

<https://doi.org/10.1038/s41746-024-01070-3>

Indigenous data governance approaches applied in research using routinely collected health data: a scoping review

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Globally, there is a growing acknowledgment of Indigenous Peoples' rights to control data related to their communities. This is seen in the development of Indigenous Data Governance standards. As health data collection increases, it's crucial to apply these standards in research involving Indigenous communities. Our study, therefore, aims to systematically review research using routinely collected health data of Indigenous Peoples, understanding the Indigenous Data Governance approaches and the associated advantages and challenges. We searched electronic databases for studies from 2013 to 2022, resulting in 85 selected articles. Of these, 65 (77%) involved Indigenous Peoples in the research, and 60 (71%) were authored by Indigenous individuals or organisations. While most studies (93%) provided ethical approval details, only 18 (21%) described Indigenous guiding principles, 35 (41%) reported on data sovereignty, and 28 (33%) addressed consent. This highlights the increasing focus on Indigenous Data Governance in utilising health data. Leveraging existing data sources in line with Indigenous data governance principles is vital for better understanding Indigenous health outcomes.

The adoption of electronic medical records (EMRs) across healthcare systems is rapidly accelerating, particularly in Asia and Europe¹. EMRs play a crucial role in capturing and storing a wide range of health data, encompassing medical history, clinical information, and personal details^{2,3}. This wealth of health data has the potential to improve patient care and generate value within healthcare organisations⁴. The value of EMRs within healthcare organisations is created by enabling clinicians to access patient records from within the same system at any time, streamlining care and facilitating innovation⁵. Further work is needed to ensure that EMR systems prioritise patient-centeredness, delivering equitable benefits at a population health level while enabling seamless data sharing across multiple agencies. Moreover, enhancing the utilisation of this data in technologies like Artificial Intelligence and Machine Learning is essential. Despite the considerable advantages presented by the electronic collection and sharing of patient information between service providers and clinicians, there are still challenges, particularly regarding privacy, security and governance⁶. These

challenges are further exacerbated for many Indigenous people⁷, for whom the willingness to embrace new technology may be tainted by past experiences of unethical data collection and management, including through research, stemming from inherent racism biases and failure to recognise and respect the rights of Indigenous peoples⁸.

The Declaration on the Rights of Indigenous Peoples (UNDRIP) was adopted by the United Nations in 2007 to establish universal minimum standards for the rights of Indigenous Peoples⁹. The UNDRIP Article 31 specifically includes standards for Indigenous Peoples to exercise control over intellectual property pertaining to their communities, lands, and resources¹⁰. In addition, Article 18 addresses the data rights of Indigenous Peoples, emphasising their inclusion in decision-making processes that impact their rights in alignment with their own established procedures⁸. These standards offer comprehensive approaches to managing Indigenous Peoples' data beyond mainstream notions of research processes, knowledge generation and intellectual property¹¹.

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Indigenous Data Governance (IDG) and Indigenous Data Sovereignty (IDS) are relatively new methodologies increasingly advocated for in Indigenous communities to be able to govern the collection, analysis and interpretation of data that relates to their sovereign rights. These principles have been developed largely from standards contained within the UNDRIP, and generally, they reaffirm the rights of Indigenous Peoples to control the collection, access, analysis, interpretation, management, dissemination, and reuse of data relating to their communities¹². The implementation of Indigenous data sovereignty revolves around two fundamental principles: (i) the sovereignty of Indigenous People concerning data pertaining to them, regardless of its location or custodian, and (ii) the entitlement to access the data necessary for Indigenous Peoples' nation-building efforts¹³. While standards exist to advocate for Indigenous data sovereignty, the practical application of these standards in research activities involving data from Indigenous communities remains unclear.

This prompts the research question: What are the current practices used in research for governing Indigenous Peoples' routinely collected health data? The primary objective of this study is to systematically review the data governance approaches employed when using routinely collected health data for Indigenous Peoples for research purposes. The secondary objective was to understand the advantages and challenges of using this data for research, which is particularly relevant for Indigenous Peoples given the burden of research on Indigenous Peoples, who are some of the most researched groups in the world¹⁴.

Methods

This scoping review was guided by Arksey and O'Malley's framework for scoping studies¹⁵. In addition, the study selection and presentation followed the PRISMA extension for scoping reviews (PRISMA-ScR) guideline¹⁶. The PRISMA-ScR checklist is available in Supplementary Table 1. The scoping review methodology was selected for this study because, unlike systematic reviews, it is particularly effective in synthesising research and mapping literature in areas that were either not extensively reviewed or are complex and diverse in nature¹⁷.

Search strategy

We searched five electronic databases (PubMed, EMBASE, CINAHL, Web of Science, ATSIHealth), including one database which focuses on Aboriginal and Torres Strait Islander health studies (ATSIHealth), for materials published from 2013 to 6 December 2022. A professional librarian provided help to develop the search strategy; full search terms are available in Supplementary Table 2.

The search strategy was designed to identify papers that included: (1) Indigenous Peoples across various countries worldwide and (2) Access to routinely collected health data. To identify studies which included Indigenous Peoples, we used subject headings such as 'Health Services, Indigenous', 'Indigenous People's', 'United States Indian Health Services' and related free text searches. Similarly, studies which accessed routinely collected health data were found using subject headings such as 'Medical Record Linkage', 'Routinely Collected Health Data' and related free text searches.

Study selection

Title and abstract review inclusion and exclusion criteria were drafted, and a sample of 50 papers were reviewed by two researchers (T.E. and J.W.) to refine and agree on the final criteria. The same sample of 50 papers was reviewed by the other researchers (H.W. and S.K.), and conflicts were discussed to ensure all reviewers had a consistent understanding of the criteria. Inclusion and exclusion criteria are described in Table 1.

The title and abstract review of each article was performed by two independent researchers, randomly assigned by Covidence to members of the research team (T.E., J.W., H.W., S.K.). Conflicts were resolved through group discussions with at least two researchers.

Full-text review was also conducted by two researchers independently, randomly allocated by Covidence to research team members (T.E., J.W., H.W., S.H., S.K., S.O.), with conflicts resolved through a group discussion with at least two researchers. Papers were excluded if: (1) could not locate a full-text article; (2) full text not available in English; or (3) not peer-reviewed original research article; or (4) not focused on Indigenous People (at least 90% of study participants); or (5) did not use routinely collected health data; or (6) study outcome was not a health outcome; or (7) did not use personal level health data.

Cohen's Kappa was extracted from Covidence, and a weighted average was calculated to compare inter-rater reliability for both stages of the review.

Data extraction

Study characteristics, Indigenous data governance approaches and advantages and disadvantages of using routinely collected health data were extracted from the included papers. One reviewer (T.E.) developed a data extraction template in Covidence and tested it with four other reviewers (H.W., J.W., S.K., S.O.) independently extracting five articles each. Conflicts were discussed, and refinements were made to the data extraction template. Double data extraction was then completed by six reviewers (T.E., H.W., J.W., S.K., S.O., E.L.). One reviewer (T.E.) resolved conflicts for consistency.

A risk of bias assessment was not conducted as part of this scoping review, as the purpose is to examine Indigenous data governance practices reported, not to report on the outcomes of the studies.

Data analysis

Data extracted from Covidence was exported into a spreadsheet. The study characteristics were analysed using descriptive statistical techniques. A table was produced summarising the number of studies in each category. For the extraction of qualitative data, a thematic analysis approach was employed, following the methodology of Braun and Clarke¹⁸. This thematic analysis methodology involved two reviewers (E.L., H.W.) familiarising themselves with the data to generate coding elements and then iteratively comparing these coding elements to identify recurrent themes and subthemes.

The frequency of the main Indigenous data governance approach being reported in the included studies was summarised in a table. The Indigenous data governance approaches, advantages and disadvantages described in the studies were distilled into a checklist of considerations for using Indigenous Peoples' routinely collected health data for research. The table was structured according to the horizons of digital transformation in health¹⁹, a commonly used framework in digital health. The horizon names were amended to focus on data selection, access and use.

Results

The combined searches identified a total of 1012 articles; after removing duplicates using EndNote and Covidence, 580 unique articles remained. After the title and abstract screening, 145 articles were included for full-text retrieval. Reviewer agreement was moderate for title and abstract screening ($\kappa = 0.58$). All full-text articles were found and assessed for eligibility, which resulted in 85 articles being included (Fig. 1). The reviewers had a substantial agreement on study inclusion ($\kappa = 0.63$).

Characteristics of included studies

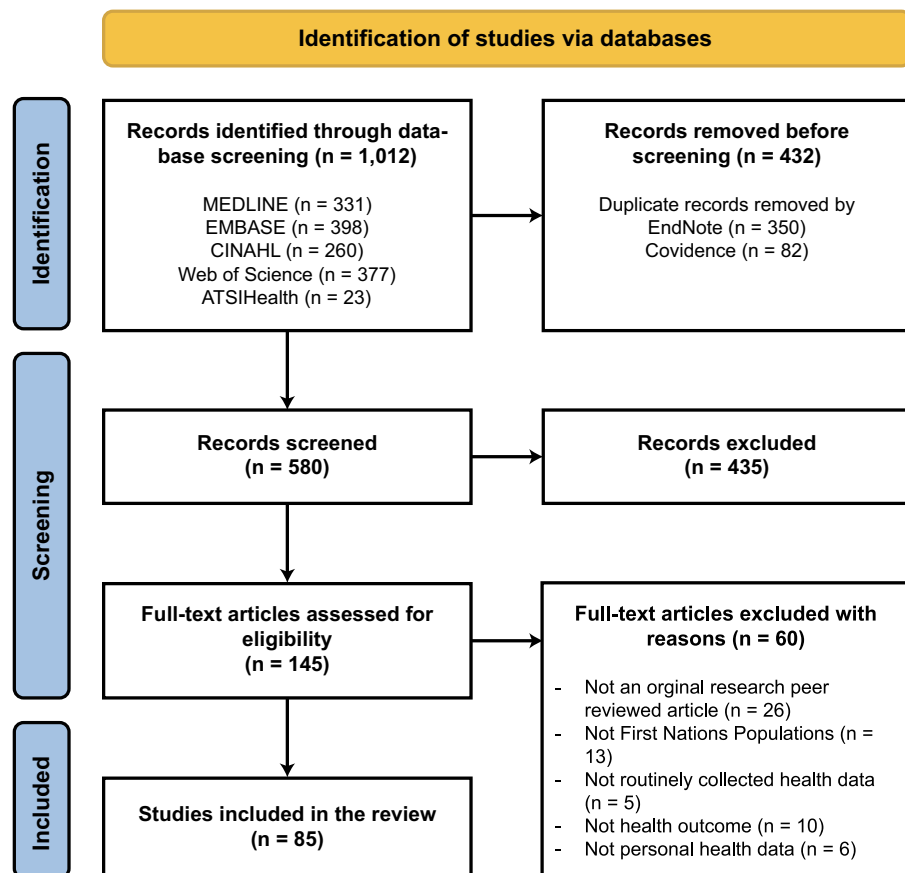
The characteristics of the studies included in this review are summarised in Table 2, and the details of each study are available in Supplementary Table 3. The included studies were published between 2013 and 2022. Studies were carried out in four countries, including Australia ($n = 38$; 44.7%), the United States ($n = 25$; 29.4%), Canada ($n = 19$; 22.4%), and New Zealand ($n = 3$; 3.5%).

Amongst the 85 articles included in this review, 82 articles reported on the number of participants, ranging from 8 to 138,551. One article considered the number of visits (i.e., 5373) of the target population, while another included 29 Aboriginal Community Controlled Health Services representing 34 individual clinics and 5 clinical hubs. One article did not

Table 1 | Title and abstract review inclusion and exclusion criteria

Criteria	Include	Exclude
Study type	Peer-reviewed original research paper	Protocol, review, commentary, etc.
Study population	Access data for Indigenous Peoples predominantly (90%+)	Accessed data for the general population or some other group not defined by Indigenous status (even if it includes some Indigenous People)
Data source	Accessed data from ieMR or administrative dataset that was already collected as part of routine healthcare	Used/collected custom data specifically for the purpose of this study only
Study outcome	Studies of health outcomes, access, etc., or implementation studies related to these outcomes	Studies looking at data quality only, data governance only or data principles only
Level of data	Personal individual-level health data	Population-level/summary health data only

Fig. 1 | PRISMA study selection diagram. From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. <https://doi.org/10.1136/bmj.n71>. For more information, visit <http://www.prisma-statement.org/>.



describe the number of participants/visits. A majority of articles considered all genders (n = 70; 82.4%), while 10 studies focused on women only (11.8%). The articles included participants of one or more Indigenous backgrounds, with a majority being Aboriginal Australian (n = 38; 44.7%), Torres Strait Islander (n = 24; 28.2%), Alaska Native (n = 19; 22.4%), American Indian (n = 18; 21.2%) and First Nations living in Canada (n = 14; 16.5%). More than half (n = 45; 52.9%) of the studies focused on populations in rural or regional populations, 14.1% considered urban areas only, and 28.2% considered both.

The studies examined one or more health outcomes including healthcare utilisation and access (n = 24; 28.2%), maternal and child health (n = 17; 20%), chronic diseases and comorbidities (n = 15; 17.6%), infectious diseases (n = 10; 11.8%), mental health and suicide risk (n = 8; 9.4%), public health and prevention (n = 6; 7.1%), dental health (n = 2; 2.4%), and other health conditions (n = 7; 8.2%).

Indigenous data governance

The frequency of Indigenous data governance approaches described in the studies is included in Table 3. A checklist of considerations for using

Indigenous Peoples routinely collected health data for research synthesised from the included studies is shown in Table 4, structured by the horizons of digital transformation¹⁹.

Indigenous data sovereignty. Data sovereignty aspects were described in 34 (40%) of the studies. Eighteen studies outlined the requirement of the state health services to maintain control of the data^{20–36}, while 15 studies outlined Indigenous Peoples or Communities sovereignty over their own data^{27,31,32,37–48}. Fourteen (16.5%) studies described the researchers’ inability to share data publicly^{24,26,33–35,41,45–52} due to privacy and ethical restrictions^{31,35,41,47,49,51,52}. However, in 11 (12.9%) studies, the researchers described the data can be obtained upon reasonable request^{30,31,35,37,41,47–52}, subject to additional institutional^{23,26–36,44,45,49,52,53} or Tribal^{27,31,32,37,41–46,48} approvals, and/or compliance with privacy policies^{26,27,34,46,47}. Furthermore, researchers had considered the use of de-identified data to analyse and present information with the intention to promote the anonymity of the Indigenous People whose data was accessed in the research study^{20–27,29–33,36,38,41,46,48,50,54–72}.

Table 2 | Study characteristics of included studies

Characteristics	Number of studies	
	<i>n</i>	%
<i>Published Year</i>		
2021–2022	25	29.4
2019–2020	27	31.8
2017–2018	11	12.9
2015–2016	8	9.4
2013–2014	14	16.5
<i>Country</i>		
Australia	38	44.7
United States	25	29.4
Canada	19	22.4
New Zealand	3	3.5
<i>Region study was conducted</i>		
Rural	45	52.9
Urban	12	14.1
Both	24	28.2
Not described	4	4.7
<i>Indigenous group/s*</i>		
Aboriginal Australian	38	44.7
Torres Strait Islander	24	28.2
Alaska Native	19	22.4
American Indian	18	21.2
First Nations living in Canada	14	16.5
Inuit	4	4.7
Māori	2	2.4
Métis	2	2.4
Pacific Islander	2	2.4
<i>Gender</i>		
All	75	88.2
Female	10	11.8
<i>Outcome measured</i>		
Healthcare Utilisation and Access	24	28.2
Maternal and Child Health	17	20.0
Chronic Diseases and Comorbidities	15	17.6
Infectious Diseases	10	11.8
Mental Health and Suicide Risk	8	9.4
Public Health and Prevention	6	7.1
Dental Health	2	2.4
Other Health Conditions	7	8.2

In addition to the approvals, studies highlight that data collected should be securely stored in various repositories^{21,31,32,50} and regulated by organisations such as Tribal health Organisations⁴⁰, healthcare/government departments^{38,39}, and data custodians^{25,30}. Access to the data is restricted to research investigators²¹ or people who meet prespecified criteria for data access^{27,31,35,47,50,51}. This information was most commonly included in a Data Availability Statement, which is increasingly being required by journals, and hence was more prevalent in recent studies (10% of studies published 2013–2015 vs. 63% of studies 2020–2022).

In terms of data sovereignty principles and access, the procedures vary with individual context. For example, in Manitoba, approval from specific entities is required to access data^{27,31–34}. The Navajo Nation⁴¹ and Western Australia^{24,35,47} also have specific processes for data access, while at the Sioux

Table 3 | Frequency of Indigenous Data Governance Approaches Described in Included Studies

Indigenous data governance approach	Described in study <i>n</i> (%)	
	Yes	No
Data sovereignty	35 (41.2%)	50 (58.8%)
Approach to consent	28 (32.9%)	57 (67.1%)
Indigenous Peoples and Communities involved in research	65 (76.5%)	20 (23.5%)
Ethics approval	79 (92.9%)	6 (7.1%)
Indigenous guiding principles	18 (21.2%)	67 (78.8%)
Advantages of using routinely collected health data	28 (32.9%)	57 (67.1%)
Disadvantages of using routinely collected health data	39 (45.9%)	46 (54.1%)

Lookout, access and management of data need to be conducted in accordance with the principles of ownership, control, access and possession (OCAP)⁴⁰.

Approach to consent. The majority of studies (*n* = 57, 67.1%) did not describe how consent was approached. Of the 28 (32.9%) studies which did include this information, nine studies obtained consent from individual participants^{28,31,61,65,73–77}. Fifteen studies employed a waiver of consent to access participants' health data^{21,23,24,33,36,37,41–43,47,49,55,63,66,71}. Another approach to consent was to obtain permission from Community Leaders⁴⁶ or Community Organisations (Aboriginal Community Controlled Health Services) involved⁴⁸. Furthermore, in studies that required follow-up care⁷⁸ or further review of specific individuals' documents⁷⁹, additional consent was sought from the participants at that stage.

Involvement of indigenous community and people in research. The researchers in 65 (76.5%) studies described various measures undertaken to ensure their research was conducted with the involvement and approval of the Communities they worked with. In several studies, researchers obtained approvals from Indigenous Leaders^{32,33,55,74,80}, institutional organisations^{34,37,39,44,52,56,59,61–63,74,81–83}, and Tribal health Organisations^{21,23,31–33,35,37,39,42–45,47,50–53,56,59,61–63,68,72,81–89} to commence, undertake and/or disseminate findings at various stages of the research study. In addition, partnerships were established with various Indigenous Leaders^{34,55,61,74}, Communities^{22,30,31,34,44,49,52,62,66,69,73,75,79,80,90} and Organisations^{21,23,26,29,31,33,35,39–41,46–48,50,53,55,56,59,66,67,69,71,73–75,77,79,80,85,87,88,91–93} to incorporate their perspectives and ensure cultural relevance^{23,34,50,51,56,62,73,79}.

In one study by Struck, et al.⁵⁶, the researchers described that the research needs to be conducted in the spirit of truth and reconciliation with recognition of the harms conducted to Indigenous People. By focusing on transparency, mutual respect, and maintaining a shared understanding of Indigenous data,^{56,81} it may be possible to achieve deep trust⁸¹ and respectful collaboration with Indigenous People⁶¹. While in some studies^{21,23,24,33,36,37,41–43,47,49,55,63,66,71,81} researchers received approval for a waiver of informed consent, efforts were made to maintain transparency and trust between researchers and Indigenous Communities⁸¹.

Indigenous organisation author affiliations. The inclusion of Indigenous Organisations in the research study was evident in 60 (70.6%) studies where one or more co-authors were affiliated with Indigenous Health, Research or Community Organisations. These co-authors participated in the design, development, data collection and analysis of the research study^{24,35,42,60,65,71}.

Indigenous ethics approval. Thirty-five (41.2%) studies reported receiving ethics approval from an Indigenous-specific ethics committee for their study^{23,24,29,35–37,39–48,56,59,61,63,64,68,69,80,82–87,90,92–95}. Forty-three (50.6%) studies

Table 4 | Considerations for selecting, accessing, and using Indigenous Peoples Routinely Collected Health Data for Research

Horizon	Action
Horizon 1: Data selection	<ul style="list-style-type: none"> Indigenous People should be reliably identified in the data Data should be of sufficient quality and completeness Using routinely collected health data should alleviate potential participant burden and cost of collecting new data Using routinely collected data should allow in-depth analysis not otherwise possible—e.g. longitudinal analysis, or linking across multiple sources to provide a more holistic view
Horizon 2: Data access and sovereignty	<ul style="list-style-type: none"> Seek appropriate Indigenous Community and Organisational approvals to access the data Employ an appropriate model of consent—Individual, Community, or waiver of consent Get formal ethics approval from an Indigenous-specific ethics committee, or an ethics committee that has experience with Indigenous research Ensure Indigenous Peoples and Communities maintain sovereignty over their data throughout research process Consider additional requirements for health departments or hospitals to maintain control of data
Horizon 3: Research and translation	<ul style="list-style-type: none"> Identify appropriate Indigenous guiding principles to inform the research Research team leadership and study authors should include Indigenous Peoples and Indigenous organisations Receive approval from Indigenous Leaders, Communities, and Organisations to conduct research Research questions and study design should be Indigenous led Incorporate Indigenous perspectives into interpreting research findings

detailed receiving ethical approval to conduct their study from a non-Indigenous ethics committee. Six studies did not describe whether ethical approval was received, and one study stated ethical approval was not required.

Indigenous guiding principles. Eighteen (20%) studies described using Indigenous guiding principles to inform their research^{22,31,32,34,35,40,46,48,50,52,53,56,72,73,78,89,92}. For example, in Canada, several studies focused on the use of OCAP (ownership, control, access, and possession)^{31,32,40,46,50,92} and OCAS (ownership, control, access, and stewardship)⁵⁶ principles in Indigenous health research. These principles were followed throughout the study^{31,32} to ensure governance of Indigenous data⁴⁶. One study also described the inclusion of Chiefs of Ontario First Nations Data Governance Committee and the Grand Council Treaty towards the review of the study's compliance with the OCAP principle⁵⁰, while another study was supervised, and the data were maintained by the Sioux Lookout First Nations Health Authority in accordance with the OCAP principle⁴⁰. Other studies focused on including several ethical and scientific standards from the various Canadian Institutes (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada)⁷³. In particular, Section 6 of the Tri-Council Policy Statement regarding the Ethical Conduct for Research Involving Humans, that involves First Nation, Métis or Inuit People^{26,89}. Moreover, one study by Pena-Sanchez, et al.²² utilised the Indigenous medicine wheel as its foundational framework, supported by cultural safety and patient-oriented research principles. It was guided by two specific Calls to Action from the Truth and Reconciliation Commission (TRC) of Canada. TRC 18 emphasised acknowledging the then-current state of Aboriginal health and implementing the healthcare rights of Aboriginal Peoples, and TRC 19 called for establishing goals in consultation with Aboriginal Communities to identify and address health outcome disparities. Additionally, one study co-developed its protocol with the Isumatait Sivuliuqti, ensuring a foundation grounded in Inuit ways of knowing (Inuit Qaujimatjuqangit)³⁴.

In the United States, one study focused on promoting trust and respectful collaboration with the Indigenous People concerning research participation and patient confidentiality⁶¹. While, in Australia, four studies emphasised compliance with the National Health and Medical Research Council (NHMRC) guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research^{35,52,72,78}. Another Australian study⁷³ was driven by shared values such as spirit and integrity, reciprocity, respect, equity, cultural continuity, and responsibility in all network activities.

Advantages and challenges of using routinely collected Indigenous Peoples' health data

Advantages of using routinely collected Indigenous Peoples' health data. Out of the 85 articles, twenty-eight (32.9%) of them

discussed the benefit of using routinely collected Indigenous data in research in terms of enhanced efficiency and inclusivity while minimising biases and participant burden. One of the key benefits is that by leveraging existing data sources^{30,37} and linking them together^{23,29,34,36,49,70,96}, researchers are able to access a wealth of information^{23,28,30,34,36,37,56,62,70,75,95–97} without requiring additional input from participants. This minimises the participant burden⁷² and reduces reporting and recall bias^{33,56}, while also making the research process more efficient⁸⁷. Moreover, it can also provide data that is broadly representative of the Indigenous Communities⁷⁵. As a result, the studies can achieve more robust and representative findings.

Another significant benefit lies in the ability to extract comprehensive and detailed information on patients' diagnoses, treatments, follow-up care, and relevant outcomes^{45,59,97}. Researchers can utilise this data, which is often underutilised⁶⁹, not only to examine high-risk populations^{49,59,96} and health trends of Indigenous People^{28,29,34,36,37,48,56,70,72,75,85,88,96,97} but also to monitor service utilisation³⁴, interventions²⁰ and outcomes⁶⁹. These are essential for strategic planning and operational decision-making in healthcare services²⁹. In addition, EMRs can allow for improved data validity and reliability⁸⁷ while also automating data collection and analysis tasks^{48,65}, which enhances the sustainability of surveillance systems⁴⁸. The automation of these processes provides a significant advantage to researchers over the use of manual procedures⁶⁵. This increases the efficiency and longevity of research projects, allowing them to have a lasting impact even beyond their initial funding period⁴⁸.

Challenges of using routinely collected Indigenous Peoples' health data. Several reported challenges and potential biases in using healthcare data were identified in 39 (45.9%) studies included in this review. The most significant challenge reported in the included studies is regarding data completeness⁸⁵. Incomplete health data, including demographics and family variables³⁹, physiological and lifestyle measurements^{23,32,40}, laboratory report^{31,50,74,87}, disease history and severity^{58,71,92}, costs^{40,50,97}, socioeconomic status²³, risks^{51,77}, charts⁵³, health service utilisation^{24,46}, diagnosis and treatment^{39,40,49,55,80}, discharge abstracts²¹, and critical social and cultural dimensions²⁵, were reported as either missing, underestimated, not recorded, or inaccessible. In one study, the researchers reported missing data ranging from 0 to 15.8% depending on the database⁹⁸, while in another study, 9% of age and sex distribution data was considered to be missing⁵². The incompleteness of data was reported to be a consequence of high population mobility^{54,65}, unclear clinical catchments⁵⁴, consults in other health services^{67,80}, availability of other non-department of health services^{54,99}, unclear definitions used in the storage of data^{45,47,53,90,99}, the inability to contact participants⁶⁹ and/or limited medical consultations^{24,36,44,100}. For example, one study described that patients who seek care outside the Indian Health

Service (IHS) would not have their data recorded in the National Patient Information Reporting System⁹⁹. This would result in a small sample size⁸⁵, potential coding errors⁷⁵ and inability to provide accurate estimates regarding an outcome^{24,31,36,38,50–52,54,65,77,92,99}.

Data quality was identified to be another significant challenge reported in the included studies. From the included studies, it is evident that the health data is entered by the clinicians and is reliant on the consistency and quality of clinician recording^{54,65,71}; often criticised for its dependency on clinicians⁴¹. However, this is an ongoing challenge, especially for new staff, who need to quickly learn the system and perform the necessary actions, thus affecting the accuracy and comprehensiveness of data collection⁹¹. The challenge of data quality may also be because of the limited scale of data^{25,39}, generalisability⁸⁷ and misrepresentation or misclassification of data^{22,47,59,79} that could lead to bias^{22,33,45,62,88}. To mitigate these issues, researchers have looked towards tracing individuals through the system and by manually verifying the data⁶³; however, they have been unsuccessful due to limited access³⁰.

Discussion

This review sheds light on Indigenous data governance approaches employed by researchers when accessing Indigenous Peoples' routinely collected health data. The findings reflect that Indigenous Data Governance (IDG) is an emerging area with inconsistent reporting of these approaches. Some elements of IDG, such as ethical approval and the involvement of Indigenous Peoples in research, were widely reported, while others, such as how data sovereignty was maintained and the use of Indigenous guiding principles, were less often reported. We propose that reporting on IDG approaches provides readers with confidence that the research was conducted ethically. A reporting guideline for research using Indigenous Peoples' routinely collected health data may be useful to encourage the explicit and consistent inclusion of IDG approaches.

The benefits of utilising routinely collected health data for research are widely recognised to enhance healthcare efficiency and delivery¹⁰¹. However, its use in research poses significant ethical challenges related to patient privacy and data access, especially for Indigenous Peoples^{102,103}. Consequently, Indigenous data governance is crucial to ensure the power, authority, access to, ownership and use of data is maintained by Indigenous Populations¹⁰⁴. While the implementation of such approaches requires time, resources, education, and planning, when properly executed, it can serve as a driver for Indigenous-led strategic planning and decision-making in public health¹⁰⁵. These approaches can help develop deep trust⁸¹ and respectful collaboration with Indigenous People⁶¹ through transparent, mutual respect and shared understanding of Indigenous data^{56,81}. Including Indigenous Community Leaders and People can ensure cultural appropriateness in the process of strategic planning and operational decision-making within healthcare services^{23,34,50,51,56,62,73,79}.

Indigenous Peoples are considered to be some of the most researched groups in the world¹⁴, which has put a significant burden on these Communities to share information about their health and participate in trials. Utilising routinely collected health data provides an opportunity to conduct important research without the need to burden populations through additional data collection⁷². Routinely collected health data can make the research process more efficient and cost effective⁸⁷, it can also enable comparison or follow-up across longer periods of time and access to more people than would otherwise be practical⁴⁸. There are well-documented limitations in the quality and completeness of routinely collected health data, the most significant being the inaccurate identification of Indigenous People^{29,68}. Researchers should consider these factors when deciding whether utilising Indigenous Peoples' routinely collected health data is appropriate for their research.

Despite using rigorous methods to understand the approaches to Indigenous data governance in healthcare, this study has its limitations. The research study incorporated the ATSIHealth database which focuses on Aboriginal Australian and Torres Strait Islander, as well as other international databases, but did not include databases specific to other Indigenous

groups. While it can be argued that the research may have potential biases, the authors included research assistants from Canada and the USA and ensured a comprehensive set of search terms to encompass the diverse Indigenous Communities. This ensured thoroughness in extracting data from various health databases.

Data availability

The data that support the findings of this study are available from the corresponding author upon request.

Received: 9 October 2023; Accepted: 29 February 2024;

Published online: 15 March 2024

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Acknowledgements

This publication is forms part of the Digital Infrastructure for Improving First Nations matERNal and Child hEalth (DIFFERENCE) project, which received grant funding from the Australian Government through the Medical Research Future Fund (MRFF) 2021 Research Data Infrastructure Grant.

Author contributions

T.E. and C.S. were responsible for conceptualisation. T.E. completed database searching. T.E. and Ji.W. drafted the inclusion and exclusion criteria from a sample of 50 papers. H.W. and S.K. reviewed the inclusion and exclusion criteria. T.E., Ji.W., H.W. and S.K. completed the title and abstract screening. T.E., Ji.W., H.W., S.H., S.K. and S.O. independently completed the full-text screening. All reviewers contributed to conflict resolution during screening. Ja.W., C.N. and C.S. informed the Indigenous data governance principles to be explored. T.E., H.W., J.W., S.K., S.O. and E.L. performed data extraction. E.L. and H.W. were involved in data interpretation. T.E. and E.L. wrote the original draft; All authors edited, reviewed and approved the final version of the paper, including significant input from Ja.W. and C.N. on Indigenous data governance and applying these principles in research. K.W. and Ja.W. are First Nations Australians and provided expert guidance during this review.

Competing interests

The author(s) declare no competing interests.

Additional information

Supplementary information The online version contains supplementary material available at <https://doi.org/10.1038/s41746-024-01070-3>.

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