a highly visible and collective statement from Indigenous people about the core components of their data rights. Within this review, congruence of principle review between Aboriginal lead author and non-Aboriginal reviewer (Author Three) was high for explicitly cited principles, and low for implicitly cited principles. This suggests that there would be value in developing an Aboriginal and Torres Strait Islander quality framework for IDS&G. Future research should undertake an assessment of study quality, methodology and bias.

Second, the full range of IDS principles need to be utilised more consistently during design, planning and evaluation of Indigenous organisations, programs, and initiatives. There is currently a lack of consistency in the way Indigenous concepts of IDS and IDG are expressed and determined to be operationalised at the community and organisational level. By supporting contextualisation and anchoring to a national movement for IDS&G, the proposed framework provides an opportunity for groundswell and community-based learning to be elevated to National leadership for influence and chartering of an agreed set of international principles. This review shows that citation rates of different IDS principles is currently uneven, ranging from control, Accountable to Aboriginal and Torres Strait Islander Peoples and Sustainably self-determining being the most frequently cited (29–31 times) to access and amplifying the voice of Community less frequently cited (23 times each). This lack of consistency suggests that operationalisation is complex and requires support to nuance the concepts and contextualise to diverse communities. The findings in this systematic review also vary from anecdotal experiences of the authors and other professionals whom have experienced significant challenges in accessing data and data amplifying the voice of Community, this may suggest a number of factors such as published literature premising research which has had accessible data, published literature may not be reflective of Community voice or the experience of inadequate data access and amplification of Community voice reflecting the status quo and as such, is not commonly challenged within published literature. Whilst least stated, these principles are critical to the realisation of IDS as access to relevant data that amplifies the voice of Community is required in order to make governing decisions that benefit Indigenous peoples. The proposed framework also seeks to address this need and provide a rigorous structure for addressing the failures of Government and other agencies to genuinely recognise IDS&G, and repatriate statistical artefacts for decolonising and reconstruction within an Indigenous data ecosystem. Furthermore, the proposed framework may support Indigenous leaders across all levels of decision making to make full use of available datasets to

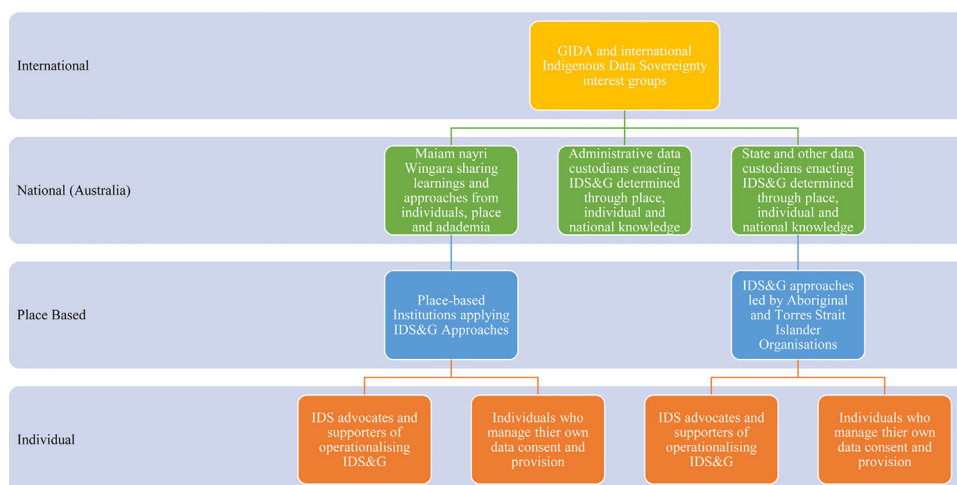


Figure 2. Potential pathway for sharing learnings and providing support in relation to implementation of Indigenous data sovereignty framework.

bring out self-determined improvements in matters described within the data.¹⁰

Third, there is currently no agreed mechanism to guide the operationalisation of IDS principles into practice to ensure that they are pragmatically, as well as intellectually, meaningful. Previous research on the conduct of Australian research according to national key principles for Indigenous research (e.g., respect, reciprocity and others) indicates that reporting around use of these principles is lacking, but that research conducted using the principles had better outcomes, highlighting the need for clear guidance to support implementation of principles into practice.^{32–34} Additionally, research indicates that uptake of Indigenous principles into research practices is an enabler to research implementation, highlighting how such a framework may benefit practice and research outcomes.^{32–34}

A recent publication considering the intersection of IDS and the Australian Government’s Closing the Gap policy, for example, has highlighted the need for applying a standardised approach for implementing and embedding IDS principles.²⁷ Given achieving consensus on IDS principles alone is unlikely to be sufficient to ensure their routine uptake into practice and policy, a framework for the operationalisation of IDS principles within Government agencies could be co-created by Indigenous peoples, Indigenous Community Controlled Organisations, IDS experts and Government departmental stakeholders. Such a commitment to co-creating the operationalisation of IDS&G within Government department policy would provide a starting point for tackling many complex challenges pertaining to Government datasets, some of those being Indigenous data being a subset of broader administrative data rather than a sovereign Indigenous dataset, Government agencies refusing to repatriate datasets for

decolonising and governing purposes, the primacy of datapoints within decision making which are not reflective of Indigenous worldviews, and the abdication of responsibilities without suitably resourcing an Indigenous data ecosystem. Figure 2 and Table 4 provide an example of how an IDS framework might be constructed and informed by the existing IDS literature. The detail in Table 4 shows how the framework could be both standardised (the four core components in column one and the specific IDS principles for core components three and four) and able to be tailored to the needs and specific circumstances of different countries, Indigenous communities, and Indigenous service providers (the examples of the different applications of the IDS principles). This concept of achieving both standardisation and tailoring to specific circumstances has been successfully applied to defining treatment programs and organisational-level data collection processes.^{35,36} Once developed, IDS experts could advocate for the global uptake of this IDS implementation framework.

The key limitation of this review is that the application of IDS principles into the proposed framework is based only on Australian IDS published papers. This decision was made to ensure the in-depth analysis of studies was limited to a number that was feasible for demonstrating how a set of internationally agreed IDS principles could be operationalised in the unique legislative and policy circumstances of a particular country. Nevertheless, it is unlikely that the Australian IDS studies introduced a bias toward IDS principles. The six Australian-specific IDS principles identified in Table 1 were spread evenly across the three categories of citation with the frequency shown in Table 2. Three were cited relatively frequently (control, accountability and sustainably self-determining); three were cited moderately frequently (amplifying community voice, access, and

relevant/reciprocal). [Table 4](#) demonstrates that the Australian-specific literature can be integrated into the proposed IDS international framework, and that this analysis could be replicated for other countries.

In addition to the focus on Australian IDS studies, it may be that the meaning of, or implications for, implicitly cited IDS principles are different to those of the explicitly cited IDS principles (the aim of identifying implicit mentions of IDS principles was to capture the intent of researchers who may not have explicitly identified an IDS principle). For example, cultural intellectual property can be considered within an IDS context. Nevertheless, excluding the IDS principles identified as implicitly cited would be highly unlikely to change the practical interpretation of the results given there were relatively few of them identified (there were eight times as many explicit citations [$n = 76$] as implicit citations [$n = 35$] and the re-classification of studies by a blinded coder provides reassurance in the likely accuracy of the lower proportion of implicitly cited IDS principles).

Data and knowledge systems are integral to the way of life for Indigenous Peoples, and they are concurrently walking in multiple data worlds: one being a Traditional space which intuitively upholds the sovereignty of Indigenous data; and the other being the western approach which has too often sought to exploit, rather than respect the sovereignty of, Indigenous data. Establishing agreement on the core principles of IDS and clear processes for their operationalisation is critical to resolving this polarity and achieving Indigenous people's IDS rights, primarily through self-determination, as outlined in UNDRIP.³⁷ Although this review has identified Australian examples of IDS being practiced, such as community-based organisations or community members intuitively treating data in a way that honours and upholds the rights of Indigenous peoples (e.g.²⁶), there needs to be a systematic approach to ensuring IDS is observed routinely and across all levels of data collection and utilisation: international; national; state and local communities and services. This systematic review has identified the increasing interest in IDS. Improvements in IDS are more likely to be achieved quickly if an agreed set of global IDS principles can be identified and a framework established for their operationalisation within the different circumstances of different countries and local communities or services. The eight IDS principles used in this review were synthesised from existing IDS principles derived from different countries^{17–19,21} and could form a starting point for an internationally agreed set of IDS principles. The authors directly recommend immediate implementation and contextualisation of the eight principles in Australia to support a groundswell movement toward IDS. To move IDS from academia into action, the principles must lend themselves to being self-determined at all levels of Indigenous governance, including the individual's rights. For tangible realisation across all levels of

implementation, the principles provide a starting point for diverse Indigenous data governance in Australia to contextualise and self-determine the operationalisation of principles in practice. The principles used in this review continue to anchor back to the National principles set by MnW^{19,21} which ensures national standardisation whilst upholding and acknowledging the diversity of Indigenous peoples in Australia. Strong consideration should be made by Indigenous Community Controlled Organisations to support a groundswell contextualisation of these principles. State and local Government agencies should resource and support a groundswell effort also, leading into Indigenous-led co-design of policy which upholds the groundswell self-determined principles. At a national level, the principles and leadership of MnW^{19,21} should be adopted, with diverse state, local, and individual conceptualisations of IDS operationalisation being supported and upheld. The framework presented in [Table 4](#) may be helpful in demonstrating how these global IDS principles might be efficiently operationalised, and the application of Australian IDS studies to this framework demonstrates the feasibility of this approach.

Data sharing statement

The authors confirm that the data supporting the findings of this study are available within the article or its supplementary materials. The dataset that supports the coding of literature reviewed for this study is available on request from the corresponding author, S.T.

Contributors

S.T. conceived the presented idea. A.S. and K.G. supported the development of the methodology for analysis and interpretation of results. S.F. conducted the blind review of findings, including critical interpretation of results. All authors commented on the manuscript. S.T. accessed and was responsible for raw data associated with the study and took the decision to submit the manuscript for publication.

Declaration of interests

Following extensive consultations with key Indigenous people about this paper, Skye Trudgett was invited to join MnW Network Membership and at time of submission, has not yet participated in any meetings or network collaborations. K.G. has conducted an evaluation for the Australian Research Council (ARC) and is a member of the National Aboriginal and Torres Strait Islander Health Research Network led by the National Health and Medical Research Council (NHMRC). Author K.G. has conducted an IDS project for Lowitja Institute and is a member of Australian Institute of Health and Welfare (AIHW), Australian Bureau of Statistics (ABS) and Indigenous Data Network (IDN); and

an Advisor to the National Indigenous Australians Agency (NIAA). All other authors confirm that this article has no conflicts of interest.

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