Trusting relationships and learning together: A rapid review of Indigenous reference groups in Australian Indigenous health research

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Abstract

Objective: This rapid review aims to identify how Indigenous research governance is conceptualised, implemented and documented within Australian Indigenous health research studies.

Methods: We searched for peer-reviewed English-language articles in two databases and for web-based grey literature published from database inception to November 2021. Reference lists were searched to identify additional articles. Data relating to research governance were extracted and analysed thematically.

Results: A total of 1120 records were screened, and 27 articles were included. Most articles providing detailed description of Indigenous research governance activities were qualitative studies (n=15, 55.6%). Key themes included members are experts; respectful relationships; flexibility; and key logistic considerations (nuts 'n' bolts).

Conclusions: Although Indigenous research governance is recognised as an essential part of ethical research, activities and contributions made by Indigenous reference group (IRG) members are underreported. This important work needs greater visibility in the published literature to share best practice in Indigenous research governance that foregrounds Indigenous expert knowledge, perspectives, and experiences.

Implications for Public Health: The study provides a synthesis of factors to consider when establishing and facilitating an IRG for research with Indigenous communities. This has implications for researchers who can adapt and apply the findings to their practice.

Key words: Indigenous reference group, advisory group, research governance, Australian Aboriginal and Torres Strait Islanders, Indigenous health research

Background

Western research has a long history of harmful practices that have been enormously damaging to Aboriginal and Torres Strait Islander peoples and communities (respectfully referred to as Indigenous herein, recognising the rich cultural diversity of Aboriginal and Torres Strait Islander communities).[1] Researchers have not always respected Indigenous ways of knowing, being and doing, and often people with little understanding or knowledge of Indigenous cultures have conducted this research.[2–4] Centralising the

Western worldview, while making assumptions about Indigenous peoples' values and concerns, has led to research being done "on" rather than "with" communities and has often failed to benefit communities.[5] The legacy of past inadequate and unethical research practices has contributed to the mistrust many Indigenous communities have of researchers and research institutions.[2,3,6,7] Furthermore, while research has a place, First Nations people across the world have expressed the sense of research fatigue and being "researched to death"[8,9] due to poor research practice.

More recently, there has been a concerted push to make amends for past exploitative research practices with Indigenous people and adopt approaches that are ethical, responsible and community driven.[3] In Australia, Indigenous researchers and community members have been leading efforts to develop meaningful documents that describe principles and guidelines for respectful and ethical research with Australian Indigenous people.[10] Commonly used ethical guidelines[11–20] for research projects involving Australian Indigenous peoples are listed in Table 1. Among the existing guidelines is a consistent theme of embedding Indigenous governance, through Indigenous research leadership and other mechanisms, such as "advisory groups," "reference groups" or "steering committees."[14,15,21] Indigenous governance provides authority over research direction, implementation of cultural protocols and control over cultural and intellectual property.[22] Indigenous governance ensures relevancy and accuracy of research, and that research is addressing what the community views as priorities in a way that community understand and own. However, practical guidance on the application or implementation of existing guidelines, and how to involve community members in governance structures, is not widely available.

Australian Indigenous communities are diverse, with many distinct languages and traditions; therefore, a "one-size-fits-all approach" to community partnerships and research collaborations is not feasible.[7,23] Moreover, there is little pragmatic detail on the mechanisms for developing and conducting advisory or reference groups for research projects with Indigenous communities.[23] As researchers in Indigenous health, in mainstream institutions, and as Indigenous Reference Group (IRG) members working with researchers, we are committed to improving our own research processes and identifying examples of research projects that elevate principles of Indigenous governance.[24] The aim of this rapid review is to identify how Indigenous research governance is conceptualised, implemented

and documented within Australian Indigenous health research studies.

Methods

The work of embedding Indigenous voices in health research through Indigenous leadership and governance is of critical importance. We chose a rapid review method to produce a contextualised synthesis of the current literature focusing on roles and function of governance groups within the field of Indigenous health research in Australia. Rapid reviews allow a streamlined approach to evidence generation[25] using components of the "gold standard" systematic review process but more simplified to produce information in a resource-efficient manner.[26,27]

Search strategy

Our search proceeded in two stages. Stage 1 of the rapid review identified articles from peer-reviewed journals via two electronic bibliographic databases (OVID Medline and PubMed) from inception to July 2021 and updated in November 2021. Stage 2 of the rapid review included a search of the grey literature via internet search engines (Google and Google Scholar) and a deep trawl of relevant websites (e.g. The Lowitja Institute and the Australian Indigenous HealthInfoNet). Additional articles were identified through hand-searching reference lists of eligible full-text publications. An experienced librarian was consulted in developing the search strategy and appropriate Medical Subject Headings (MeSH) terms or equivalent keywords. The full search strategy is presented in Supplementary Appendix 1.

Inclusion criteria

Eligible publications were written in English. No date restrictions were applied. We sought empirical research studies focusing on the health of Australian Indigenous peoples published as either journal articles, papers, books, reports, research thesis, conference presentations or proceedings, from both peer reviewed and grey literature sources.

Studies were included if they evaluated, compared or described research advisory or governance arrangements in some detail (greater than one paragraph of text). This included reflection upon the process of establishing and maintaining a governance body throughout the phases of research. Simple statements regarding the existence of

Table 1: Ethical guidelines for research involving Aboriginal and Torres Strait Islander people.		
Source and Reference	**Title**	**Year**
NHMRC[11]	Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research & companion document -	2003
NHMRC[12]	Keeping Research on Track: A Guide for Aboriginal and Torres Strait islander peoples about Health Research Ethics	2005
NHMRC[13]	The National Statement on Ethical Conduct in Human Research (the National Statement)	(2007, updated 2018)
Laycock et al. (The Lowitja Institute)[14]	Researching Indigenous Health: A practical guide for researchers	2011
AIATSIS[15]	Guidelines for Ethical Research in Australian Indigenous Studies	2012
NHMRC[18]	Australian Code for the Responsible Conduct of Research	2018
NHMRC[17]	Keeping research on track II	2018
NHMRC[16]	Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders (the Guidelines)	2018
AIATSIS[19]	AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research	2020
SAHMRI[20]	South Australian Aboriginal Health Research Accord — Version 2	2021

advisory or governance groups (less than one paragraph of text) was deemed insufficient for inclusion.

Newspaper articles, text from website pages, audiovisual files, flyers, posters and commentaries/letters were excluded. Perspective and/or opinion pieces, policy documents and/or research guidelines referencing governance arrangements were noted but not included in the final tally (Supplementary Appendix 2).

Study selection

Citations were checked for duplicates in Endnote (Version X9, Clarivate Analytics) and then manually amended in Microsoft Excel. Unique records were then imported into a custom-built Research Electronic Data Capture (REDCap) database for review.[28,29] Due to the rapid nature of this review, titles and abstracts were screened against the inclusion criteria by a single reviewer (non-Indigenous author, CLJ). The screening process was then verified by a second reviewer (Indigenous author, DC) who independently checked a random 10% sample of abstracts. Discrepancies were resolved through discussion and consensus with a third reviewer (non-Indigenous author, AD). Abstracts that did not meet the criteria for inclusion were removed and reasons for exclusion were documented. One reviewer (CLJ) read and assessed all full text articles for eligibility. The second reviewer (DC) independently checked 10% random sample of full-text articles for reliability. Inter-rater reliability analysis was performed, and good percentage agreement was achieved (88.51%).

Data extraction

The following information was extracted from all eligible articles: title, author(s), date of publication, study design, setting and population studied, name of governance body, size and composition of governance body, scope/role of governance body, frequency of meetings, remuneration of members, Indigenous authorship and terms of reference or agreements.

Data analysis

Eligible articles were imported into a qualitative data analysis software (NVivo 12 Plus, QSR International Pty Ltd). Reflexive thematic analysis (TA) was used to inductively derive themes related to Indigenous governance from the included studies. The methods implemented were based upon Braun and Clarke's refined approach to qualitative analysis.[30–32] TA is a method for identifying, analysing and reporting patterns (themes) across a dataset.[30] In this analysis, TA is used as a tool for evidence synthesis.[33] The published texts identified in this rapid review act as the "data," as we seek to find patterns of meaning within the literature to produce a rich understanding of how Indigenous research governance functions in practice. We recorded any reference made by the authors to the practical application of various ethical guidelines (listed in Table 1) and research advisory or governance arrangements. A social constructivist perspective underpins this analysis, which holds that knowledge and meaning are socially constructed, and that reality is ultimately subjective.[34]

This review followed Braun and Clarke's six-phase guide to TA.[30] Starting with Phase 1, CLJ and AD became familiar with the data by reading and re-reading all the full-text articles. Brief memos were drafted upon review of each text including individual reflections. Initial codes were then generated by CLJ in NVivo as part of Phase 2. Coding of text segments was done using a bottom-up approach

allowing the data to drive the formulation of themes rather than predefining themes. The first iteration (Phase 3) produced several finely grained themes. From this, CLJ and AD refined, classified and synthesised candidate themes (Phase 4). Researchers play an active role in the generation of new knowledge when conducting reflexive TA, and subjectivity is considered a valuable tool.[31] During analysis, the authors met to share their personal thoughts about the data and to discuss how each of their experiences and positions might shape the interpretation. The preliminary thematic map was then discussed among four of the authors (Indigenous authors VM and DC, and non-Indigenous authors AD and CLJ) until agreement resulted in the identification of four themes. Final theme names were assigned to convey the shared meaning across the texts (Phase 5) and how these relate to one another.

Quality assessment

Studies were not assessed for methodological quality as appraisal tools with assessment of Indigenous research governance have only recently become available.[22] This paper instead focuses on how ethical guidelines of best practice have been interpreted, implemented and documented. Reporting guidelines designed specifically for rapid reviews have not yet been developed.[35] Therefore, we adopted the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) (Supplementary Appendix 3). The pre-defined protocol is available upon request. This rapid review did not require ethical approval.

Results

The search yielded 1120 potential records. Of these, 857 abstracts were screened after 263 duplicates had been removed. Full-text articles (n=207) were then checked for eligibility. In total, 21 full-text articles were found to meet the eligibility criteria. An additional six full-text articles were identified by hand-searching the reference lists of all 207 full-text documents, resulting in 27 eligible articles for analysis. Figure 1 shows the search and selection outcomes at each stage of the process. Included articles comprised 15 qualitative studies (55.6%), four program or framework evaluations incorporating mixed methodologies (14.8%), five prospective cohort studies (18.5%), two Participatory Action Research (PAR) studies (7.4%) and a single randomised controlled trial (3.7%). We found a steady increase in publications describing research advisory or governance arrangements over time. The majority (74.1%) of the articles included in this review were written within the past decade (2010–2021). None of the articles were published prior to 1999. Study characteristics are summarised in Table 2.

The final themes identified were (Theme 1) Members are experts; (Theme 2) Flexibility; (Theme 3) Respectful relationships; and (Theme 4) Nuts 'n' Bolts. The thematic map (Supplementary Appendix 4) depicts how patterned meaning was charted across the dataset. Italics relate to direct excerpts from the identified publications.

Theme 1: Members are experts

The expertise and value of Indigenous governance groups in the research process was a prominent theme across the identified publications. These studies acknowledged the expertise the IRG members brought to the process and the breadth of knowledge that

Figure 1: PRISMA flow chart of articles identified, screened and included.
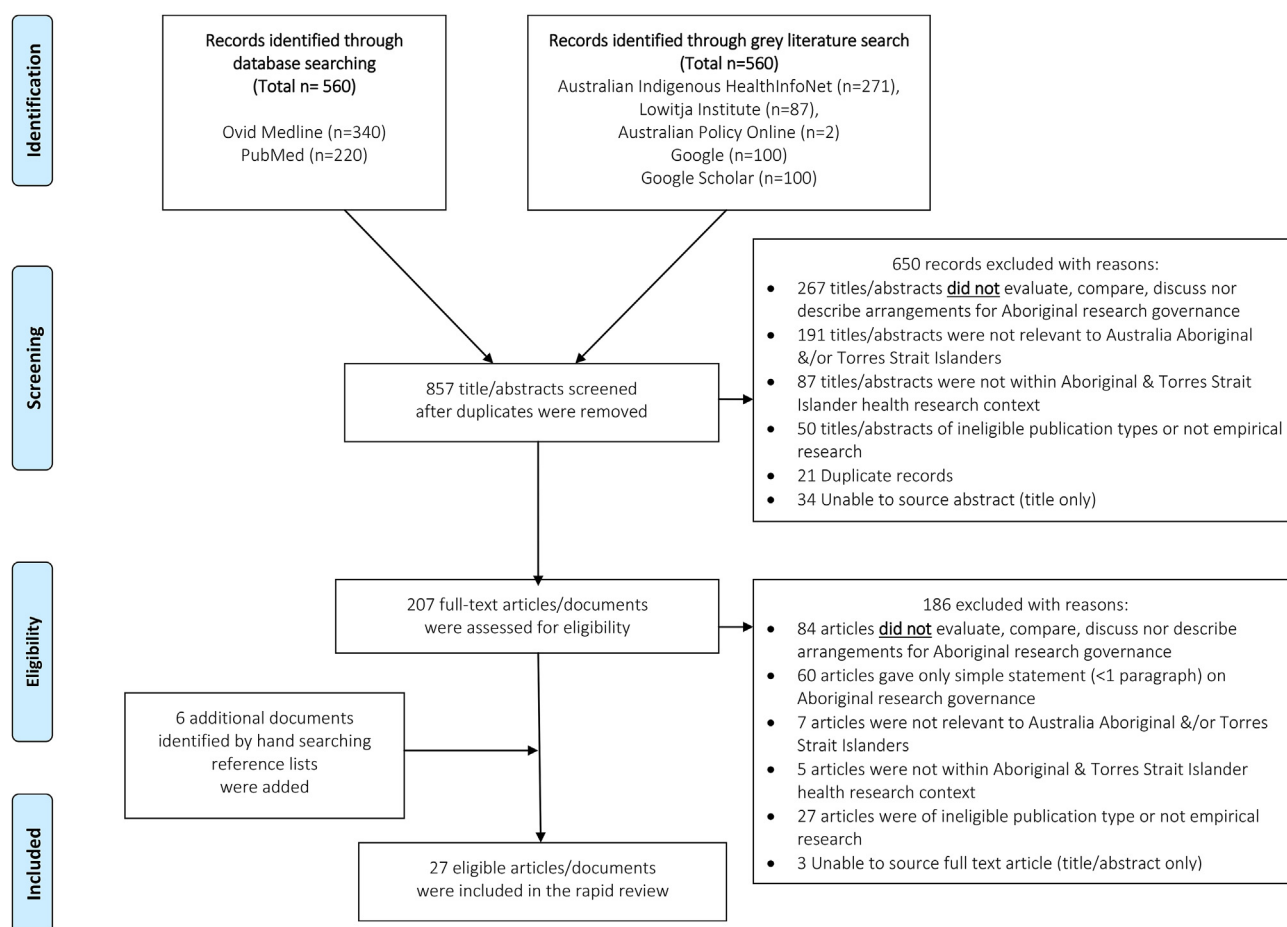
informed the research. Subthemes include (1) valued for their knowledge, (2) proper-way research, and (3) community authority.

Valued for their knowledge

Studies included in the analysis provided detailed descriptions of the different roles and responsibilities of various governance group members. IRG members were described as *expert peers*[36] valued for their diverse interests, lived experience and expert knowledge. Many of the publications referred simply to members "providing expert advice." In one study, IRG members reflected that being valued as experts is not always the case in other areas of their professional lives external to the advisory group (AG):

> "Members of the AG who represent Aboriginal community organizations reveal that having their expertise, experience, and authority recognized can be a struggle…[this] has implications for the way [they] are able to contribute to knowledge production."[37]

Many of the included publications documented the valued role IRG members played in the direct implementation of research including the recruitment of participants, training of Indigenous staff and in data collection:

> "(Participants) were recruited by the IRG members…through their personal contacts or by snowball sampling."[38]

> "Members of the Aboriginal Reference Group (ARG) conducted inpatient interviews in order to minimise perceptions of power

imbalance in eliciting stories and to enhance participant comfort."[39]

In some cases, IRG members had direct input into the development of study materials. We also found reference to IRG members contributing to the final analysis:

> "In consultation with a number of research reference group members, a template was developed to provide guidance and analytical rigor to the thematic analysis of each transcript."[9]

Some of the included publications did describe the IRG members contributing to the final write-up and being listed as co-authors (refer to Table 2). This active role of IRG members reportedly improved the quality of research in the community context by:

> ". . . enhancing individual researcher skills and knowledge, community accountability and more respectful and appropriate engagement with Indigenous knowledge and perspectives. . ."[40]

Proper-way research

Members' knowledge and deep appreciation for culturally sensitive approaches to research was also highly valued. Their role on IRGs was crucial to ensuring that local protocols were adhered to and respected. This has been described as setting "ground rules" for local site-based activities, and included:

> "(setting up) …suitable times/places for interactions, appropriate processes for managing (potential) issues or complaints arising from interviewees, and accessibility of services."[41]

Table 2: Study characteristics of the 27 eligible publications included in the rapid review.									
First author (Year, Publication Type and Reference)	Study Design	Location	Name given to Governance Group	Members	Reported role of IRG members	Number of Members in Governance Group	Frequency of Governance Group meetings	Formal agreement	Reported examples of reciprocity
Eades et al., 1999 (Journal article)[52]	Cohort study	Perth, Western Australia	Community Reference Group	Members were from the local Indigenous community with an interest in maternal and child health	• Negotiated principles/ priorities from onset • Co-produced agreement & protocol • Provided interface between research team and community • Provided overall guidance of research project • Assisted project team with ad hoc issues • Ensured research is carried out in a culturally appropriate and ethical manner	~10–12 members per meeting (range 6–30)	Every 6 weeks	Yes	• Co-authorship • Members were paid for their contributions
Tchacos et al., 2002 (Journal article) 42	Qualitative study	Kalgoorlie & Esperance, Western Australia	Aboriginal Reference Group	Members were 'key opinion leaders' selected by Aboriginal people living in the 5 communities studied	• Involved in decisions concerning with whom, when and where the research would be undertaken • Involved in the selection and training of Aboriginal Research Assistants • Approved research materials/ interview questions • Took part in fieldwork activities • Ensured research was "culturally in tune with the community"	At least 5 members (1 representative from each of the 5 sites)	Not reported	Not reported	Not reported
Manderson et al., 2006 (Journal article) 47	Qualitative study	Queensland	State-wide Indigenous Reference Group	Members were Indigenous health workers and other women who were respected for their public views on Indigenous rights.	• Provided support and advice to researchers • Facilitated research by brokering entry into communities • Took part recruitment of participants • Advocated for the project externally	Not reported	Not reported	Not reported	Not reported

(continued)

Table 2: Continued									
First author (Year, Publication Type and Reference)	**Study Design**	**Location**	**Name given to Governance Group**	**Members**	**Reported role of IRG members**	**Number of Members in Governance Group**	**Frequency of Governance Group meetings**	**Formal agreement**	**Reported examples of reciprocity**
Kelly et al., 2007 (Journal article) 58	Qualitative study	Adelaide, South Australia	Reference Group	Members were Aboriginal women recognised for their experience in Aboriginal women's health	• Guided all aspects of the study • Ensured that the methods, analysis, and final report were culturally safe • Took part recruitment of participants • Approved research materials/ interview questions	Not reported	Not reported	Not reported	Not reported
Street et al., 2007 (Journal article) 36	Qualitative study	Australia wide	Steering Group	Members were Aboriginal and non-Aboriginal stakeholders engaged in Aboriginal research	• Provided input in & approved development of research questions/ materials/ themes & final report • Provided input into scope and focus of the literature review • Took part recruitment of participants, community consultation and feedback of findings • Encouraged to raise issues that might impact credibility and rigour of the project	12 members	Not reported	Not reported	Not reported

First author (Year, Publication Type and Reference)	Study Design	Location	Name given to Governance Group	Members	Reported role of IRG members	Number of Members in Governance Group	Frequency of Governance Group meetings	Formal agreement	Reported examples of reciprocity
Devitt et al., 2008 (Journal article) 41	Qualitative study	Australia wide	Reference Group	Members included representatives of the key stakeholder groups (including patients and Aboriginal renal staff)	• Acted as site specific point of contact for research team • Acted as representative to ensure stakeholder interests during the course of the research • Advised on 'ground rules' for the site-based activities (specific cultural protocols/ instructions) • Advised on protocols for managing concern or complaints • Took part recruitment of participants	Not reported	Not reported	Yes	Not reported
Kildea et al., 2009 (Journal article) 59	Qualitative study	Arnhem Land in the Northern Territory, Australia	Critical Reference Group	Members included two of the researchers and 5 Aboriginal health workers/ practitioners or support staff	• Evaluated and validated cultural and community information documented • Provided input into study resources • Involved in decisions concerning with whom to approach • Took part in PAR	7 members	Not reported	Yes	• Co-authorship • Members were paid for their contributions
Hayes et al., 2010 (Journal article) 60	Cohort study	Townsville, Queensland	Indigenous Women's Reference group	Members were Aboriginal and/or Torres Strait Islander women	• Provided authoritative input for development of site-specific screening packages	Not reported	Every month	Not reported	Not reported
Lang et al., 2017 (Journal article) 61	Evaluation study	Katherine, Northern Territory, Australia	Ngumpin Reference Group	Members were group of past and present Aboriginal Health Workers and Board Members of KWHB	• Guided the development of culturally appropriate health promotion resources • Involved in roll-out of health promotion resources	12 members	4 meetings per year	Not reported	Not reported
Buckskin et al., 2013 (Journal article) 45	Cohort Study	South Australia	Aboriginal Advisory Group	Members were representatives from health services, the AHCSA, Aboriginal Elders' Council and Aboriginal Health Workers with expertise in maternity and postnatal care	• Guided the community and key stakeholder consultations • Provided input in the development of the study protocol, questionnaire & interviewer guidelines • Provided input in the conduct of the research	11 members	~6–8 times per year	Yes	• Co-authorship

Table 2: Continued									
First author (Year, Publication Type and Reference)	Study Design	Location	Name given to Governance Group	Members	Reported role of IRG members	Number of Members in Governance Group	Frequency of Governance Group meetings	Formal agreement	Reported examples of reciprocity
Wendt et al., 2013 (Journal article) 48	Qualitative study	South Australia	Reference Group	Members were representatives from DFC and FaHCSIA	• Advised on methodology, ethics processes • Advised on presentation of findings • Involved in continual reflections about working in anti-oppressive and culturally sensitive ways	Not reported	4 times over the life of the project	Not reported	Not reported
Sherwood et al., 2015 (Journal article) 37	Qualitative study	New South Wales & Western Australia	Indigenous-led Advisory Group	Members of the AG represented diverse stakeholders including Aboriginal women's community services and organisations, elders, mainstream NGOs, and government departments.	• Shared knowledge & expertise on wide range of issues impacting Aboriginal women in prison and post-release • Facilitated collaborations and partnerships among Indigenous communities, government agencies, non-government Indigenous and non- Indigenous organisations, and academics. • Provided input into research design/tools used • Developed communication strategy with Aboriginal women and mothers	Not reported	Not reported	Not reported	• Co-authorship
Assoulin et al., 2016 (Conference Proceedings) 49	Qualitative study	Southwest Victoria, Australia	Aboriginal Reference Group	Not reported	• Approved the research to take place • Collaborated on the development of the art making program/tools and processes • Facilitated training of an Indigenous co-facilitator • Approved findings for publication	<10 members	Not reported	Verbal agreement preferred by ARG	Not reported

Table 2: Continued									
First author (Year, Publication Type and Reference)	Study Design	Location	Name given to Governance Group	Members	Reported role of IRG members	Number of Members in Governance Group	Frequency of Governance Group meetings	Formal agreement	Reported examples of reciprocity
Wain et al., 2016 (Journal article) 38	Qualitative study	Western Australia	Indigenous Reference Group	Members were male and female leaders in Aboriginal health and research	• Provided input into research methodology • Involved in the training of Research Assistants • Involved in the conduct of the research (recruitment and data collection) • Identified themes from the narratives and provided questions/discussion points for educators to incorporate into lesson plans • Involved in analysis of data and dissemination of findings	9 members	Not reported	Not reported	• Co-authorship
Thorpe et al. 2016 (Report) 51	Evaluation Study	Victoria	Gathering Place Reference Group	Aboriginal and Torres Strait Islander community members	• Provide advice regarding type of information to be collected and methodology • Provide advice on engagement and cultural protocols • Identified potential risks • Involved in the conduct of the research (recruitment and data collection) • Took part in reflection workshops discussing preliminary findings	14 members	2 times over the life of the project	Yes	• Co-authorship • Members were paid for their contributions
Bond et al., 2016 (Journal article) 40	Qualitative study	Brisbane, Queensland, Australia	Community Jury	Members were purposefully selected to ensure a mix of ages, gender and both Aboriginal and Torres Strait Islanders.	• Reviewed all research undertaken • Assessed the spirit and integrity of the research and the researchers • Engaged with researchers to help with recruitment strategies • Reviewed all findings prior to publication	14 members	Quarterly for between 4 to seven hours each meeting.	Not reported	• Co-authorship • Members were paid for their contributions

First author (Year, Publication Type and Reference)	Study Design	Location	Name given to Governance Group	Members	Reported role of IRG members	Number of Members in Governance Group	Frequency of Governance Group meetings	Formal agreement	Reported examples of reciprocity
Table 2: Continued									
Zubrzycki et al., 2017 (Journal article) 9	Qualitative study	Southern New South Wales, Australia	Aboriginal led Research Reference Group	Members reflected diversity in relation to gender, health disciplines, service delivery contexts, and Aboriginal community backgrounds.	• Provided cultural guidance to the non-Indigenous researchers in areas such as data collection • Involved in analysis of data & dissemination of findings	Not reported	Not reported	Not reported	• Co-authorship
Farnbach et al., 2017 (Journal article) 62	Nested evaluation study within Cohort Study	Australia wide	Aboriginal and Torres Strait Islander Advisory Group	Aboriginal and Torres Strait Islander researchers and staff members from the research project's participating sites.	• Provided cultural oversight • Provided input in methodology, data collection, analysis and reporting	Not reported	Not reported	Not reported	• Co-authorship
Davy et al., 2017 (Journal article) 43	Participatory Action Research	Western Australia, New South Wales, Queensland & the Northern Territory	National Reference Group	Aboriginal and Torres Strait Islander community members including community Elders, as well as representatives from Government & NGOs	• Identified nationally and internationally recognised values and assumptions to underpin wellbeing model • Contributed to study methodology	Not reported	Not reported	Not reported	• Co-authorship
Weetra et al., 2018 (Journal article) 44	Cohort Study	South Australia	Aboriginal Advisory Group	Members were representatives from health services, the AHCSA, Aboriginal Elders' Council and Aboriginal Health Workers with expertise in maternity and postnatal care	• Guided the process of consultation • Assisted in the development of the research protocol • Oversaw conduct of the research • Involved in analysis of data and dissemination of findings	11 members	~6–8 times per year	Yes	• Co-authorship
Kirkham et al., 2019 (Journal article) 63	Participatory Action Research/ Qualitative Study	Darwin, Northern Territory, Australia	Indigenous Reference Group	Members were local Aboriginal patients with end-stage kidney disease	• Identified patient's priorities • Provided feedback and guidance on study processes (including recruitment strategies, interpretation of findings and dissemination of results) • Actively engaged and strong advocates for patients	6 members (4 females, two males, age range 58–74 years)	Bi-monthly (April to November 2017)	Not reported	• Co-authorship • Members were paid for their contributions

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First author (Year, Publication Type and Reference)	Study Design	Location	Name given to Governance Group	Members	Reported role of IRG members	Number of Members in Governance Group	Frequency of Governance Group meetings	Formal agreement	Reported examples of reciprocity
Bradley 2019 (Thesis) 64	Qualitative Study	Northern Territory, Australia	Aboriginal Reference Group	Members were Aboriginal women from diverse backgrounds who had knowledge and experience in caring for people with mental health issues.	• Guided all aspects of the research process • Promoted the ethical advancement of knowledge and respect for the diversity and integrity of Aboriginal cultures • Acted as primary agents for information-giving, informed consent and interview processes	>5 members	Not reported	Yes	• Co-authorship
Hedges et al., 2020 (Journal article) 50	Cohort Study	South Australia	Indigenous Reference Group	Members were local Aboriginal councillors, health workers and community members.	• Provided oversight and cultural guidance on recruitment strategies and data collection. • Providing ongoing guidance on cultural sensitivity • Provided effective strategic advice • Promoted the study to their wider networks	Not reported	Not reported	Not reported	Not reported
Bradley 2020 (Journal article) 39	Qualitative Study	Northern Territory, Australia	Aboriginal Reference Group	Members were Aboriginal women from diverse backgrounds who had knowledge and experience in caring for people with mental health issues.	• Guided all aspects of the research process • Promoted the ethical advancement of knowledge and respect for the diversity and integrity of Aboriginal cultures • Acted as primary agents for information-giving, informed consent and interview processes	>5 members	Not reported	Yes	• Co-authorship
Kong 2021 (Journal article) 65	Randomised controlled trial	Northern Territory, Australia	Community Reference Group	Not reported	• Provided advice to ensure the trial is consistent with best practice • Provided advice to ensure trial is culturally appropriate and safe for Aboriginal and Torres Strait Islander communities	Not reported	Not reported	Not reported	Not reported

(continued)

Table 2: Continued									
First author (Year, Publication Type and Reference)	Study Design	Location	Name given to Governance Group	Members	Reported role of IRG members	Number of Members in Governance Group	Frequency of Governance Group meetings	Formal agreement	Reported examples of reciprocity
Murtha et al., 2021 (Journal article) 46	Evaluation Study	Far North Queensland, Australia	Aboriginal and Torres Strait Islander Reference Group	Members worked specifically in Indigenous health (3 identified as Aboriginal and/ or Torres Strait Islander).	• Provided direct guidance/ input into changes to be made to the original LEAPS professional development program in terms of program content, activities, resources, format, engagement of communities/educators, facilitation of the professional development and evaluation methods and tools.	5 members	Not reported	Not reported	Not reported
Maher et al., 2021 (Journal article) 66	Qualitative Study	Canberra, Australia	'Thiitu Tharrmay' is an Aboriginal and Torres Strait Islander Reference Group at ANU	Members were experts in Indigenous health and community- based research, research methods and policy.	• Provide input and 'sense making' of the results/ outcomes to capture Indigenist standpoint in line with Indigenist approaches	Not reported	Not reported	Not reported	Not reported

Abbreviations: AHCSA = Aboriginal Health Council of South Australia: ARG = Aboriginal Reference Group: AG = Advisory Group: ANU = Australian National University: FaHCSIA = Department of Families, Housing: Community Services and Indigenous Affairs: IRG = Indigenous Reference Group: KWHB = Katherine West Health Board: LEAPS = Learning, Eating, Active Play and Sleep project: NGOs = Non-Government Organisations: PAR = Participatory Action Research: DFC = South Australian Government's Department for Families and Communitie.

More generally, another study stated:

> "At every step of the research process ARG members confirmed that cultural values were appropriately observed."[39]

Another valued function IRGs provide is permission to enter or access local communities for the purpose of conducting research. This is vital for the success of research projects in this context.

A "community jury" oversees an expanding research program at an Indigenous Primary Health Care Service in the outer suburbs of Brisbane, Queensland. The jury is reported as being empowered to support or reject research in the community:

> "If the jury supports a proposed research project, a letter of support signed by the jury Chair is provided to the researchers. If a research proposal is not supported, the research cannot progress."[40]

Having "access" to Indigenous communities and individual participants was described in one study) as being a:

> "[negotiation] at a number of levels with the input from the Aboriginal reference group."[42]

We found reference to some concerns raised by IRG members who felt advice on cultural protocols for engagement within community was obtained as merely a "tick box" exercise. One study warned that this approach could result in members' advice being ignored:

> "Getting heard or influencing outcomes in systems is tough and often frustrating because we know with the deep certainty of long experience that our knowledge is valid, and we also know how great the need of our people is."[37]

Community authority

IRGs were highly valued for their local knowledge of community needs and their ability to inform and set agendas to address these priorities. One study reiterates this important function saying that IRG members are "*not simply 'subjects' of research.*" Research has now "*repositioned Indigenous people as 'contributors' and to some extent 'drivers' of Indigenous health research.*"[40] A demonstration of how one of the studies valued this priority setting role is clear in this aspirational statement:

> "Community needs to be at the forefront, of all these decision-making processes."[43]

However, specific examples of how and when IRG members directly influenced research agendas were scarce. We found reference to governance groups having direct decision-making responsibilities in few included publications. Only two publications[44,45] explicitly specified how the research had been directly informed by local priorities voiced by IRG members. An example of an IRG contributing to overall decision-making is listed below:

> "The Reference Group went through a process of professional conversations and came to a consensus regarding the changes to be made…in terms of program content, activities, resources, format, engagement of communities/educators, facilitation of the professional development and evaluation methods and tools."[46]

Theme 2: Respectful relationships

Respect was a strong theme threaded through all the published work. Two subthemes were generated (1) Reciprocity and (2) What's in a name?

Reciprocity

Reciprocal and respectful relationships were identified as fundamental to working with IRGs:

> "Respect is an important foundational concept of Aboriginal philosophies, ethical and law systems and one that needs to ground working partnerships."[37]

One study explained that a "*genuine alliance*" is necessary rather than the more common tokenistic Indigenous participation, such as "*superficial representation on steering committees.*"[38] Another referred to "*equal partnerships*" that saw the project collaboratively developed, where the researchers, Reference Group members and the primary healthcare service sites each had matched input into the study objectives and methods.[43]

Genuine partnerships and two-way learning were identified as facilitating the development of more meaningful relationships between non-Indigenous researchers and Indigenous researchers/IRG members:

> "Attention [was] paid to the value of learning from each other as women from different cultural backgrounds and in doing so, discovering commonalities."[47]

Studies described the reciprocal exchange between researchers and IRG members who were able to "*[reflect] together about working in anti-oppressive and culturally sensitive ways.*"[48]

There was consensus among papers included in this review that the contributions from IRG members are critical to the development and implementation of culturally respectful and ethical processes. Non-Indigenous researchers acknowledged that fostering respect and trust with IRG members promoted opportunities to interrogate practice and misconceptions:

> "Trusting relationships with the IRG allowed for naïve questions about cultural issues and constructive feedback."[38]

As a demonstration of reciprocity, several of the identified articles reported some form of remuneration paid to IRG members for their time (refer to Table 2). According to one of these studies, the return on their investment was "substantial."[40]

What's in a name?

Various names and titles were used across the identified papers for the different governance bodies. This included Aboriginal Reference Group (ARG), Indigenous Reference Group (IRG), Community-Controlled Governance Group, Community Reference Group, Cultural Reference Group or simply Advisory Group, Steering Committee or Advisory Committee. Most papers used the term "advisory" or "reference" seemingly interchangeably, and only one used the term "steering." Table 2 lists the specific term used by each of the studies included in this rapid review, with a description of the roles.

Whether the title Aboriginal or Indigenous is used has depended on the location and the preference of the groups. One research group reported that as the study progressed, it became clear that all members and potential participants identified as "Aboriginal," and so, the name of the guiding body was changed to "Aboriginal Reference Group" to reflect this. Regardless of the final term chosen, one study described that the governance group is:

> "a mechanism through which respect for community, ownership and control, as well as accountability to the community, and

appropriateness and relevance of the research can be demonstrated."[49]

Theme 3: Flexibility

We identified that flexibility was a vital part of successful research governance. Two subthemes were identified: (1) Members wear many hats and (2) It takes time.

Members wear many hats

We found that community members often have multiple roles and therefore responsibilities which is important to consider in planning processes:

"*There were many competing demands… at any given time [including] but… not limited to, cultural events, sorry business (deaths, funerals, grieving), inclement weather*" high demand for… [expertise/services], and…limitations on staff availability."[50]

This means that agendas need to be flexible and responsive to a broad range of external demands.[50] Being flexible also applied to "*times, dates, ways to meet, places at which to meet and ways that information [is] recorded.*"[51] Flexibility went some way to addressing the risk of burdening members.

It takes time

While flexibility is recognised as critical to engaging IRGs, timelines, funding and capacity constraints in research projects means it is sometimes difficult to provide adequate time and space for such flexibility:

"*Collaborative arrangements with Aboriginal communities are costly in terms of the time taken to consult in the development of the research study.*"[42]

"*Having adequate time for the project; engaging with Indigenous people, building a relationship and trust called for a timeframe not necessarily congruent with the duration of the project's funded period.*"[38]

Being flexible also means allowing sufficient time for IRG members to inform the development of culturally appropriate and relevant research resources and materials. Working collaboratively with IRGs does not lend itself to short timeframes. However, "*the benefits out way the costs for all partners in the research exercise.*"[42]

Theme 4: Nuts 'n' bolts

The final theme generated from the analysis centred on the operational aspects of IRGs. This included reference to (1) IRG membership, (2) Formal agreements, and (3) Timing and frequency of meetings.

IRG membership

In this rapid review, we found that members were drawn from a diverse range of backgrounds including government and non-government health/education agency representatives; health and social service providers; Indigenous clients/patients and community representatives/leaders; health/education workers; and cultural advisors. The makeup of IRGs was considered important:

"*Attention was paid to ensuring that members reflected diversity in relation to gender, health disciplines, service delivery contexts, and Aboriginal community backgrounds.*"[9]

Our findings suggest that composition of the group varied from local community members to more diverse national representation, depending on the nature of the research undertaken. Approaches to recruitment varied, including select personal invitations to inviting "*any member of the Indigenous community with an interest in [the research area].*"[52]

Membership size also differed. Not all publications reported the size of their IRG, and those that did reported a range of between 5 and 14 members per group (see Table 2). The reason for the size of the group was not generally reported. However, one study did specifically favour a smaller group: "*maintaining an effective work size (i.e. not too big).*"[41]

Formal agreements

A few studies reported the establishment of a formal agreement. This was particularly important to the Aboriginal Families Study:

"*Establishing agreed governance arrangements for the research phase of the study has been an important tool for clarifying roles and expectations of partner organisations and study investigators….*"[45]

However, we did not find agreement on this issue across all studies. Some reported that trying to formalise governance arrangements did not align with Indigenous ways of knowing, doing and being:

"*There was no need for constant review of study goals… [IRG] members preferred conversation on a need basis to regular mechanism of monitoring, and that rather than urgency on producing a memorandum of understanding, they preferred we honour a verbal agreement ….*"[49]

Timing and frequency of meetings

As indicated in Table 2, not all the identified studies provided detail on the frequency of their IRG meetings. Of those that did report on meeting frequency, this varied considerably: from regular 4–8 weekly meetings, through to meetings twice a year.

A number of studies acknowledged the risk that meetings could place further strain on already overburdened individuals. This reference to member burden is found throughout the literature. Some studies reflected that while members expressed genuine willingness to sit on an ARG, it had the potential to place a substantial burden on individuals and could establish an expectation that one member in particular "*carry the load for the group.*" This tension was evident in several of the studies, with one describing that often "*the daily reality of members includes far more urgent business that requires their attention.*"[49] The relatively small number of community members who have the time, interest and capacity to join IRGs was further acknowledged as a dilemma.[49]

Discussion

We aimed to explore the literature to identify how Indigenous governance is conceptualised, implemented and documented within Australian Indigenous health research studies. This rapid review focused on the interpretation and application of best practice guidelines and highlighted that the detail of IRG mechanics is under-reported in peer-reviewed journals. We identified four key themes: (1) Members are experts, (2) Respectful relationships, (3) Flexibility, and (4) Nuts 'n' Bolts. There is overwhelming consensus among the studies included in this rapid review of the value of governance groups and community experts' involvement in Indigenous health research.

However, this review has confirmed that most published studies in this context do not provide detail of IRG processes and practices employed. Eighty-four full text articles were excluded from our analysis because they did not document governance arrangements at all, while a further 60 were excluded for providing only minimal information (less than one paragraph of text). This under-reporting of details of IRG mechanisms does not align with policy documents and the recommendations for practice, indicating the process is limiting opportunity for learning about best practice approaches to Indigenous governance. Furthermore, we found few references to IRG members being remunerated for their time. This suggests the value of Indigenous knowledges is not sufficiently accounted for in project budgets and current funding systems.

Not only was there an under-reporting of the application of ethical guidelines for research in this context (Table 1), but often what was reported was predominantly under the domain of non-Indigenous researchers. Our review did identify two studies, Weetra et al.[44] and Buckskin et al.,[45] that exemplified best practice in privileging Indigenous voices by reporting the deep involvement of their IRG and clearly describing the processes undertaken. For most other studies, it was inferred that Indigenous perspectives and experiences were included by virtue of having an IRG and Indigenous co-authors. In general, we found a lack of *visibility* of IRG member voices. This does not align with the acknowledged need for community control and input into Indigenous health research activities and the calls for increasing the visibility of Indigenous scholarship in health research.[53] While IRGs are clearly an essential part of ethical and appropriate research in this context, other aspects of Indigenous research governance needs to be supported and fostered. This was a finding from an evaluation of a long-term research collaboration within Indigenous health research that established an Indigenous Advisory Group consisting of senior, experienced Indigenous health researchers.[54] Despite good intent, the group did not operate as planned due to members being overcommitted. For the collaboration, this required a pivot on Indigenous research governance to a distributed model of Indigenous leadership across early- and mid-career positions within its projects and programs. There were multiple benefits to this approach of shared and dispersed leadership, strengthening relationships, respect and trust across the collaboration.[54]

We consistently found reference to the importance of fostering genuine relationships between IRG members and non-Indigenous researchers. However, little was reported on the power imbalance that may exist or ways of minimising this. There is a risk that researchers apply governance processes to comply with ethics recommendations, as a "tokenistic" gesture, without reflecting or considering their respective roles.[40] In a report by Baunach et al., IRG members were frustrated with external partners who only pay lip service to their advice: "*Don't bother asking us if you are not going to listen to what we say!*"[55] Respectful relationships, that address the power imbalance between IRG members and non-Indigenous researchers, are essential for genuine partnerships and inclusive, meaningful participation.

While it was acknowledged that the most commonly used terms (reference group or advisory group) have been used to demonstrate respect,[49] this review found that the terms did not always adequately denote the level of involvement or responsibility of governance group members. This mismatch is unhelpful. Laycock et al. point out that the group title adopted should be a reflection of roles and decision-making power.[14] In addition to the importance of choosing an accurate name for the group, formalising an agreement was also identified as a way of addressing roles and responsibilities. Buckskin et al. described this as an effective way of ensuring clarity around roles and expectations.[45]

This review has provided a synthesis of lessons (Table 3) that can offer some guidance to the considerations researchers should apply when establishing IRGs. However, it is important to remember that there is no "one-size-fits-all." Certain recommendations, such as establishing formal agreements, may not suit all communities. For example, Hawkes et al. explained that with time it became apparent that formalising the Aboriginal Reference Group (ARG) in their study was not a priority. This was later understood to be a preference by that

Table 3: Synthesis of lessons learnt for IRGs.	
Acknowledge Expertise	Recognise and appropriately recompense IRG members as experts
	Provide the opportunity for the IRG to set ongoing research priorities
	Avoid tokenism and a 'tick-box' approach
Be Respectful	Establish respectful relationships
	Agree on a name with the group that reflects the role and decision-making power of the group
	Foster two-way learning
	Agree on responsibilities early
	Consult the group about timing and frequency of meetings
Be Flexible	Build flexibility into the project design
	Develop specific place-based approaches with each community rather than following a 'one size fits all' approach
	Be mindful of multiplicity of member roles. Beware of overburdening members
	Accommodate members being unavailable
Allow Time	Go slow; allow sufficient time to establish the IRG
	Allow sufficient time for IRG meetings and processes
	Be conscious that there may be a small number of community members who have the time, interest and/or capacity to take part
	Relationship building takes time. Don't push timelines if the project is not a community priority
Consider membership carefully	Consult the community about who should be invited
	Try to maintain "the person, not the position"
	Ensure IRG roles and objectives are co-designed and clearly communicated
Establish a Formal Agreement	Establish a formal agreement that is meaningful to the group. This may not be relevant to all governance groups

community for "consultation based on need."[56] Hawkes et al. reflect on how "*strictly following a 'Western' epistemology, by demanding that members establish the ARG the 'right' way, was in this case, the wrong way.*" Continually reflecting on activities and consulting the group is essential to maintaining respectful, relevant governance processes.

Indigenous scholars have led the way in mandating application of Indigenous values and ethics in research approval processes involving First Nations communities. This review has highlighted a variety of ways these principles have been enacted, from project specific advisory groups to long-term established "community juries" vetting research ideas and approaches. Such structures strengthen Indigenous control, research relevancy, accountability and ultimately community benefit, all key aspects of ethical conduct. However, there is currently a transparency gap, while there is a lack of visibility in journal articles of how Indigenous governance has been applied. There are benefits to reporting these processes: sharing of different governance models leads to greater understanding of the importance of these structures both within research funding and academic institutions, which may lead to potentially better resourced, more widespread and continuous practice improvement. For these reasons, specific guidance should be placed in journal guidelines for authors to report Indigenous governance processes in line with best practice Indigenous research.[22]

Strengths and limitations

To the best of our knowledge, this is the first synthesis of the literature focusing on how Indigenous research governance is conceptualised, implemented and documented within Australian health research. Another major strength is the systematic and comprehensive search strategy employed, which included searching the grey literature and hand-searching reference lists. Finally, this rapid review was conducted in partnership with Indigenous co-authors, both senior and junior. There are limitations. First, dual independent screening is considered the gold standard for systematic reviews. However, it is not uncommon for accelerated reviews to use a single reviewer with subset verification. In lieu of dual screening and selection, we made the pragmatic decision for the second reviewer to screen a random subsample (10%) of abstracts and full text articles. Inter-coding reliability is not conducted as part of reflexive TA[31,32] because that practice is rooted in a positivist paradigm[57] which is not aligned with the social constructivist approach adopted. Instead, CLJ and AD performed "collaborative coding" whereby they worked together to develop codes through discussion and reflection on their ideas and assumptions. Indigenous co-authors VM and DC worked closely with AD and CLJ to verify themes identified in the final analysis. This is a strength of reflexive TA rather than a limitation. The resulting interpretation of findings are more nuanced and richer.[32] Second, we did not appraise the included studies for methodological quality. However, historically appraisal tools did not capture the level of engagement or involvement in research governance, which was the primary focus of this rapid review.[22] Finally, we only included studies providing sufficient written reference to research governance practices, which may have resulted in some studies with appropriate research governance being excluded if the information was unpublished. Furthermore, we were restricted to the information reported in the included manuscripts; we recognise that the authors may have undertaken additional activities that were not reported due

to journal word limits. However, it was beyond the scope of this review to contact authors to request this information.

Conclusion

This rapid review highlights the underreporting of IRG processes in the literature. Although Indigenous research governance is recognised as an essential part of ethical research, IRG activities and contributions are not well documented. The study provides a synthesis of factors to consider when establishing and facilitating an IRG for research with Indigenous communities. This has important implications for researchers who can adapt and apply the findings to their practice. Continued efforts are needed to make this important aspect of Indigenous health research more visible in the published literature, with greater reporting and sharing of best practice in Indigenous research governance that foregrounds Indigenous expert knowledge, perspectives and experiences.

Conflicts of interest

The authors have no competing interests to declare.

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Ethics

Ethical approval was not required for this scoping review.

Author contributions

This paper is the result of close collaboration between the Aboriginal authors* (VM, DC, AW, CH, CD, MN, RB and JC) and non-Aboriginal authors (AD and CLJ). AD conceived the initial subject of the rapid review with input from the ASQ-STEPS IRG (AW, CH, CD, MN, RB and JC). CLJ carried out the search. DC checked a subsample of abstracts and AD checked all the full text publications. AD & CLJ drafted the initial manuscript with input from VM and DC. The ASQ-STEPS IRG co-authors (AW, CH, CD, MN, RB and JC) participated in a discussion about the interpretation of the findings and verified the validity of the synthesis. All authors contributed to the refinement of the final manuscript. The authors alone are responsible for the views expressed in this article and they do not necessarily represent the views, decisions, or policies of the institutions with which they are affiliated.

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Data availability

All papers included in this rapid review were available on non-restricted websites at the time the study was conducted. The dataset

used and/or analysed during the current study are available from the corresponding author on reasonable request.

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Appendix A Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.anzjph.2023.100051.