Indigenous health equity in health register ascertainment and data quality: a narrative review

Karen Wright1*, Rachel M. Tapera1, N. Susan Stott2,3, Alexandra Sorhage3, Anna Mackey3 and Sian A. Williams4,5

Abstract

Background: Health registers play an important role in monitoring distribution of disease and quality of care; however, benefit is limited if ascertainment (i.e., the process of finding and recruiting people on to a register) and data quality (i.e., the accuracy, completeness, reliability, relevance, and timeliness of data) are poor. Indigenous peoples experience significant health inequities globally, yet health data for, and about, Indigenous peoples is often of poor quality. This narrative review aimed to (i) identify perceived barriers for the ascertainment of Indigenous peoples on health registers, and (ii) collate strategies identified and used by health registers to support comprehensive ascertainment and high-quality data for Indigenous peoples.

Methods: A Kaupapa Māori theoretical framework was utilized to guide this work. Four electronic databases were systematically searched for original articles and screened for eligibility. Studies involving health registers with Indigenous population(s) identified were included if either ascertainment or data quality strategies were described. Data extraction focused on the reporting of research involving Indigenous peoples using the CONSIDER checklist domains, ascertainment, and data quality.

Results: Seventeen articles were included spanning publication between 1992 and 2020. Aspects of four of eight CONSIDER domains were identified to be included in the reporting of studies. Barriers to ascertainment were themed as relating to ‘ethnicity data collection and quality’, ‘systems and structures’, ‘health services/health professionals’, and ‘perceptions of individual and community-level barriers’. Strategies to support ascertainment were categorized as ‘collaboration’, ‘finding people’, and ‘recruitment processes’. Categorized strategies to support data quality were ‘collaboration’, ‘ethnicity data collection and quality’, ‘systems-level strategies’, and ‘health service/health professional-level strategies’.

Conclusions: Poor-quality data for Indigenous peoples in health registers prevents the achievement of health equity and exemplifies inaction in the face of need. When viewed through a critical structural determinants lens, there are visible gaps in the breadth of strategies, particularly relating to the inclusion of Indigenous peoples in health register and research governance, and actions to identify and address institutional racism. Indigenous led research, meaningful collaboration, and a sharing of knowledge and experiences between health registers is recommended to enable research and health registers that support Indigenous self-determination and health equity.

Keywords: Indigenous health, Health equity, Health register, KAUPAPA Māori, Ascertainment, Data quality

*Correspondence: karen.wright@auckland.ac.nz

1 Faculty of Medical and Health Sciences, Te Kupenga Hauora Māori, University of Auckland, Auckland, New Zealand

Full list of author information is available at the end of the article

© The Author(s) 2022. Open Access This article is licensed under a Creative Commons Attribution 4.0 International License, which permits use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if changes were made. The images or other third party material in this article are included in the article’s Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article’s Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit http://creativecommons.org/licenses/by/4.0/. The Creative Commons Public Domain Dedication waiver (http://creativecommons.org/publicdomain/zero/1.0/) applies to the data made available in this article, unless otherwise stated in a credit line to the data.
Background
Significant health inequities in life expectancy at birth, mortality, and morbidity exist for Indigenous peoples in Aotearoa New Zealand (NZ) and many other Indigenous populations around the world [1]. Despite these pervasive and persisting inequities, health data related to Indigenous peoples are often inconsistent, irrelevant and of poor quality [2]. Health registers, standardised datasets relevant to a health condition (e.g., cerebral palsy, cancer, rheumatic fever), collect demographic and clinical information from registered participants. As such, they differ from administrative datasets and play an important role in answering specific health questions and monitoring distribution of disease and quality of care [3, 4]. However, poor ascertainment and data quality limit potential benefit to Indigenous health and equity.

Health inequities, differences in health that are unnecessary, avoidable, unfair and unjust [5], are complex and multifactorial. Social and economic policies act as structural drivers, shaping access to the conditions of daily living [6] and, therefore, creating stratification and social class divisions. Ethnicity is one such social status category, created by socio-political environments and racism [7, 8]. Ethnicity as a biological determinant of health has been rejected [8] and ethnic inequities are theorised to be produced by three main pathways: (i) differential access to social determinants of health, (ii) differential access to health care, and (iii) differences in quality of care received [9]. Williams & Mohammed (2013) describe how pathways to inequities are driven by basic determinants including biology, geographic origins, societal institutions, and importantly, by racism and discrimination.

Racism, a form of oppression based on beliefs, attitudes and behaviours concerning differences between groups defined by ethnicity [11] operates at multiple levels. Institutional racism is defined as “differential access to the goods, services, and opportunities of society by race” [7] and, being the most fundamental level, is a basic determinant of ethnic inequities. For Indigenous peoples, colonisation and colonial systems act as the underlying driver of pathways to inequities, creating power structures, policies and attitudes that advantage non-Indigenous peoples and disadvantage Indigenous peoples [12]. Health organizations have an obligation to decolonise systems and services to contribute towards achieving health equity.

The New Zealand Cerebral Palsy Register has partnered with researchers from Te Kupenga Hauora Māori, University of Auckland to support Māori health equity centred research. The aims of this study were to identify commonly perceived barriers for the ascertainment of Indigenous peoples on health registers, and to collate strategies identified and used by health registers for supporting comprehensive ascertainment and the achievement of high-quality data for Indigenous peoples on their registers. Māori are the Indigenous people of Aotearoa NZ and a Kaupapa Māori theoretical framework was utilised to guide this work. Kaupapa Māori is a culturally defined and determined approach, supporting critical, transformational, and empowering research that is ‘by’, ‘with’ and ‘for’ Māori [13–15]. The principal investigator is Māori; co-investigators are Shona and non-Māori non-Indigenous.

Methods
An adapted version of a Kaupapa Māori narrative review framework, Ngā Poutama Whetū, provided the framework for both a systematic and critical Indigenous perspective [16]. Ngā Poutama Whetū, translated to ‘stairway to the stars’, examines power relations and privileges Māori perspectives in order to “counter the privileged mono-cultural voice within academic literature” [16]. Methods are described below under the following headings: Kaupapa, Tino rangatiratanga, Kia piki i ngā raruraru o te kainga, Ako, Taonga tuku iho, Whānau, and Kaupapa.

Kaupapa: collective aims and aspirations for Māori
The Kaupapa stage identifies the study parameters, which, for this study focused on two aspects of health registers relevant to Indigenous health and equity: (i) ascertainment (i.e., the process of finding and recruiting people on to a register) and (ii) data quality. For the purpose of this study, ‘data quality’ refers to accuracy, completeness, reliability, relevance, and timeliness – an adaptation of the six dimensions of data quality described by Kerr, Norris & Stockdale [17]. Indigenous people are characterised by the United Nations Declaration on the Rights of Indigenous Peoples (UNDIRP) “working definition”, recognising that there is no internationally agreed upon definition of Indigenous peoples [18].

Tino rangatiratanga: self-determination
The autonomy of researchers is identified in this stage and demonstrated throughout the study methods. The research team determined the databases, search terms, and inclusion and exclusion criteria as relevant to the review’s Kaupapa and is outlined below.

Kia piki ake i ngā raruraru o te kainga: socioeconomic mediation
This stage identifies whose and what knowledge counts as valid and legitimate. An electronic research database search was completed by one author on 2 February 2021 for original publications (including editorials and opinion pieces) within the following databases: Ovid MEDLINE,
Scopus Elsevier, EMBASE, and PubMed. Acknowledging that specificity would be reduced, the search terms ‘Indigenous’ and ‘register’ along with related terms specific to each database (i.e., Aborigine, American Indian, First Nation, Inuit, Māori, Native American, Sami, Torres Strait Islanders) were used to conduct a wide search of potential publications but was refined to also include ‘ascertainment’ and ‘data quality’ for Ovid MEDLINE to narrow the number of articles returned from \( n = 4,479 \).

**Ako: culturally preferred pedagogies**

Ako identifies alignment of research ‘by’, ‘with’, and ‘for’ Māori. In this review, the research team recognised that research ‘by’ and ‘with’ Māori and Indigenous peoples was likely to be limited in this research domain. As such, findings that are ‘for’ Indigenous peoples were included and the involvement of Indigenous peoples in research included as a data variable. Data were extracted using the eight domains (governance, prioritization, relationships, methodologies, participation, capacity, analysis and interpretation, and dissemination) of the CONSIDER (consolidated criteria for strengthening reporting of health research involving Indigenous peoples) checklist described by Huria et al. [19], and presented in Table 1.

To ensure benefit, data that were deficit framing of Māori and Indigenous peoples or culture was excluded from analysis. Deficit framing focuses on Indigenous peoples as the problem [20] and identifies internal deficiencies, such as ability, motivation and behaviour, as cause of disparities [21]. Five pieces of data attributed inequitable health and health care access outcomes to the values and behaviour of Indigenous individuals and communities and were excluded from analysis.

**Taonga tuku iho: treasures to pass on**

The *Taonga tuku iho* stage included the two-step appraisal and evaluation of included articles with Kaupapa-aligned inclusion and exclusion criteria. Inclusion criteria included focusing on a health register, Indigenous population(s) identified, and either ascertainment or data quality strategies described. Theses and dissertations were excluded, in addition to data that were deficit framing, as previously described.

Title and abstract screening were completed independently by two reviewers (RT and SW) with conflicts resolved by the research team. All full text articles were then read in full by two researchers (RT and either SW or KW) for suitability for inclusion in alignment with the research aims and the set inclusion/exclusion criteria.

**Whānau: extended family structure**

Whānau represents the analytical stage of the review. Data were extracted under six predetermined variables: description of register, Indigenous population(s), Indigenous involvement in research, barriers to ascertainment, ascertainment strategies, and strategies supporting data quality. Consistent with thematic analysis as described by Braun & Clarke [22], data were coded (whānau—family), inter-relatedness identified (Hapū – sub-tribe), and categorised into themes (Iwi—tribe).

**Kaupapa: collective aims and aspirations for Māori**

Wide dissemination supports the translation of findings into meaningful change and benefit for Indigenous peoples. The final stage of the review includes reconnecting with the Kaupapa and dissemination of findings through publication, and presentation and reporting to health register stakeholders. This study was reported in accordance with the CONSIDER statement, used to strengthen the reporting of health research involving Indigenous peoples [19].

**Results**

**Study characteristics**

A total of 1,057 records were initially identified, with 905 (all in English) being screened for eligibility after removal of duplicates, and 58 articles included for full text review (Fig. 1). Seventeen articles were finally included in this review, spanning publication between 1992 and 2020. Of the 17 studies included, the majority were based in North America \( (n = 12) \) followed by Aotearoa NZ \( (n = 3) \) and Australia \( (n = 1) \). One article included global Indigenous populations [23]. Full study characteristics are outline in Table 2.

Aspects of at least one of four CONSIDER checklist domains were identified in each of the included articles. All articles identified how research aims emerged, therefore fulfilling the prioritization domain. Research aims emerged from community-based organizations [24] and empiric evidence [23, 25, 26, 28–39]. However, the inclusion of Indigenous stakeholders in the prioritization process was not identified. The relationship domain was identified in 10 articles and included authors from Indigenous health services [24, 26, 27], approval from Indigenous organizations or boards specifically identified to have Indigenous members [26, 27, 31, 32, 37], tribal access to local level data [34], Indigenous team members [35], involvement of Indigenous research units [36–38], and Indigenous advisory groups [37]. Governance was identified in three articles, specifically partnership with Indigenous health organizations [32, 34, 35]. Finally, participation was identified in three articles in terms of resource demands placed on Indigenous peoples. This included involvement of personnel in the research process [31, 32] and training [27], and grant support from Indigenous health organisations [32, 34].
Table 1  CONSIDER statement checklist of items to include when reporting health research involving Indigenous Peoples [19]

| Item Checklist item | Description |
|---------------------|-------------|
| Governance           | Describe partnership agreements between the research institution and Indigenous-governing organization for the research, (e.g., Informal agreements through to MOU (Memorandum of Understanding) or MOA (Memorandum of Agreement)) |
|                      | Describe accountability and review mechanisms within the partnership agreement that addresses harm minimization |
|                      | Specify how the research partnership agreement includes protection of Indigenous intellectual property and knowledge arising from the research, including financial and intellectual benefits generated (e.g., development of traditional medicines for commercial purposes or supporting the Indigenous community to develop commercialization proposals generated from the research) |
| Prioritization       | Explain how the research aims emerged from priorities identified by either Indigenous stakeholders, governing bodies, funders, non-government organization(s), stakeholders, consumers, and empirical evidence |
| Relationships (Indigenous stakeholders/participants and research team) | Specify measures that adhere and honor Indigenous ethical guidelines, processes, and approvals for all relevant Indigenous stakeholders, recognizing that multiple Indigenous partners may be involved, e.g., Indigenous ethics committee approval, regional/national ethics approval processes |
|                      | Report how Indigenous stakeholders were involved in the research processes (i.e., research design, funding, implementation, analysis, dissemination/recruitment) |
| Relationships (Indigenous stakeholders/participants and research team) | Describe the expertise of the research team in Indigenous health and research |
| Methodologies         | Describe the methodological approach of the research including a rationale of methods used and implication for Indigenous stakeholders, e.g., privacy and confidentiality (individual and collective) |
|                      | Describe how the research methodology incorporated consideration of the physical, social, economic and cultural environment of the participants and prospective participants. (e.g., impacts of colonization, racism, and social justice). As well as Indigenous worldviews |
| Participation         | Specify how individual and collective consent was sought to conduct future analysis on collected samples and data (e.g., additional secondary analyses; third-parties accessing samples (genetic, tissue, blood) for further analyses) |
|                      | Described how the resource demands (current and future) placed on Indigenous participants and communities involved in the research were identified and agreed upon including any resourcing for participation, knowledge, and expertise |
|                      | Specify how biological tissue and other samples including data were stored, explaining the processes of removal from traditional lands, if done, and of disposal |
| Capacity              | Explain how the research supported the development and maintenance of Indigenous research capacity (e.g., specific funding of Indigenous researchers) |
|                      | Discuss how the research team undertook professional development opportunities to develop the capacity to partner with Indigenous stakeholders? |
| Analysis and interpretation | Specify how the research analysis and reporting supported critical inquiry and a strength-based approach that was inclusive of Indigenous values |
| Dissemination         | Describe the dissemination of the research findings to relevant Indigenous governing bodies and peoples |
|                      | Discuss the process for knowledge translation and implementation to support Indigenous advancement (e.g., research capacity, policy, investment) |

Of the 17 articles, 13 included barriers to ascertainment [23, 24, 27–33, 35, 36, 38, 39]; strategies to support ascertainment and data quality were identified in six [23, 26, 29, 34, 35, 37] and 16 articles respectively [23–28, 30–39]. Both barriers and strategies to ascertainment were identified in three studies [23, 29, 35], two of which also identified data quality strategies [23, 35]. Details of the barriers and strategies are expanded below.

**Barriers to ascertainment**

Four overarching themes (iwi) were identified as barriers to ascertainment of Indigenous peoples on health
registers: ethnicity data collection and quality, systems and structures, health services / health professionals, and perceptions of individual and community barriers (summarised in Table 3).

1. Ethnicity data collection and quality

Of the 13 articles [23, 24, 27–33, 35, 36, 38, 39] where barriers to the ascertainment of Indigenous peoples to health registers were identified, ethnicity data collection and quality was identified as a barrier in most (n = 9). Incomplete data on Indigenous status was identified as a barrier in three articles [23, 33, 38], resulting from failure to collect multiple ethnicities, variable collection of ethnicity or Indigenous status, and poor-quality ethnicity data from contributing data sources (i.e., laboratory data, administrative datasets). Inconsistent data was identified as a barrier in three articles [24, 30, 39], resulting from non-systematic ethnicity collection processes. Inaccurate data was recognised as a barrier in five articles [23, 27, 28, 32, 33], and resulted in misclassification of ethnicity through use of other data sources with poor ethnicity data quality, and inappropriate ethnicity data collection practices such as blood quantum, using name, religion, or geographical location as a proxy for ethnicity.
Table 2  Characteristics of included articles, ordered chronologically. Region/country, name of registry, Indigenous population(s), CONSIDER domain(s) identified for reporting of research involving Indigenous peoples, whether or not the study included / identified/ discussed barriers and/or strategies to ascertainment, and/or strategies supporting data quality are indicated

| Author, year | Region/country | Name of registry | Indigenous Population(s) | CONSIDER domain(s) | Ascertainment strategies | Data quality strategies |
|-------------|----------------|------------------|--------------------------|--------------------|--------------------------|------------------------|
| Lieb et al., 1992 [24] | Los Angeles, USA | Los Angeles County AIDS Surveillance Registry | Indigenous American and Indigenous Alaskan | Prioritization, relationships | Yes | Yes |
| Wiggins, 1996 [25] | USA | Cancer registries (non-specific) | Indigenous American | Prioritization | Yes | |
| Dannenbaum et al., 1999 [26] | James Bay, Canada | Cree Board of Health and Social Services of James Bay Diabetes Registry | Cree of Eeyou Istchee | Prioritization, relationships | Yes | Yes |
| Beeker et al., 2002 [27] | Portland Area, USA | Oregon State Cancer Registry, the Washington State Cancer Registry, and the Cancer Data Registry of Idaho | Indigenous American and Indigenous Alaskan | Not identified | Yes | Yes |
| Espey et al., 2008 [28] | USA | 49 state cancer registries | Indigenous American and Indigenous Alaskan | Prioritization | Yes | Yes |
| Perdue et al., 2008 [29] | Indian Health Service regions (Alaska, Pacific Coast, Northern Plains, Southern Plains, Southwest, and East), USA | National Program of Cancer Registries | Indigenous American and Indigenous Alaskan | Prioritization | Yes | Yes |
| Shaw et al., 2009 [30] | New Zealand | Cancer Registry | Māori | Prioritization | Yes | Yes |
| Johnson et al., 2009 [31] | Detroit, USA | National Program of Cancer Registries | Indigenous American and Indigenous Alaskan | Prioritization, relationships, participation | Yes | Yes |
| Hoopes et al., 2010 [32] | Washington State, USA | Northwest Tribal Registry, Washington State Cancer Registry | Indigenous American and Indigenous Alaskan | Governance, prioritization, relationships, participation | Yes | Yes |
| Zhang et al., 2011 [33] | Australia | Eight Australian cancer registries | Indigenous Australians | Prioritization | Yes | Yes |
| Hoopes et al., 2012 [34] | Portland IHS administrative area (Idaho, Oregon, and Washington), USA | Idaho, Oregon, Washington Cancer Registries | Indigenous American and Indigenous Alaskan | Governance, prioritization, relationships, participation | Yes | Yes |
| Creswell et al., 2013 [35] | Wisconsin, USA | State cancer registry | Indigenous American and Indigenous Alaskan | Governance, prioritization, relationships | Yes | Yes |
| Page et al., 2017 [36] | New Zealand | Australia and New Zealand Dialysis and Transplant Registry | Māori | Prioritization, relationships | Yes | Yes |
| Boden-Albala et al., 2017 [37] | Alaska | Alaska Native Stroke Registry | Indigenous Alaskan | Governance, prioritization, relationships | Yes | Yes |
| Scott et al., 2018 [38] | New Zealand | Waikato Trauma Registry | Māori | Prioritization, relationships | Yes | Yes |
| Layne et al., 2019 [39] | USA | State cancer registries | Indigenous American and Indigenous Alaskan | Prioritization | Yes | Yes |
| Diaz et al., 2020 [40] | Global | International Association for Cancer Registries | Global Indigenous populations | Prioritization | Yes | Yes |
2. Systems and structures
Five articles describe barriers at a ‘systems and structures’ level [23, 29, 31, 32, 36], including i) limitations in ethnicity collection systems (i.e., non-systematic and inconsistent processes, information systems unable to record all ethnicity responses, inconsistent with standard ethnicity data protocols) [23, 31, 32, 36] and data information systems [23] (i.e., ability to record and transfer information), ii) a lack of other standard protocols [29], and iii) legislation preventing collection of Indigenous status (related to historical and current socio-political recognition of Indigenous peoples) [23].

3. Health services / health professionals
Three articles discussed barriers relating to health services and health professionals (both clinical and non-clinical staff, i.e., professional staff) [23, 29, 35], including: staff capability (i.e., ability to collect Indigenous status [23] and insufficient training [35]), staff capacity [23, 29, 35], limited availability of services [29], insufficient funding [29], and the perception that collecting Indigenous status was not important [23].

4. Perceptions of individual and community-level barriers
From the perspective of authors of included articles, individual and community level barriers were identified as potential barriers in three articles [23, 24, 29] including discrimination by ethnicity [23, 24] and the accessibility of services [29].

### Ascertainment strategies

Three overarching themes (iwi) were identified from strategies supporting ascertainment of Indigenous peoples on health registers: collaboration, finding people, and recruitment processes (Summarised in Table 2).

1. Collaboration

Four articles included strategies involving working with other groups including Indigenous leaders [26], Indigenous communities [29, 34] (i.e., education forums, support groups) and existing health systems [37] (i.e., integrating registries into existing health systems).

2. Finding people

Four articles described strategies related to ‘finding people’ to enrol in a health register including raising community awareness through media and Indigenous leaders [26], recruiting from Indigenous health providers [34, 35], and legislation mandating collection of Indigenous status [23].

3. Recruitment processes

Four articles described strategies around the registration process itself including staff training [23, 35], Indigenous language speaking staff [26], and making enrolment resources available [34].

### Strategies supporting data quality

Nearly all articles identified strategies to support data quality (n = 16) [23–28, 30–39], with the following four themes (Iwi) identified: collaboration, ethnicity data collection and quality, systems-level strategies, health service / health professional-level strategies, and adequate resource.
collection and quality, systems-level strategies, and health service / health professional-level strategies.

1. Collaboration

Strategies categorised as ‘collaboration’ included engaging with Indigenous health providers to foster reciprocal reporting relationships [35], and with Indigenous peoples in the development [25] and governance of registries [23], supporting appropriate and ethical collection and use of data. Collaboration with both tribal and urban Indigenous health services supported improved data quality [32], including through direct reporting from clinics to health registers [35]. Non-Indigenous health organisations [31, 32], other registers [25, 28, 34], and international strategic networks [23] were also recognised to support data quality. Data linkage was identified as a strategy to improving ethnicity data [31, 32], specifically using census data [30, 33], hospital data [33], Indigenous health service data [28, 39], and tribal enrolment data [23, 34]. Furthermore, collaboration between tribes, states, and academic institutions regarding data linkage was recognised as supporting both data quality and trusting relationships [31].

2. Ethnicity data collection and quality

Strategies were identified as supporting quality ethnicity data in seven articles [24, 28, 30, 32, 33, 36, 39] including standardised processes (i.e., using standard ethnicity protocols [24, 30, 33, 36] and uniform data collection tools [28], collecting Indigenous status on laboratory forms [33], recording ethnicity data source [33], auditing Indigenous status [33]), collecting self-reported ethnicity [32, 36, 39], and validating ethnicity [24, 39].

3. Systems-level strategies

System-level strategies were described in just less than half of included articles (n=8) [23, 25, 26, 30, 32, 37–39]. Information systems supported quality data and were recognised as requiring appropriate safeguards [26], being easy to use [25, 26], and integrated to enable data linkage [23]. Standard protocols [26, 38, 39] and processes [38], such as multiple data collection points [37] and effective point of care data collection [23], were identified to support quality data collection. System-level strategies were inclusive of reporting, specifically regular reporting [26, 30, 38], regular evaluation [26], the reporting of Indigenous data [23], and reporting through publications and annual auditing [26]. Related to standard protocols was registry standards [32] and a formal quality assurance plan [30].

4. Health service / health professional-level strategies

Health service-level strategies were predominantly related to adequate funding and financial commitment [23, 25, 26] but also included responsive and tailored protocols to address regional variation in barriers [23]. Health professional-level strategies focused on staff capability, particularly staff training [38] around ethnicity [27, 30], and capturing relevant information [23]. Skilled staff supported high quality data [25]. Staff feedback was described as an approach to identify and incorporate improvement recommendations [26], with representation across the data system [23].

Discussion

This study provides a comprehensive overview of commonly perceived barriers and proposed strategies supporting ascertainment and high-quality data of Indigenous peoples on health registers. Multiple interventions at health professional, service and system levels have been identified and may provide guidance for health registers seeking to prioritize health equity for Indigenous peoples.

Of note, poor ethnicity data quality was identified as a significant barrier to ascertainment and high-quality ethnicity data central to the achievement of high-quality data for Indigenous peoples. The existence of poor-quality ethnicity data in health registers is, unfortunately, unsurprising, with Indigenous population data stated to often be inconsistent, irrelevant, of poor quality, produced in an environment of mistrust, and controlled by those external to Indigenous nations [2]. Subsequently, data often undercounts Indigenous peoples, does not accurately reflect Indigenous realities, and does not inform Indigenous peoples’ needs [2]. For health registers, these critical data issues limit the potential to identify, prioritize, and address Indigenous health and health service-related inequities.

Despite the breadth of barriers identified for ascertainment, there are noticeable gaps in the barriers and pathways to inequities when a socioecological framework, such as that proposed by Williams [8] is applied. Barriers identified include some basic causes (e.g., legislation) and proximal pathways (e.g., discrimination, access to health services, and health service orientation). However, racism, specifically institutional racism, and broader political and economic institutions are noticeably absent.

Findings from this review indicate a disconnect between perceived barriers and solutions. Strategies to support ascertainment and data quality are predominantly orientated towards individual responses and proximal pathways, thus focusing on access to
services, general processes/systems, and individual or community responsibility. Although important, such strategies are unlikely to eliminate ethnic inequities if fundamental causes, such as institutional racism, are left unaddressed [10, 40].

The reporting of the CONSIDER checklist [19] for health research involving Indigenous peoples provides potential insight into the degree of collaboration between health registers and Indigenous peoples and organizations. Few studies included within this review overtly described governance and partnership agreements with Indigenous organizations, suggesting either absence in existence or in reporting. An absence of Indigenous leadership or Indigenous participation in Indigenous health research is common, raising significant concerns regarding the appropriateness of approach, methods, interpretation and reporting, and prioritizing of health research itself [41]. Indigenous methodologies, strength-based analysis and interpretation, activities to support Indigenous research capacity, and dissemination to Indigenous governing bodies were also not explicitly identified within the studies included within this review. Favourable research impact and benefit is more likely when issues are relevant to Indigenous peoples, Indigenous peoples are participants, Indigenous knowledges and perspectives are incorporated, findings meaningful, and potential end-users engaged from the outset [42]. Importantly, benefit from Indigenous research must be meaningful and valued by diverse Indigenous communities [43].

In contrast, collaboration with Indigenous communities and organizations in the development and governance of health registers was identified as a potential strategy supporting Indigenous health equity. This finding is consistent with Indigenous data sovereignty scholarship articulating both the right and need for Indigenous knowledges and approaches to be integrated into policy and practice [44]. Indigenous data sovereignty is defined as the right of a nation to “... control the collection, ownership, and application of its own data” (US Indigenous Data Sovereignty Network) [45]. Importantly, it is derived from inherent rights of Indigenous peoples to govern their peoples, lands, and resources, and is inclusive of data from and about Indigenous peoples, resources and environments [44]. Furthermore, it provides the opportunity to enhance community trust in data and improve data availability, quality, and relevance to support population health gain [2, 46].

Through colonial practices, including the suppression of Indigenous knowledge systems and exclusion of Indigenous peoples from data sovereignty, Indigenous peoples have been divorced from data infrastructure and capacity into a state of “data dependency” [46]. Health registers that predominantly reflect non-Indigenous ways of knowing and doing may, although potentially unintentional, fail to identify and adequately address issues relevant to Indigenous peoples. Therefore, to support high quality Indigenous data and realise Indigenous data sovereignty in health registers, systematic and structural change is required. Three main themes supporting successful Indigenous data sovereignty have previously been identified: (i) strategic responses to data challenges; (ii) engaging with community to educate leaders and citizens about data; and (iii) using data to inform policy decisions and resource allocation to strengthen Indigenous self-determination [2]. Such transformation requires transfer of power and control [47], and both organizational and resource commitment to Indigenous health gain and equity.

This study has several strengths. A Kaupapa Māori approach and use of the Ngā Poutama Whetū framework supported a robust narrative review process that centred Māori worldviews and Indigenous health gain. The systematic approach and deliberate exclusion of deficit framing support findings that are of benefit to Indigenous health and equity. Inevitably, there are also some limitations to identify and discuss. Outcomes of this narrative review are limited to research published in English and those available and identified within the select databases. Of note, most research is in North America and, therefore, the generalisability of findings outside of North America should be considered. Few articles overtly aimed to identify barriers and strategies relating to ascertainment and data quality of Indigenous peoples on health registers. As such, an inclusive approach was used within our screening process (i.e., research articles continued through to a full text review even though no clear mention of barriers or strategies were made). Even with this inclusive and systematic approach, it is possible that further eligible studies are available that were not included within this review. In addition, as Indigenous involvement in research was limited, barriers (real or perceived) and strategies identified in this review may not reflect Indigenous peoples’ perspectives and preferences. Finally, assessing the ‘success’ or effectiveness of strategies was outside the scope of this study. There is significant opportunity for future research, led by or conducted in partnership with Indigenous researchers and organizations, to review, audit and evaluate targeted approaches to the ascertainment of Indigenous peoples and achievement of high data quality in health registers.

Conclusion
Health registers are central to the accurate monitoring of disease prevalence and outcomes. Although there is a considerable body of peer reviewed published evidence
pertaining to ascertainment and data quality of health registers, there is more limited evidence to identify strategies specific to Indigenous peoples. From the literature included in this systematic narrative review, it is apparent that multiple interventions at many levels (system, service, and community) are used to ascertain Indigenous peoples on health registers and ensure high quality data. However, when viewed through a critical structural determinants lens, there are visible gaps in the breadth of strategies, particularly the inclusion of Indigenous peoples in health register and research governance, and actions to identify and address institutional racism. These gaps perpetuate the collection of inconsistent, incomplete, and poor-quality data for Indigenous peoples in health registers, preventing the achievement of health equity and exemplifying inaction in the face of need. Recognising that, though unique barriers and strategies may exist for different Indigenous populations across the world, we propose that potential commonalities present an opportunity for Indigenous led research and a sharing of knowledge and experiences between health registers. Sharing, networking, and meaningful collaboration with Indigenous communities and organizations supports health registers to be structured and operate to achieve Indigenous health equity.

Abbreviations
IP: Indigenous people; NZ: Aotearoa New Zealand; USA: United States of America.

Acknowledgements
Not applicable.

Authors’ contributions
KW, SW, NSS, AS and AM contributed to the project design and were involved in securing funding for this work. KW, SW and RT refined the study protocol, completed the search and screening of data and aided the data analysis, interpretation, and the drafting of the manuscript. RT and KW undertook the data extraction. All authors contributed to the critical revision of the manuscript and approval of the article.

Funding
This research was supported by a New Zealand Health Research Council Activation Grant (20/1139) “Cerebral palsy and Māori health inequities in New Zealand”. SW was partially funded by the Australasian Cerebral Palsy Clinical Trials Network, a Centre for Research Excellence funded by the National Health Medical Research Council (Australia).

Availability of data and materials
The datasets analysed during the current study are available from the Medical Research Council (Australia). Availability of data and materials

Competing interests
The authors declare that they have no competing interests.

Author details
1 Faculty of Medical and Health Sciences, Te Kupenga Hauora Māori, University of Auckland, Auckland, New Zealand. 2 Department of Surgery, University of Auckland, Auckland, New Zealand. 3 New Zealand Cerebral Palsy Register, Starship Child Health, Auckland, New Zealand. 4 Liggins Institute, University of Auckland, Auckland, New Zealand. 5 Curtin School of Allied Health, Curtin University, Perth, Australia.

Received: 30 August 2021   Accepted: 22 February 2022
Published online: 12 March 2022

References
1. Anderson I, Robson B, Connolly M, Al-Yaman F, Bjertness E, King A, et al. Indigenous and tribal peoples’ health (Lowitja Institute Global Collaboration): a population study. Lancet. 2016;388(10040):131–57.
2. Raine SC, Schultz JL, Briggs E, Riggs P, Palmenteer-Holder NL. Data as a Strategic Resource: Self-determination, Governance, and the Data Challenge for Indigenous Nations in the United States. Int Indig Policy J. 2017;8:1–29.
3. Page E, Doyle K, Jorm L, Banks E, Hsu M-P, Nekoff L, et al. A Versatile Big Data Health System for Australia: Driving Improvements in Cardiovascular Health. Heart Lung Circ. 2021;30(10):1467–76.
4. Aliksson-Schmidt AI, Amer M, Westborn L, Krumlinde-Sundholm L, Nordmark E, Rodby-Bousquet E, et al. A combined surveillance program and quality register improves management of childhood disability. Disabil Rehabil. 2017;39(8):830–6.
5. Whitehead M. The concepts and principles of equity and health. Int J Health Serv. 1992;22(3):429–45.
6. Marmot M, Friel S, Bell R, Houweling TAJ, Taylor S. Closing the gap in a generation: health equity through action on the social determinants of health. Lancet. 2008;372(9650):1661–9.
7. Jones CP. Levels of racism: a theoretic framework and a gardener’s tale. Am J Public Health. 2000;90(8):1212–5.
8. Williams DR. Race and health: basic questions, emerging directions. Ann Epidemiol. 1997;7(5):322–33.
9. Jones CP. Invited commentary: “race,” racism, and the practice of epidemiology. Am J Epidemiol. 2001;154(4):299–304.
10. Williams DR, Mohammed SA. Racism and Health I: Pathways and Scientific Evidence. Am Behav Sci. 2013;57(8):1152–73.
11. Paradies YC. Defining, conceptualizing and characterizing racism in health research. Crit Public Health. 2006;16(2):143–57.
12. Reid P, Cormack D, Paine SJ. Colonial histories, racism and health: The experience of Māori and Indigenous peoples. Public Health. 2019;172:119–24.
13. Pihama L. Kaupapa Māori theory: transforming theory in Aotearoa. He Pukenga Korero. 2012;6(2):5–14.
14. Smith LT. Decolonizing methodologies. Second edition. London: Zed Books Ltd; Chapter 10. Towards developing Indigenous methodologies: Kaupapa Māori research; 2012. p. 185–97.
15. Smith G, Hoskins TK, Jones A. Interview: Kaupapa Māori: the dangers of domestication. N Z J Educ Stud. 2012;47(2):10.
16. Hapeta J, Palmer F, Kuurota Y, Hermansson G. A Kaupapa Māori, culturally progressive, narrative review of literature on sport, ethnicity and inclusion. Kōtuitui: N Z J Soc Sci Online. 2019;14(2):209–29.
17. Kerr K, Norris T, Stockdale R. Data quality information and decision making: a healthcare case study. Toowoomba: Australasian Conference on Information Systems; 2007. p. 5–7 December 2007.
18. United Nations. United Nations Declaration on the Rights of Indigenous Peoples. 2007.
19. Huna T, Palmer SC, Pitama S, Beckert L, Lacey C, Ewen S, et al. Consolidated criteria for strengthening reporting of health research involving indigenous peoples: the CONSIDER statement. BMC Med Res Methodol. 2019;19(1):173.
20. Reid P, Robson B. Understanding health inequities. In: Robson B, Harris R, editors. Hauora Māori Standards of Health IV: A study of the years 2000–2005. Wellington: Te Ropu Rangahau Hauora a Eru Pomare, 2007.
21. Valencia RR, Solórzano DG. The evolution of deficit thinking: Educational thought and practice. Oxon: Routledge Falmer; 1997. Chapter 6, Contemporary deficit thinking, p. 160–210.

22. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77–101.

23. Diaz A, Soejmomataram I, Moore S, Whop LJ, Bray F, Hoberg H, et al. Collection and Reporting of Indigenous Status Information in Cancer Registries Around the World. JCO Glob Oncol. 2020;6:133–42.

24. Lieb LE, Conway GA, Hedderman M, Yao J, Kerndt PR. Racial misclassification of American Indians with AIDS in Los Angeles County. J Acquir Immune Defic Syndr (1988). 1992(5):1137–41.

25. Wiggins CL. Issues to consider when choosing a computer program to assist Native American collection of accurate cancer data. Cancer. 1996;78(7 Suppl):1569–73.

26. Dannenbaum D, Verronneau M, Torrie J, Smeye H, Robinson E, Dumont C, et al. Comprehensive computerized diabetes registry serving the Cree of Eeyou Ischee (eastern James Bay). Can Fam Physician. 1999;45:364–70.

27. Becker TM, Bellles J, Lapidus I, Campo J, Johnson CJ, Shipley D, et al. Improving cancer incidence estimates for American Indians and Alaska Natives in the Pacific Northwest. Am J Public Health. 2002;92(9):1469–71.

28. Espey DK, Wiggins CL, Jim MA, Miller BA, Johnson CJ, Becker TM. Methods for improving cancer surveillance data in American Indian and Alaska Native populations. Cancer. 2008;113(S Suppl):120–30.

29. Perdue DG, Perkins C, Jackson-Thompson J, Coughlin SS, Ahmed F, Havercamp DS, et al. Regional differences in colorectal cancer incidence, stage, and subsite among American Indians and Alaska Natives, 1999–2004. Cancer. 2008;113(S Suppl):1179–90.

30. Shaw C, Atkinson J, Blakely T. (Mis)classification of ethnicity on the New Zealand Health Survey: 1981–2006. NZ Med J. 2009;122(1294):10–22.

31. Johnson JC, Soliman AS, Tadgerson D, Copeland GE, Seefeld DA, Pingatore NL, et al. Tribal linkage and race data quality for American Indians in a state cancer registry. Am J Prev Med. 2009;36(6):549–54.

32. Hoopes MJ, Tayarri M, Weiser TM, Brucker R, Becker TM. Including self-reported race to improve cancer surveillance data for American Indians and Alaska Natives in Washington state. J Regist. 2010;37(2):43–8.

33. Zhang X, Condon JR, Rumbold AR, Cunningham J, Roden DM. Estimating cancer incidence in Indigenous Australians. Aust N Z J Public Health. 2011;35(5):477–85.

34. Hoopes MJ, Petersen P, Vinson E, Lopez K. Regional differences and tribal use of American Indian/Alaska Native cancer data in the Pacific Northwest. J Cancer Educ. 2012;27(1 Suppl):S73–9.

35. Creswell PD, Strickland R, Stephenson L, Pierce-Hudson K, Matloub J, Waukau J, et al. Look local: the value of cancer surveillance and reporting by American Indian clinics. Prev Chronic Dis. 2013;10:E197.

36. Page M, Wyeth EH, Samaranyakya A, McNoe B, Walker R, Schollum J, et al. Accuracy of ethnicity data recorded in hospital-based patient clinical records and the Australia and New Zealand Dialysis and Transplant Registry. N Z Med J. 2017;130(1454):65–71.

37. Boden-Alba R, Allen J, Roberts ET, Bulkow L, Trimbile A. Ascertainment of Alaska Native Stroke Incidence, 2005–2009: Lessons for Assessing the Global Burden of Stroke. J Stroke Cerebrovasc Dis. 2017;26(9):2019–26.

38. Scott N, Clark H, Kool B, Ameratunga S, Christey G, Cormack D. Audit of ethnicity data in the Waikato Hospital Patient Management System and Trauma Registry: pilot of the Hospital Ethnicity Data Audit Toolkit. N Z Med J. 2018;131(1488):21–9.

39. Layne TM, Ferrucci U, Jones BA, Smith T, Gonsalves L, Cartmel B. Concordance of cancer registry and self-reported race, ethnicity, and cancer type: a report from the American Cancer Society’s studies of cancer survivors. Cancer Causes Control. 2019;30(1):121–9.

40. Reid P. Good governance: The case of equity. In: Tawhai V, Gray-Sharp K, editors. Always Speaking The Treaty of Waitangi and Public Policy. Wellington: Huia Publishers; 2011. p. 35–48.

41. Kinchin I, McCallman J, Bainbridge R, Tsey K, Lui F. Does Indigenous health research have impact? A systematic review of reviews. Int J Equity Health. 2017;16(1):52.

42. Silbun R, Mi, White V, Hanley F, Marsh G. Evaluation of the cooperative research centre for aboriginal health. Final report. Melbourne: Lowitja Institute; 2010. p. 261.

43. Bainbridge R, Tsey K, McCallman J, Kinchin I, Saunders V, Watkin Lui F, et al. No one's discussing the elephant in the room: contemplating questions of research impact and benefit in Aboriginal and Torres Strait Islander Australian health research. BMC Public Health. 2015;15(1):696.

44. Carroll SR, Garba I, Figueroa-Rodriguez C, Holbrook J, Lovett R, Mater-echera S, Parsons M, Rasmoka K, Rodrigue-Lonebear D, Rowe R, Sara R, Walker J, Anderson J, Hudson M. The CARE principles for Indigenous data governance. Data Science Journal. 2020;19:5–14.

45. Raine CS, Rodrigue-Lonebear D, Martinez A. Policy Brief (Version 2): Data Governance for Native Nation Rebuilding. Tucson: Native Nations Institute; 2017.

46. Carroll SR, Akee R, Chung P, Cormack D, Kukutai T, Lovett R, et al. Indigenous Peoples’ Data During COVID-19: From External to Internal. Front Sociol. 2021;6:617895.

47. Kukutai T, Taylor J. Indigenous data sovereignty: Toward an agenda. Canberra: ANU press; 2016. p. 320.

Publisher’s Note
Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.