Epilepsy in the Indigenous peoples in Canada, Australia, New Zealand, and the USA: a systematic scoping review

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Summary

Background Indigenous peoples have inequitable health access and outcomes yet are under-represented in health research and policy. The Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders 2022–2031 highlights Indigenous peoples as high priority groups. We aimed to provide a summary of existing knowledge regarding epilepsy among Indigenous peoples in Canada, Australia, New Zealand, and the USA (CANZUS).

Methods In this systematic scoping review, we searched Embase, MEDLINE, APA PsychInfo, Cochrane, Scopus, CINAHL databases and grey literature for reports published in any language between Jan 1, 1985, and April 16, 2023, using search terms related to seizures, epilepsy, and Indigenous peoples. Studies were assessed independently by three reviewers. Articles including epilepsy data in an Indigenous group were included. Articles were excluded if they combined Indigenous and non-Indigenous peoples as one population or if the outcomes did not include a separate analysis by Indigenous group. Case reports were also excluded. We extracted data on epilepsy epidemiology, access to health care, treatment, and health outcomes in Indigenous people. The methodological quality of studies was assessed through a methodological appraisal and an Indigenous perspective appraisal. This study is registered with Open Science Framework, https://doi.org/10.17605/OSF.IO/9JRHG.

Findings Our search identified 2037 studies, of which 42 peer-reviewed articles and nine grey literature reports met inclusion criteria: these studies were in Canada (n=3), Australia (n=17), New Zealand (n=9), and the USA (n=22). With the exception of Māori children in New Zealand, who seem to have similar rates of epilepsy to children of European ancestry, the incidence and prevalence of epilepsy seemed to be higher in Indigenous peoples in these regions than non-Indigenous populations. In the included studies, Indigenous peoples showed a higher number of epilepsy hospital presentations, decreased access to specialists, decreased access and longer waits for antiseizure medication, and increased prescriptions for enzyme-inducing antiseizure medications when compared with non-Indigenous peoples. In Australia, the number of disability-adjusted life years among Aboriginal and Torres Strait Islander peoples with epilepsy was double that for non-Indigenous people with epilepsy. Mortality rates for Indigenous peoples with epilepsy in New Zealand and Australia were higher than in non-Indigenous people with epilepsy.

Interpretation Although Indigenous people from CANZUS have unique cultural identities, this review identified similar themes and substantial disparities experienced by Indigenous versus non-Indigenous people in these nations. Concerningly, there were relatively few studies, and these were of variable quality, leaving substantial knowledge gaps. Epidemiological epilepsy research in each specific Indigenous group from CANZUS countries is urgently required to enable health policy development and minimise inequity within these countries.

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Introduction

In 2022, WHO adopted the Intersectoral Global Action Plan (IGAP) on Epilepsy and other Neurological Disorders 2022–2031.[1] The aims of IGAP are to reduce the impact of epilepsy, improve epilepsy health care, and eliminate health disparities. IGAP specifically highlights Indigenous peoples as high priority groups.[1]

Indigenous peoples are sovereign groups of people with long-established customary and traditional links to precolonial cultures, knowledge systems, and land.[2] Indigenous peoples in Canada, Australia, New Zealand, and the USA are often collectively referred to using the term CANZUS.[2] However, it needs to be emphasised that each of these Indigenous groups, both within and between each country, are unique, with their own distinct cultures, histories, and beliefs.[2] Despite these differences, these groups do share many commonalities since they were all colonised by European nations, with resulting land, generational wealth, and cultural loss. They also comprise a small, but growing, proportion of their overall national populations.[2] In this systematic scoping review, we aimed to summarise the literature describing epilepsy in the Indigenous peoples in CANZUS. Although throughout this review we respectfully refer to more than

Research in context

Evidence before this study

As defined in the UN Declaration on the Rights of Indigenous Peoples, Indigenous peoples are equal citizens with the right to health equity. Despite this fundamental right, Indigenous peoples have inequitable access to health services and worse overall health outcomes compared with non-Indigenous populations. To our knowledge, no previous reviews focusing on epilepsy in the Indigenous peoples in Canada, Australia, New Zealand, and the USA (CANZUS) have been published. Although these groups of Indigenous peoples have their own unique identities and culture, they share many commonalities because they were colonised by European nations, with resulting land, generational wealth, and cultural loss. We searched Embase, MEDLINE, APA PsycInfo, Cochrane Central Register of Controlled Trials, Scopus, and CINAHL databases for reports published between Jan 1, 1985 and April 16, 2023, using search terms related to epilepsy, seizures, and the Indigenous peoples in CANZUS.

Added value of this study

To our knowledge, we provide the first comprehensive summary of epilepsy in the Indigenous peoples in CANZUS. This review addresses the issues raised in the WHO Intersectoral Global Action Plan (IGAP) on Epilepsy and Other Neurological Disorders 2022–2031, which has highlighted Indigenous peoples to be a high-priority group. We identified that in each of the four nations, common inequities in the epidemiology, management, and outcomes of Indigenous peoples with epilepsy exist. This review is strengthened by considering an Indigenous perspective and discusses an approach for future Indigenous research.

Implications of all the available evidence

In the past 10 years, an increasing number of studies on epilepsy in Indigenous peoples has been published; however, studies are of variable quality and large knowledge gaps exist. This review highlights the urgent need for high-quality research in Indigenous peoples with epilepsy. We emphasise the importance of including Indigenous researchers in all research involving Indigenous populations.

one Indigenous group as Indigenous peoples, we acknowledge the important and essential customary differences between each group.

Methods

Search strategy and selection criteria

This review was performed in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews.[3] The study protocol was registered on the Open Science Framework. We searched Embase (Ovid), Medline (Ovid), APA PsycInfo (Ovid), Cochrane Central Register of Controlled Trials (Ovid), Scopus, CINAHL, and grey literature resources (appendix pp 1–17) for publications in any language between Jan 1, 1985 and April 16, 2023.[4] The search strategy comprised Medical Subject Headings (MeSH), truncations, and keywords to include all Indigenous peoples within CANZUS and the terms "seizure*", "epilep*", or "convulsion*". References of identified articles were manually searched for additional publications to include in our review.

Titles and abstracts were reviewed independently by three investigators (NFK, SGA, and LGS). All quantitative and qualitative studies reporting on any aspect of epilepsy within the Indigenous peoples in CANZUS were included. Articles were excluded if they combined Indigenous and non-Indigenous peoples as one ethnic group or if the outcomes did not include a separate analysis by Indigenous group. Case reports were also excluded. A standard data abstraction form was developed and tested by two investigators (NFK and LGS) who then independently charted the data and extracted summary estimates from each included study. Any discrepancies were resolved by consensus. This study is registered with Open Science Framework.

For the **Open Science Framework** see https://doi.org/10.17605/OSF.IO/9JRHG

For the **study protocol** see https://archive.org/details/osf-registrations-9jrhg-v1

See **Online** for appendix

Data analysis

Extracted data included cohort size, age, sex, Indigenous group, comparator group, source of ethnicity data, epilepsy incidence and prevalence, management, treatment, outcomes, and neurodevelopmental comorbidities of epilepsy within the Indigenous peoples in CANZUS. Study findings were summarised as per the original source document: when available, incidence is reported per 100 000 population and prevalence per 1000 population; and rate ratios or odds ratios (ORs) for comparisons of outcomes by Indigenous and non-Indigenous groups are reported as per the original study. Two quality appraisals of each publication were implemented: a methodological quality appraisal using Joanna Briggs Institute checklists for critical appraisals[5] and an Indigenous perspective appraisal (appendix pp 17–18). Scores were calculated based on the responses to each question. Appraisal scores were categorised as very low (≤25%), low (26–50%), moderate (51–75%), or high (>75%). Descriptive statistics were employed to describe the number of included studies as a count and as a proportion.

Role of the funding source

The funder had no role in the study design, data collection, data analysis, data interpretation, or writing of the report.

Results

Our search yielded 2037 abstracts (figure 1); of which, 42 peer-reviewed and nine grey literature reports met

eligibility criteria: these reports were from Canada (n=3),[6–8] Australia (n=17),[9–25] New Zealand (n=9),[26–34] and the USA (n=22).[35–56] Ten studies focused on children, 21 on adults, and the remainder included people of all ages. A secular trend was evident with 33 (65%) of 51 of studies published within the past 10 years (figure 2).

Two-thirds of studies had a methodological quality score ranging from very low (three [6%] of 51 studies) and low (nine [18%] studies), to moderate (23 [45%] studies; table 1). Administrative data were the primary source of information in 29 (57%) of 51 studies. Epilepsy diagnosis was confirmed from review of clinical notes in 11 (22%) of 51 studies. Confounding factors were documented in 25 (49%) of 51 studies; however, only six (12%) studies analysed associations between social factors and ethnicity. For the Indigenous perspective analysis, most studies scored very low (27 [53%] of 51 studies) or low (22 [43%] studies). The highest scoring aspects were inclusion of a representative sample of Indigenous peoples (47 [92%] of 51 studies), discussion on improving the health of Indigenous peoples (17 [33%] studies), and community consultation and engagement (19 [37%] studies).

The incidence or prevalence of epilepsy in Indigenous peoples was reported in eight studies (appendix p 21).[6,7,9,26,35–38] One Saskatchewan study identified individuals aged older than 2 years with new onset epilepsy.[6] The standardised incidence of epilepsy among First Nations peoples was 1·6 times higher (95% CI 1·5–1·8) than that in non-self-identified First Nations individuals. The incidence of epilepsy in children was 60·1 cases per 100 000 person-years. Incidence of epilepsy was higher in males (140·4 cases per 100 000 person-years [95% CI 125·2–154·5]) than females (104·7 cases per 100 000 person-years [92·5–116·7]).[6] A non-peer-reviewed dissertation,[7] which used data from the 2006 Canadian Aboriginal Children's Survey to determine the rate of self-reported epilepsy in First Nations, Métis, and Inuit children reported an epilepsy prevalence of 5·4 cases per 1000 children.

The only data available from Australia were from the 2018–19 National Health Survey of Aboriginal and Torres Strait Islanders (comprising 33% of the Aboriginal and Torres Strait Islander population), which reported a prevalence of 11 cases per 1000 persons (95% CI 7·0–15·0).[9] This prevalence was double the prevalence of epilepsy reported in the 2017–18 National Health Survey of non-Indigenous peoples.[9]

In New Zealand, the period prevalence rate of treated epilepsy among Māori children (aged ≤18 years) was 3·4 cases per 1000 children (95% CI 3·1–3·8)[26] and the incidence was 75·5 cases per 100 000 person-years (95% CI 59·6–94·3). The prevalence of epilepsy was similar to that in other ethnic groups. After adjusting for socioeconomic status, the prevalence of epilepsy in Māori children was significantly lower than that of children with

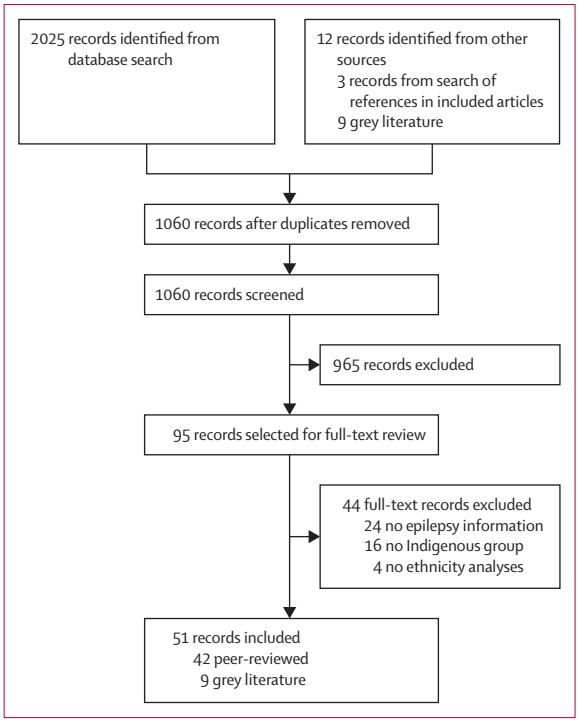

Figure 1: **Study selection flowchart**

European ancestry (rate ratio 0·74 [95% CI 0·63–0·86]).[26] In two population-based studies, epilepsy prevalence was higher among different Native American tribes than that reported by previous research investigating epilepsy in the general US population.[37,38] A 1998–2002 study of Navajo people of all ages living on the Navajo Nation who received health care from the Indian Health Services reported an age-adjusted epilepsy prevalence of 10·2 case per 1000 individuals.[37] Age-adjusted prevalence of epilepsy was 1·5 times higher in males (12·2 cases per 1000 individuals) than in females (8·3 cases per 1000 individuals).[37] An earlier study done between 1972 and 1976 also showed higher prevalence rates among four Native American tribes (Tewa, Hopi, Navajo, and Zuni; 7·5–9·1 cases per 1000 individuals) than that reported by previous research investigating epilepsy in children from Rochester, NY, USA.[38] Two studies, which both used Medicare insurance claims data, reported contradictory results regarding the prevalence and incidence of epilepsy in Native Americans older than 65 years.[35,36] The 2009–11 study from Arizona, a US state with a large Native American population, reported a substantially higher incidence (620 cases *vs* 110 cases per 100 000 person-years) and prevalence (21·2 cases *vs* 7·7 cases per 1000 individuals)[35] of epilepsy among Native Americans than did an older study, which analysed national claims made between 2001 and 2006.[36] In the 2001–06 study, the incidence and prevalence of epilepsy was lower in Native Americans than in White populations,[36] whereas in the 2009–11 Arizona study, the

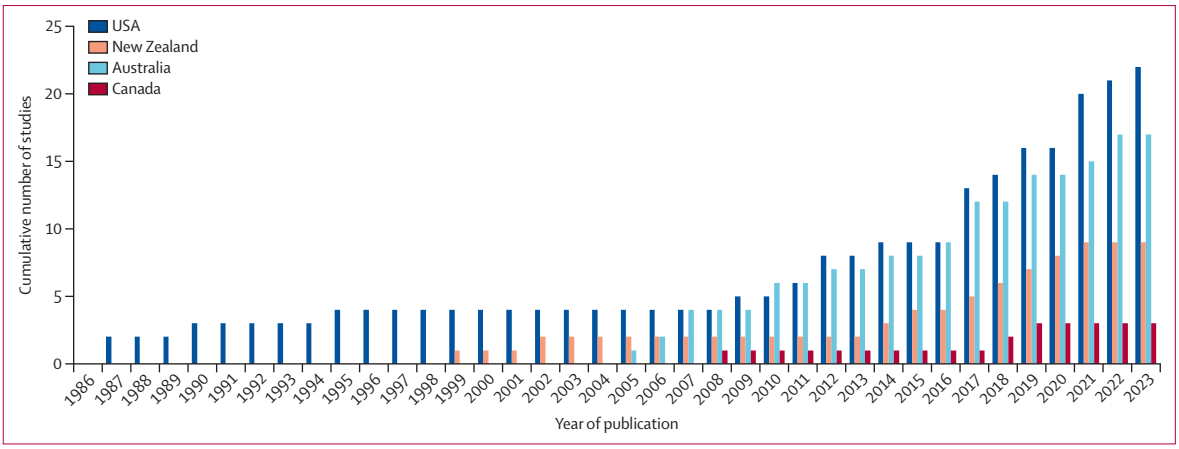

Figure 2: **Cumulative number of published studies on epilepsy within an Indigenous population in Canada, Australia, New Zealand, or the USA**

prevalence of epilepsy among Native Americans was significantly higher and incidence was similar compared with White populations (appendix p 21).[35] No studies describing the aetiology or types of epilepsy in the Indigenous peoples in CANZUS were identified (table 2).

Access to hospital-based services for Indigenous peoples was reported in 17 studies.[8,10–14,27–32,39–43] Although these studies differed in their study population, methodology, and the countries' health systems, common themes emerged (figure 3). In New Zealand, Māori adults comprised a larger proportion of seizure-related emergency department presentations than expected considering the proportion of the population who were Māori in each region.[31,32] Government reports reported a higher incidence of hospital admissions for epilepsy or status epilepticus among Māori children than non-Māori children.[28,29]

Similar findings were reported in 2006 and 2012 in Cairns, QLD, Australia.[10,12] Two studies reported that Aboriginal and Torres Strait Islander peoples comprised a higher proportion of seizure-related emergency department visits and hospital admissions than would be expected considering the proportion of Aboriginal and Torres Strait Islander peoples living within the region.[10,12] This finding was corroborated in a 2014 study, which reported that the rate of seizure-related hospital admissions among Aboriginal and Torres Strait Islander peoples was 5·6 times higher than that among non-Indigenous people.[11] The ratio of hospital admissions among Aboriginal and Torres Strait Islanders to non-Indigenous peoples was highest in males (rate ratio 7·4 [95% CI 7·3–7·6]) and people aged 40–64 years (13·8 [13·3–14·3]).[11] Hospital admissions among Aboriginal and Torres Strait Islander peoples were highest in areas of low deprivation; whereas, among non-Indigenous peoples, hospitalisation rates were higher in individuals from areas of high deprivation.[11]

Seizure-related emergency department presentations in Native Americans were reported in three studies.[39,42,43] Each study included only a small proportion of Indigenous peoples in their cohorts (0·2–3·6%), limiting the ability to describe disparities. Although statistical significance was not achieved, higher rates of seizure-related emergency department visits were reported among Indigenous peoples than among other ethnic groups.[39,42,43] A Canadian study used inpatient, outpatient, and emergency coding data to identify people with epilepsy, reporting that First Nations peoples with epilepsy were more likely to present to emergency department (OR 2·3 [95% CI 1·09–4·98]) and were more likely to be admitted to hospital than non-Indigenous peoples with epilepsy (OR 2·8 [1·49–5·13]).[8]

A prospective study from New Zealand reported that Māori peoples had a higher incidence of status epilepticus (29·3 cases per 100 000 person-years [95% CI 23·5–37·1]) compared with individuals of European ancestry (19·13 cases per 100 000 person-years [17·1–21·4]).[27] Similarly, an Australian study reported that Aboriginal and Torres Strait Islander children admitted to hospital with seizure-like events were more likely to have status epilepticus than non-Indigenous children (OR 2·37 [95% CI 1·11–5·06]).[14] No differences were identified in the length of hospital stay between the groups.[14]

A large nationwide US study done between 2017 and 2019 reported that, among people experiencing a seizure attended to by a paramedic, Native American (including Alaska Native) peoples were 1·57 times (95% CI 1·48–1·62) more likely to only receive basic life support from emergency medical services compared with White individuals, who were more likely to receive advanced life support (relative risk for basic life support 0·91 [95% CI 0·90–0·92]).[44]

Seven peer-reviewed studies investigated access to outpatient epilepsy services.[8,10,13,39,40,42,45] Five studies reported lower rates of specialist visits for Indigenous peoples.[8,10,39,40,42] In Calgary, Canada, First Nations peoples with epilepsy were 3·1 times less likely to see a neurologist

	Population	Study type	Study period	Cohort size, n (% Indigenous)	Source of data on ethnicity	Indigenous groups included	Comparator group	Quality appraisal*	Indigenous appraisal*	Report type
Australia										
Archer and Bunby (2006)[10]	Children and adults with epilepsy	Service-based retrospective cross-sectional study	2001–04	486 (11–31%)	Self-identified administrative data	Aboriginal, Torres Strait Islander	Regional population	Moderate (5/8)	Very low (3·5/15)	Peer- reviewed article
Australian Bureau of Statistics (2019)[9]	Indigenous children and adults with epilepsy	Population-based cross-sectional survey	2018–19	10 500 (100%)	Self-identified	Aboriginal, Torres Strait Islander	Non-Indigenous	Moderate (6/9)	Low (4/15)	Grey literature
Australian Institute of Health and Welfare (2016)[23]	Indigenous children and adults	Population-based retrospective crosssectional study	2011	NA	Self-identified administrative data	Aboriginal, Torres Strait Islander	Non-Indigenous	Moderate (6/8)	Low (6/15)	Grey literature
Australian Institute of Health and Welfare (2022)[24]	Indigenous children and adults	Population-based retrospective cross-sectional study	2018	NA	Self-identified administrative data	Aboriginal, Torres Strait Islander	Non-Indigenous	Moderate (6/8)	Low (5/15)	Grey literature
Charlson et al (2021)[21]	Indigenous individuals with psychosis	Service-based retrospective cross-sectional study	1992–2015	426 (100%)	Self-identified administrative data	Aboriginal, Torres Strait Islander	NA	Moderate (6/8)	Low (4/15)	Peer- reviewed article
Franklin et al (2017)[20]	Children who died from drowning	Population-based retrospective cross-sectional study	2002–12	468 (<1%)	Self-identified administrative data	Aboriginal, Torres Strait Islander	Non-Indigenous	Moderate (5/8)	Very low (0/15)	Peer- reviewed article
Glasson et al (2005)[19]	Indigenous children with intellectual disability	Population-based retrospective cross-sectional study	1953–2000	734 (100%)	Self-identified administrative data	Aboriginal, Torres Strait Islander	NA	Low (4/8)	Very low (2/15)	Peer- reviewed article
Lo Giudice et al (2010)[16]	Indigenous adults with pain, falls, or urinary incontinence	Cross-sectional survey	2004–06	363 (100%)	Self-identified	Aboriginal, Torres Strait Islander	NA	Moderate (5/8)	Low (6/15)	Peer- reviewed article
Nguyen et al (2017)[14]	Children admitted to hospital for a seizure	Service-based retrospective cross-sectional study	2014–15	373 (9%)	Self-identified administrative data	Aboriginal, Torres Strait Islander	Non-Indigenous	Low (4/8)	Very low (2/15)	Peer- reviewed article
Orr et al (2022)[18]	Children exposed to family violence	Population-based retrospective cross-sectional study	2004–08	49 014 (52%)	Self-identified administrative data	Aboriginal, Torres Strait Islander	Non-Indigenous	Moderate (5/8)	Low (4·5/15)	Peer- reviewed article
Plummer et al (2014)[11]	Children and adults with seizures	Population-based retrospective cross-sectional study	1998–2004	71 185 (16%)	Self-identified administrative data	Aboriginal, Torres Strait Islander	Non-Indigenous	High (8/8)	Low (7/15)	Peer- reviewed article
Queensland Health (2017)[25]	Indigenous children and adults	Population-based retrospective cross-sectional study	2011	NA	Self-identified administrative data	Aboriginal, Torres Strait Islander	Non-Indigenous	Moderate (6/8)	Low (6/15)	Grey literature
Radford et al (2019)[17]	Older Indigenous adults with dementia	Cross-sectional survey	2010–12	336 (100%)	Self-identified	Aboriginal, Torres Strait Islander	NA	High (7/8)	Low (6/15)	Peer- reviewed article
Rothstein et al (2007)[13]	Children treated by a paediatric outreach clinic	Service-based retrospective cross-sectional study	2001–06	3562 (62%)	Self-identified administrative data	Aboriginal, Torres Strait Islander	Non-Indigenous	Moderate (5/8)	Very low (2/15)	Peer- reviewed article
Smith et al (2010)[15]	Older Indigenous adults (>45 years) with dementia	Cross-sectional survey	NA	363 (100%)	Self-identified	Aboriginal, Torres Strait Islander	NA	Moderate (5/8)	Low (4/15)	Peer- reviewed article
Vos et al (2009)[22]	Indigenous children and adults	Population-based retrospective cross-sectional study	2003	19 881 469 (2%)	Self-identified administrative data	Aboriginal, Torres Strait Islander	Non-Indigenous	Moderate (6/8)	Low (6/15)	Grey literature
Wilson et al (2012)[12]	Adults presenting to emergency for a seizure	Service-based retrospective cross-sectional study	2006–07	260 (22%)	Self-identified	Aboriginal, Torres Strait Islander	Non-Indigenous	Low (3/8)	Very low (3·5/15)	Peer-reviewed article

(Table 1 continues on next page)

	Population	Study type	Study period	Cohort size, n (% Indigenous)	Source of data on ethnicity	Indigenous groups included	Comparator group	Quality appraisal*	Indigenous appraisal*	Report type
(Continued from previous page)										
Canada										
Hernández-Ronquillo et al (2018)[6]	Children and adults in Saskatchewan	Population-based retrospective prevalence study	2001–10	3804 (16%)	Self-identified administrative data	First Nations	Non-Indigenous	High (9/9)	Very low (3/15)	Peer-reviewed article
Jetté et al (2008)[8]	Children and adults with epilepsy	Population-based retrospective cohort	1999–2001	1431 (4%)	Self-identified administrative data	First Nations	Non-Indigenous	High (11/11)	Low (4/15)	Peer-reviewed article
Lysenko (2019)[7]	Children <6 years with epilepsy	Population-based cross-sectional survey	2006–07	111 270 (10%)	Self-identified	First Nations; Métis; Inuit	Indigenous peoples without epilepsy	Low (4/8)	Moderate (9/15)	Grey literature
New Zealand										
Ali et al (2021)[26]	Children with treated epilepsy	Population-based retrospective prevalence study	2015	1717 (20%)	Self-identified administrative data	Māori	New Zealand European	High (9/9)	Low (7/15)	Peer-reviewed article
Bergin et al (2019)[27]	Children and adults with status epilepticus	Service-based retrospective cross-sectional study	2015–16	367 (16%)	Self-identified administrative data	Māori	New Zealand European	High (7/9)	Low (5/15)	Peer-reviewed article
Craig et al (2014)[29]	Children admitted to hospital for a seizure	Population-based retrospective cross-sectional study	2005–09	3500 (29%)	Self-identified administrative data	Māori	Non-Māori-Non-Pacific	Moderate (6/8)	Low (7/15)	Grey literature
Hamilton et al (2020)[30]	Children and adults with new onset epilepsy	Population-based retrospective cohort	2007–15	3366 (20%)	Self-identified administrative data	Māori	Non-Māori	Moderate (8/11)	Very low (2/15)	Peer-reviewed article
Hills and MacKenzie(2002)[34]	Adults from a regional town	Cross-sectional survey	NA	100 (10%)	Self-identified	Māori	Non-Māori	Very low (2/8)	Very low (3/15)	Peer-reviewed article
Joshi et al (2015)[31]	Adults presenting to emergency for a seizure	Service-based retrospective cross-sectional study	2013	500 (19%)	Self-identified administrative data	Māori	Regional population	Moderate (5/8)	Low (4/15)	Peer-reviewed article
Lance and Kumar (2017)[32]	Adults presenting to emergency for a seizure	Service-based retrospective cross-sectional study	2015	37 (30%)	Self-identified administrative data	Māori	Regional population	Low (4/8)	Very low (2/15)	Peer-reviewed article
Simonsen (1999)[33]	Adults with epilepsy and their carers	Interview-based qualitative study	1998	19 (100%)	Self-identified	Māori	NA	Very low (2/10)	Low (7/15)	Peer-reviewed article
Simpson et al (2018)[28]	Children admitted to hospital for a seizure	Population-based retrospective cross-sectional study	2011–15	4336 (28%)	Self-identified administrative data	Māori	Non-Māori-Non-Pacific	Moderate (6/8)	Low (4/15)	Grey literature
USA										
Bensken et al (2021)[51]	Adults with epilepsy	Population-based retrospective cross-sectional study	2010–14	81 963 (1%)	Self-identified administrative data	Native American and Alaska Natives	Multiple ethnic groups	Moderate (5/8)	Very low (3/15)	Peer-reviewed article
Bensken et al (2023)[40]	Adults with treated epilepsy	Population-based retrospective cross-sectional study	2010–14	78 534 (1%)	Self-identified administrative data	Native American and Alaska Natives	White people	Moderate (6/8)	Low (4/15)	Peer-reviewed article
Debruyn (1990)[55]	Native American children with epilepsy	Interview-based qualitative study	1979–1981	31 (100%)	Self-identified	Native American (Tewa)	NA	Low (3/10)	Moderate (8/15)	Peer-reviewed article
Faught et al (2012)[36]	Older adults with epilepsy	Population-based retrospective prevalence study	2001–06	704 243 (<1%)	Self-identified administrative data	Native American	White people	High (8/9)	Very low (2/15)	Peer-reviewed article
Gaddam (2021)[44]	Children and adults seen by an ambulance for a seizure	Population-based retrospective cross-sectional study	2017–19	624 011 (1%)	Self-identified administrative data	Native American and Alaska Natives	White people	Moderate (6/8)	Very low (3/15)	Peer-reviewed article

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	Population	Study type	Study period	Cohort size, n (% Indigenous)	Source of data on ethnicity	Indigenous groups included	Comparator group	Quality appraisal*	Indigenous appraisal*	Report type
Greenlund et al (2017)[54]	Children and adults with an epilepsy related death	Population-based retrospective cross-sectional study	2005–14	4722 (1%)	Self-identified administrative data	Native American and Alaska Natives	Multiple ethnic groups	Low (4/8)	Very low (2/15)	Peer-reviewed article
Ho et al (2019)[53]	Individuals with psychogenic non-epileptic seizures	Service-based retrospective cross-sectional study	2014–18	139 (25%)	Self-identified administrative data	Native Hawaiian	Multiple ethnic groups	Moderate (6/8)	Very low (2/15)	Peer-reviewed article
Horan K (1987)[52]	Native American rehabilitation clients	Service-based cohort study	1980–1984	80 (100%)	Self-identified	Native American (Navajo)	NA	Moderate (6/11)	Very low (1/15)	Grey literature
Ip et al (2018)[35]	Older adults with epilepsy	Population-based retrospective prevalence study	2009–11	11 967 (3%)	Self-identified administrative data	Native American	White people	High (8/9)	Very low (2/15)	Peer-reviewed article
Levy (1987)[56]	Children and adults with epilepsy	Service-based retrospective cross-sectional study	1971–1978	195 (100%)	Self-identified administrative data	Native American (Navajo)	Native American (Pueblo)	Very low (2/8)	Very low (3/15)	Peer-reviewed article
Levy et al (1995)[38]	Children and adults with epilepsy	Population-based retrospective prevalence study	1972–76	195 (100%)	Self-identified	Native American (Navajo, Pueblo)	NA	Moderate (6/9)	Very low (3/15)	Grey literature
Martin et al (2017)[42]	Older adults (≥67 years) with new onset epilepsy	Population-based retrospective cohort	2008–10	3706 (2%)	Self-identified administrative data	Native American and Alaska Natives	White people	High (11/11)	Very low (3/15)	Peer-reviewed article
McConnell et al (2014)[50]	Adults with epilepsy	Service-based cross-sectional survey	2011	120 (3%)	Self-identified	Native American and Alaska Natives	Multiple ethnic groups	Low (3/8)	Very low (1/15)	Peer-reviewed article
Ouellette et al (2011)[43]	Individuals presenting to the emergency department for a seizure	Service-based retrospective cross-sectional study	2005–08	1103 (4%)	Self-identified administrative data	Native American	Multiple ethnic groups	Moderate (5/8)	Very low (3/15)	Peer-reviewed article
Parko and Thurman (2009)[37]	Children and adults with epilepsy	Population-based retrospective prevalence study	1998–2002	4181 (100%)	Self-identified administrative data	Native American (Navajo)	NA	High (9/9)	Low (5/15)	Peer-reviewed article
Piper et al (2017)[48]	Older adults (≥66 years) with epilepsy	Population-based retrospective cohort	2008–10	36 912 (2%)	Self-identified administrative data	Native American and Alaska Natives	White people	High (10/11)	Very low (2/15)	Peer-reviewed article
Pisu et al (2012)[39]	Older adults (≥65 years) with a first seizure	Population-based retrospective cohort	2001–06	186 547 (<1%)	Self-identified administrative data	Native American	White people	High (11/11)	Very low (2/15)	Peer-reviewed article
Pisu et al (2017)[47]	Older adults (≥67 years) with epilepsy	Population-based retrospective cohort	2008–10	36 912 (2%)	Self-identified administrative data	Native American and Alaska Natives	Multiple ethnic groups	High (10/11)	Low (4/15)	Peer-reviewed article
Pisu et al (2019)[41]	Older adults (>65 years) with epilepsy	Population-based retrospective cohort	2008–10	36 912 (2%)	Self-identified administrative data	Native American and Alaska Natives	White people	High (11/11)	Low (4/15)	Peer-reviewed article
Sirven et al (2022)[46]	Children and adults with new onset epilepsy	Population-based retrospective cohort	2015–19	5965 (11%)	Self-identified administrative data	Native American	White people	High (10/11)	Very low (3/15)	Peer-reviewed article
Terman et al (2021)[49]	Older adults (>65 years) with new onset epilepsy	Population-based retrospective cohort	2010–13	24 923 (1%)	Self-identified administrative data	North American Indigenous	White people	High (10/11)	Very low (3/15)	Peer-reviewed article
Wong et al (2021)[45]	Adults with epilepsy	Population-based retrospective cross-sectional study	2018–19	122 (29%)	Self-identified administrative data	Native Hawaiian	White people	Low (3/8)	Very low (3/15)	Peer-reviewed article

NA=not available. *Quality appraisal was scored using Joanna Briggs Institute critical appraisal checklists (number of questions varied depending on study type). Indigenous perspective quality appraisal (15 questions; appendix pp 17–18). Scores were calculated based on the question responses: yes=1, partial=0·5 [Indigenous appraisal only], no, not applicable, or unclear=0; appraisal scores were categorised as very low (≤25%), low (26–50%), moderate (51–75%), or high (>75%).

Table 1: **Summary of included studies**

	Indigenous Peoples included in study	Lower standard of care for Indigenous *vs* non-Indigenous peoples	No evidence of a difference	Higher standard of care for Indigenous *vs* non-Indigenous peoples
Emergency department and hospital visits				
Archer and Bunby (2006)[10]	Torres Strait Islander and Aboriginal	↑Emergency or hospital visits		
Bergin et al (2019)[27]	Māori	↑Hospital visits		
Craig et al (2014)[29]	Māori	↑Hospital visits		
Hamilton et al (2020)[30]	Māori		Similar rate of hospital visits	
Jetté et al (2008)[8]	First Nation	↑Emergency department or hospital visits		
Joshi et al (2015)[31]	Māori	↑Emergency department visits		
Lance et al (2017)[32]	Māori	↑Emergency department visits		
Martin et al (2017)[42]	Native American and Alaska Native		Similar emergency department visits	
Nguyen et al (2017)[14]	Torres Strait Islander and Aboriginal	↑Visits for status epilepticus	Similar seizure visits	
Ouellette et al (2011)[43]	Native American		↑Emergency department (not statistically significant)	
Pisu et al (2012)[39]	Native American		↑Emergency department (not statistically significant)	
Plummer et al (2014)[11]	Torres Strait Islander and Aboriginal	↑Hospital visits		
Simpson et al (2018)[28]	Māori	↑Hospital visits		
Wilson et al (2012)[12]	Torres Strait Islander and Aboriginal	↑Emergency department visits		
Outpatient clinics				
Archer and Bunby (2006)[10]	Torres Strait Islander and Aboriginal		Similar proportion of neurology visits	
Bensken et al (2023)[40]	Native American and Alaska Native	↓Neurology visits		
Jetté et al (2008)[8]	First Nation	↓Neurology visits		
Martin et al (2017)[42]	Native American	↓Neurology visits		
Pisu et al (2012)[39]	Native American	↓Neurology visits		
Rothstein et al (2007)[13]	Torres Strait Islander and Aboriginal		Similar proportion of paediatric visits	
Antiseizure medications treatment				
Bensken et al (2023)[40]	Native American and Alaska Native	↓Third *vs* first and second generation antiseizure medications	Similar compliance	↑Second or third *vs* first generation antiseizure medications
Hamilton et al (2020)[30]	Māori	↓Treatment; if received, treatment was delayed		
Martin et al (2017)[18]	Native American and Alaska Native	↑Phenytoin		↑Guideline concordance
Nguyen et al (2017)[14]	Torres Strait Islander and Aboriginal	↓Compliance		
Piper et al (2017)[48]	Native American and Alaska Native	↓Compliance		
Pisu et al (2017)[41]	Native American and Alaska Native	↑Enzyme inducers	Similar guideline concordance	
Sirven et al (2022)[48]	Native American	↓Treatment		
Terman et al (2021)[49]	North American Indigenous*	↓Compliance		
Wilson et al (2012)[12]	Torres Strait Islander and Aboriginal	↑Phenytoin; ↓compliance		

***Figure 3*: Comparison of epilepsy health care in Indigenous peoples versus non-Indigenous populations across Canada, Australia, New Zealand, and the USA**
*Terminology used in study refers to North American Indigenous peoples, without more detail.

(OR 0·3 [95% CI 0·17–0·61]) and 3·3 times less likely to see a physician (OR 0·30 [0·12–0·74]) than non-Indigenous peoples with epilepsy.[8] Similarly, in Australia, although the proportion of neurology clinic visits for Aboriginal or Torres Strait Islanders (11%) was comparable with the proportion of Aboriginal and Torres Strait Islander peoples in the region (13%), it was substantially lower than the proportion of Aboriginal and Torres Strait Islander peoples presenting to hospital for a seizure (30–31%).[10] One Australian study done in north Queensland reported that only a small proportion of children seen in the outpatient clinics had epilepsy and no clear differences were identified between ethnic groups.[13]

Several studies reported that Native American or Alaska Native adults with new onset seizures were less likely to visit a neurologist than White individuals.[39,40,42]

	Canada			USA			Australia		New Zealand (Māori)
	First Nations	Métis	Inuit	Native American	Alaska Natives	Native Hawaiian	Aboriginal	Torres Strait Islander	
Incidence or prevalence									
Active epilepsy (children)	Peer-reviewed research	Grey literature	Grey literature	Peer-reviewed research	NA	NA	Grey literature	Grey literature	NA
Active epilepsy (adults)	Peer-reviewed research	NA	NA	Peer-reviewed research	NA	NA	NA	NA	NA
Treated epilepsy (children)	NA	NA	NA	NA	NA	NA	NA	NA	Peer-reviewed research
Treated epilepsy (adults)	NA	NA	NA	NA	NA	NA	NA	NA	NA
Cause									
International League Against Epilepsy aetiology classifications	NA	NA	NA	NA	NA	NA	NA	NA	NA
Preventable epilepsy	NA	NA	NA	NA	NA	NA	NA	NA	NA
Provision of care									
Emergency department visits (children)	NA	NA	NA	NA	NA	NA	NA	NA	NA
Emergency department visits (adult)	NA	NA	NA	Peer-reviewed research	Peer-reviewed research	NA	Peer-reviewed research	Peer-reviewed research	Peer-reviewed research
Emergency department visits (all)	Peer-reviewed research	NA	NA	Peer-reviewed research	NA	NA	Peer-reviewed research	Peer-reviewed research	NA
Hospital admissions (children)	NA	NA	NA	NA	NA	NA	Peer-reviewed research	Peer-reviewed research	Grey literature
Hospital admissions (adult)	NA	NA	NA	NA	NA	NA	Peer-reviewed research	Peer-reviewed research	Peer-reviewed research
Hospital admissions (all)	Peer-reviewed research	NA	NA	NA	NA	NA	Peer-reviewed research	Peer-reviewed research	Peer-reviewed research
Neurology care (children)	NA	NA	NA	NA	NA	NA	NA	NA	NA
Neurology care (adult)	NA	NA	NA	Peer-reviewed research	Peer-reviewed research	Peer-reviewed research	NA	NA	NA
Neurology care (all)	Peer-reviewed research	NA	NA	NA	NA	NA	Peer-reviewed research	Peer-reviewed research	NA
Antiseizure medication type	NA	NA	NA	Peer-reviewed research	Peer-reviewed research	NA	Peer-reviewed research	Peer-reviewed research	NA
Time to antiseizure medication	NA	NA	NA	Peer-reviewed research	NA	NA	NA	NA	Peer-reviewed research
Comorbidities									
Comorbidities (children)	NA	NA	NA	NA	NA	NA	Peer-reviewed research	Peer-reviewed research	NA
Comorbidities (adults)	NA	NA	NA	Peer-reviewed research	Peer-reviewed research	NA	NA	NA	NA
Outcomes									
Drug resistance	NA	NA	NA	NA	NA	NA	NA	NA	NA
Epilepsy burden	NA	NA	NA	NA	NA	NA	Grey literature	Grey literature	NA
Mortality	NA	NA	NA	Peer-reviewed research	Peer-reviewed research	NA	NA	NA	Peer-reviewed research

NA=not available.

Table 2: **Available epilepsy data for the Indigenous peoples in Canada, Australia, New Zealand, and the USA**

However, a study of older beneficiaries with epilepsy reported these groups had similar health costs to White individuals.[41] Native Hawaiians living in the US state of Hawaii on islands other than Oahu were seen at in-person seizure clinics held in Oahu (32%) more often than at telemedicine seizure clinics (23%).[45]

Ten peer-reviewed articles included information on antiseizure medication treatment in Indigenous peoples.[12,14,30,40,42,46–50] Māori peoples were less likely to receive immediate antiseizure medication treatment (90·4% *vs* 93·4%; p=0·008) and more likely to remain untreated than non-Māori people (5·0% *vs* 3·1%; p=0·026).[30] Similarly, Native Americans were more likely to remain untreated compared with White individuals (relative risk 2·2 [95% CI 1·51–3·24]); however, no difference was identified in the time to treatment with antiseizure medication, if treatment was received.[46] Another US study of older people with treated epilepsy found no differences in the time to start an antiseizure medication between Native American and White populations.[42]

Studies from Australia and the USA reported that Indigenous peoples were more likely to be prescribed an enzyme-inducing antiseizure medication than non-Indigenous individuals.[12,42,47] In two studies, phenytoin was the most commonly prescribed antiseizure medication to Indigenous peoples, whereas non-Indigenous peoples were more likely to be prescribed a newer antiseizure medication, such as levetiracetam.[12,42] However, a US Medicaid study that included only a small proportion of Indigenous peoples (1%) found Native American and Alaska Native peoples were more likely than White individuals to be prescribed a second-generation or third-generation antiseizure medication (OR 1·30 [95% CI 1·03–1·64]).[40] Several reports found that Native American and Alaska Native peoples were just as likely, or more likely, to meet epilepsy treatment guideline standards than other ethnic groups.[42,47]

Antiseizure medication adherence was reported in five peer-reviewed studies.[12,14,40,48,49] Australian studies reported that non-Indigenous adults and children were less likely than Aboriginal and Torres Strait Islander peoples to miss antiseizure medication doses.[12,40] Non-Indigenous individuals were also almost four times less likely to have their antiseizure medication levels measured, but if tested, were just as likely to have a subtherapeutic medication level.[14] In the USA, conflicting findings were reported, with two Medicare studies reporting higher antiseizure medication adherence in White adults than Indigenous peoples,[48,49] whereas a Medicaid study found inconclusive evidence of higher antiseizure medication adherence.[40]

Data on neurodevelopmental comorbidities in Indigenous people with epilepsy were scarce. A US Medicaid study reported a higher proportion of Native American and Alaska Native peoples with epilepsy had anxiety, mood disorders, headaches, and developmental disorders than White people with epilepsy; however, no statistical analysis was performed.[51] Another US study found that older Native Americans (aged ≥65 years) with epilepsy had a higher prevalence of stroke-related (OR 1·87 [95% CI 1·50–2·32]) and psychiatric (1·28 [1·03-1·58]) comorbidities than older White adults with epilepsy.[35] In Australia, Aboriginal and Torres Strait Islander children with seizures were more likely to have psychiatric (OR 2·37 [95% CI 1·11–5·06]) or behavioural (4·71 [2·11–10·52]) comorbidities than non-Indigenous children with seizures, but no differences were identified in the prevalence of developmental delay or autistic spectrum disorder.[14] Nine publications were identified that reported the number of people with epilepsy within cohorts of individuals with other morbidities;[15–21,52,53] however, these studies were not population-based and only included a small number of Indigenous people with epilepsy.

In Aboriginal and Torres Strait Islander peoples, epilepsy is one of the top 20 contributors to health burden, and Aboriginal and Torres Strait Islander people have more than twice the rate of disability-adjusted life-years (DALYs) than non-Indigenous populations.[22–25] Few reports regarding mortality have been published, and the report findings are conflicting. A 2014 US study, which examined death certificates, reported no difference in mortality rates between Indigenous peoples versus White people with epilepsy.[54] However, a New Zealand study of admissions data reported that mortality was 1·4 times higher in Māori than non-Māori people with new onset epilepsy.[30] The mortality rate of Aboriginal and Torres Strait Islander peoples with epilepsy in 2003 was 6·3 times higher than that in the overall Australian population.[22]

Only four older studies (completed >20 years ago) have reported on how Indigenous peoples view epilepsy.[33,34,55,56] In New Zealand, Māori were reported to be less likely to have heard of epilepsy than people of European ancestry[34] and had both modern and traditional beliefs of epilepsy.[33] In the USA, Tewa families engaged with health professionals but kept traditional healing practices separate from Western medicine.[55]

Discussion

To achieve the IGAP epilepsy goals of improving care and eliminating health inequities, it is essential that we understand current epidemiology, management, and outcomes of people with epilepsy.[1] This understanding is particularly important for Indigenous peoples, who have longstanding cultural evidence of social and health inequities secondary to historical and present day factors such as colonisation and a legacy of discriminatory laws, policies, and practices.[2] To our knowledge, this systematic scoping review is the first review of epilepsy within the Indigenous peoples in Canada, Australia, New Zealand, and the USA.

In this review, only 42 peer-reviewed articles and nine grey literature reports provided data on Indigenous peoples with epilepsy from these four countries in the

past 25 years. It is possible that publication bias contributed to the small number of studies. However, we would speculate it is more likely that researchers have either not specifically undertaken research including Indigenous people, or not analysed their findings based on Indigenous heritage. The majority of studies were conducted in the USA, including only two from Hawaii.[45,53] There were no peer-reviewed studies in Métis and Inuit peoples. This finding is likely due to the lack of Indigenous identifiers in Canadian administrative health datasets and jurisdictional issues in the way health care is provided to Indigenous peoples in Canada.[57] The number of publications has increased substantially in the past 10 years; however, these papers represent a small proportion of the existing literature on epilepsy.

The quality of research was variable, with only about one in three reports scoring highly in the methodological appraisal, and no studies scoring highly in our Indigenous perspective appraisal. Grey literature accounted for 18% of the identified studies, so caution was taken when interpreting the results since grey literature is not peer-reviewed. Another limiting feature is that most studies included only a small proportion of Indigenous peoples, leading to a lack of statistically precise and generalisable data. Additionally, the outcomes and language did not adopt a strength-based narrative. Strength-based narratives are important because they limit unnecessary stigma and discrimination.[58] Another problem is that likely due to the availability of the source data, many studies combined several Indigenous groups into a single ethnic category. In the USA, all tribes (at the time of writing there were 574 federally recognised tribes and 326 federally recognised American Indian reservations) are categorised as Native American;[59] thus, data for individual Indigenous populations (which might vary greatly) were not available.

Our scoping review highlights that due to a paucity of research, detailed information on epilepsy among Indigenous peoples in CANZUS is largely absent. The rate of epilepsy in Native American, First Nations, Australian Aboriginal, and Torres Strait Islander peoples has been reported to be 1·4 to 2 times higher than non-Indigenous groups.[6,9,35] However, in New Zealand, the prevalence of epilepsy in Māori children was found to be similar to that in non-Indigenous populations.[26] The discrepancies in the incidence and prevalence epilepsy observed in older Native Americans (aged ≥65 years) might relate to the short so-called clean periods used to calculate incidence and the inaccuracies of the Medicare datasets in identifying Native Americans.[60] Suboptimal and inequitable epilepsy health care is a commonly identified theme, evidenced by inequitable access to outpatient specialist services[8,10,39,42] and antiseizure medication treatments,[12,30,42,46,47] delay or absence of antiseizure medication treatment,[30,46] prescription of more enzyme-inducing antiseizure medications,[12,42,47] and decreased antiseizure medication adherence in Indigenous peoples than non-Indigenous peoples.[12,14,48,49] This suboptimal epilepsy care could contribute to an increased epilepsy burden, as reflected by an increased rate of seizure-related emergency department visits,[10,12,8,31,32] hospital admissions,[8,10,11,14,28,29,39] neurodevelopmental comorbidities,[14,35,51] DALYs,[22–25] and mortality rate in Indigenous populations found across studies.[22,30]

Socioeconomic status is a well-known social determinant of health.[61] Considering that Indigenous peoples within all four nations are over-represented within areas of high deprivation,[2] it is plausible that the identified disparities are influenced by social confounding factors. Unfortunately, most studies did not consider social factors: of those that did, people from areas of high deprivation had increased incidence and prevalence of epilepsy,[26] suboptimal epilepsy care,[62] and decreased quality of life[63] compared with those from areas of low deprivation.

This review had several limitations. First, grey literature (including governmental, university, and non-profit societal reports) is not routinely registered in databases and it can be challenging to identify. In larger countries, grey literature containing epilepsy data for Indigenous people might be published in each state. We were unable to find such reports despite searching the health websites of each state in the four included nations. Another limitation is that data on epilepsy among Indigenous peoples might only be available within the supplementary material of published research, and it would therefore have been missed in our search if Indigenous peoples were not mentioned in the main text.

Our comprehensive search strategy is a major strength. Search terms for all Indigenous peoples within the four countries were included to maximise the identification of published literature. Additionally, our research team not only includes representatives from all four countries but also comprises Indigenous (NFK, EA, PR, ADS, and JLS) and non-Indigenous co-authors, enabling us to evaluate the literature in a culturally appropriate manner. There is a risk when researchers report data from another country or culture that they unintentionally present it in a way that is culturally insensitive, focused on deficits, or in a way that reflects negatively on Indigenous people.[57] Collaborations between nations is important in global research, but it is crucial that the cultural values of each Indigenous group are acknowledged and respected. Relatedly, this systematic scoping review evaluated the literature not only from a standard methodological perspective but also from an Indigenous perspective.

This review identified large knowledge gaps regarding epilepsy in the Indigenous peoples in CANZUS. Of particular concern is the limited epidemiological data, absence of any data on aetiology or type of epilepsy, limited information regarding service provision, and absence of research exploring health improvement strategies. Identifying and subsequently alleviating health inequalities requires research that identifies risk factors for epilepsy and assesses outcomes for Indigenous peoples with

epilepsy to inform public health strategies.[1] Additionally, the datasets used for identification of Indigenous peoples, especially Native Americans in the US Medicare and Medicaid systems, must be refined to accurately identify Indigenous peoples. Ideally, epilepsy research for Indigenous peoples should acknowledge Indigenous peoples' values,[64] and be led by Indigenous researchers,[64] to provide context and ensure results are presented in a culturally appropriate strength-based manner.[58]

In summary, this systematic scoping review identified common inequities in epilepsy diagnosis and treatment in each of the four nations and across different Indigenous groups. This review addresses the WHO IGAP epilepsy agenda by identifying considerable knowledge gaps in our understanding of epilepsy in Indigenous peoples in Canada, Australia, New Zealand, and the USA. To achieve equitable health outcomes for Indigenous peoples with epilepsy, we recommend a three-pronged strategy to future research. As a minimum, all epilepsy research should provide ethnicity data that includes Indigenous peoples. Additionally, researchers should undertake more epilepsy research that has an Indigenous focus. And, ultimately, as recognised by the UN Declaration on the Rights of Indigenous Peoples,[64] Indigenous epilepsy research should involve Indigenous researchers.

Contributors

NFK conceptualised the study, and was involved in data curation, data interpretation, methodology, data validation, writing the original draft, and reviewing and editing the manuscript. SGA was involved in data curation, data interpretation, data validation, and writing, reviewing, and editing the manuscript. NJ, KP, PR, JA, and EA conceptualised the study and were involved in methodology, data interpretation, and writing, reviewing, and editing the manuscript. ADS conceptualised the study, and was involved in data interpretation, and writing, reviewing, and editing the manuscript. JLS conceptualised the study, and was involved in the methodology, supervision, data interpretation, writing the original draft, and writing, reviewing, and editing the manuscript. JS conceptualised the study, acquired funding, and was involved in methodology, supervision, data validation, data interpretation, writing of the original draft, and writing, reviewing, and editing of the manuscript. LGS conceptualised the study, acquired funding, and was involved in data curation, data interpretation, methodology, supervision, data validation, writing of the original draft, and writing, reviewing, and editing the manuscript. Each author had access to the study data and had final responsibility for the decision to submit for publication. The data were accessed and verified by NFK, SGA, and LGS. The decision to submit the manuscript was made by NFK, LGS, and JS.

Declaration of interests

LGS reports funding from Cure Kids New Zealand and the Health Research Council of New Zealand; and is a consultant for the Epilepsy Consortium. NJ received grant funding paid to her institution for grants unrelated to this work from the National Institute of Neurological Disorders and Stroke (National Institutes of Health [NIH] U24NS107201, NIH IU54NS100064, 3R01CA202911-05S1, R21NS122389, and R01HL161847) during the study period; and receives an honorarium for her work as an associate editor of *Epilepsia*. KP has an unpaid role on the International League Against Epilepsy's Global Advocacy Council. All other authors declare no competing interests.

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