Volume, scope, and consideration of ethical issues in Indigenous cognitive impairment and dementia research: A systematic scoping review of studies published between 2000-2020

Authors: Dr Jamie Bryant[1,2,3,*] Dr Megan Freund[1,2,3], Professor Nola Ries[4], Professor Gail Garvey[5], Ms Alexandra McGhie[1,2,3], Dr Alison Zucca[1,2,3], Ms Hanna Hoberg[5], A/Prof Megan Passey[6], Professor Rob Sanson-Fisher[1,2,3]

1. Health Behaviour Research Collaborative, School of Medicine and Public Health, Faculty of Health and Medicine, University of Newcastle, Callaghan, NSW, Australia
2. Priority Research Centre for Health Behaviour, University of Newcastle, Callaghan, NSW, Australia
3. Hunter Medical Research Institute, New Lambton Heights, NSW, Australia
4. Faculty of Law, University of Technology Sydney, Sydney, NSW, Australia
5. Wellbeing and Preventable Chronic Diseases Division, Menzies School of Health Research, Charles Darwin University, Causarina, Northern Territory, Australia
6. University Centre for Rural Health, University of Sydney, Lismore, NSW, Australia

*** Corresponding author**

Dr Jamie Bryant

Jamie.bryant@newcastle.edu.au

Health Behaviour Research Collaborative, University of Newcastle

University Drive, Callaghan, Newcastle NSW Australia 2308

ABSTRACT

INTRODUCTION

High quality research involving Indigenous people with cognitive impairment and dementia is critical for informing evidence-based policy and practice. We examined the volume, scope and ethical considerations of research related to dementia with Indigenous populations globally from January 2000 - December 2020.

METHODS

Studies were included if they were published in English from 2000 onwards and provided original data that focused on cognitive impairment or dementia in any Indigenous population.

RESULTS

The search yielded 10,976 papers of which, 69 met inclusion criteria. The overall number of papers increased over time. Studies were mostly conducted in Australia with Aboriginal and Torres Strait Islander people (n=28; 41%). Twenty-four papers directly involved Indigenous participants with cognitive impairment or dementia. Of these studies, ethics approval was commonly required from two or more committees (n=21, 88%). Ethical and legal governance frameworks were rarely discussed.

DISCUSSION

There is a clear need for further experimental studies examining cognitive impairment and dementia with Indigenous populations. Future research should consider the ethical aspects of involving Indigenous participants with cognitive impairment in research.

Keywords: dementia, indigenous, bibliometric

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1 INTRODUCTION

Dementia is a clinical syndrome that is characterised by the progressive deterioration of memory, thinking, reasoning, behaviour and communication from previous levels of functioning. [1] This deterioration results in functional disability, including compromised decision-making capacity. [1,2] In 2015, 47 million people globally were living with dementia and this number is projected to triple by 2050.[3]

Dementia is an emerging health concern for Indigenous populations globally. While reliable population-level data is limited, in Australia, the prevalence of dementia is estimated to be 2-3 times higher amongst Indigenous Australians compared to the wider non-Indigenous population.[4-7] Data from one province in Canada found that rates of dementia are increasing at a faster rate for First Nations people compared to non-First Nations people.[8] Indigenous people also develop dementia at a younger age,[4,9] compounding the health, social, and financial impacts of the disease. As Indigenous populations across many countries continue to rapidly increase,[10] the impacts of dementia experienced by these populations, their carers, and their families will also increase, bringing with it a need for culturally appropriate resources and support.

The World Health Organisation Global Action Plan on the Public Health Response to Dementia (2017–2025) explicitly sets a global target to double research on dementia between 2017 and 2025.[11] The establishment of this goal recognises that research is critical for informing evidence-based policy and the delivery of evidence-based healthcare. However, rapid increases in scientific output, currently estimated to double every nine years,[12] makes it difficult for researchers to keep up to date with evidence, identify new areas of research, summarise the methodologies used in prior studies, and add to what is known. Systematic literature reviews can help overcome these limitations by summarising a body of knowledge. Examining the volume of peer-reviewed research output generated over a defined period provides an indication of scientific productivity, research capacity and areas of research focus. In addition, examining the scope of peer-reviewed research including setting, design, and other features provides a way of examining key areas of research focus, areas of current knowledge, and current and emerging research gaps that can inform future research policy and prioritisation. Such knowledge therefore also provides a mechanism for improving the relevance and quality of research, and its impact on practice.

Informing evidence-based Indigenous health policy and the delivery of culturally appropriate evidence-based healthcare to Indigenous people with dementia also requires that Indigenous people have leadership of and involvement in driving research related to their needs.[13] Indigenous leadership has an important link with overall research impact and benefits to Indigenous peoples through prioritisation of acitivites that are meaningful, and represent the interests and cultural perspectives of Indigenous communities [13]. Indigenous led research and integration of research may lead to the development of regional, national, and global workforces, strategies, policies and procedures that support Indigenous people with dementia through an Indigenous lens.

A growing body of literature calls for greater inclusion of people with dementia in research and offers strategies to support ethically appropriate participation. [14]. However, there are several ethical and practical barriers to participation in research by people with dementia, including a lack of a gold ethical standard for recruitment and assessment of capacity to provide consent, concerns regarding potential risk, and the protection of individuals vulnerabilities and rights [15-17]. For Indigenous people with dementia, cultural factors including diverse attitudes and beliefs about the disease, and language barriers may further impede recruitment and participation in research[18]. High quality resesarch conducted with Indigenous people should be safe, respectful, responsible, high quality and of produce genuine benefit[19,20]. Indigenous representation in dementia research is key to the development of culturally appropriate and evidence-based best practice. In scoping the literature on

Indigenous dementia research, it is therefore important to consider the ethical aspects that may hinder involvement of Indigenous people with dementia.

Despite the higher prevalence and associated risk factors of dementia among Indigenous peoples, there is a paucity of research on dementia in Indigenous populations[21 22]. Although previous reviews have examined specific aspects of dementia and Indigenous people [22-24] to date, no comprehensive review of the amount and type of Indigenous dementia research conducted globally has been undertaken.

1.1 Aims

This systematic scoping review aims to examine the:

1. total volume of research conducted related to dementia with Indigenous populations globally from January 2000 - December 2020.
2. scope of research in terms of the: Indigenous populations included, Indigenous leadership and involvement in research, the focus of conducted research, and the study designs used.
3. ethical considerations identified in studies that involved direct participation by Indigenous people with cognitive impairment.

2 METHODS

2.1 Defining the aim and scope of the review

The idea for this review arose from a meeting of Aboriginal and non-Aboriginal researchers and clinicians working collaboratively on a National Health and Research Council funded grant to improve identification and treatment of cognitive impairment and dementia amongst Aboriginal Australians. Aims were directly informed by the lived experiences and collective knowledge of meeting attendees, and refined over time with co-author GG, a Kamilaroi woman from NSW with over 25 years of leadership and impact in Aboriginal health research, education, and capacity building. Study methodology and interpretation of results were discussed with the study Steering Group, which includes Aboriginal members.

2.2 Literature search

The electronic databases CINAHL, Embase, PsycINFO and PubMed were searched using a combination of Medical Subject Headings (MeSH) and keywords (see Additional File 1 for the full search strategy). Searches were limited to studies published between 1st January 2000 and 31st December 2020 to reflect the most contemporary research output, and studies conducted with humans. The reference lists of included studies and the reference lists of relevant review papers were also manually searched to identify any additional studies.

2.3 Inclusion and exclusion criteria

Studies were included if they were published in English from 2000 onwards and provided original data that focused on cognitive impairment or dementia in any Indigenous population. Studies were excluded if they had a purely basic science focus. Reviews, commentaries, theses, conference abstracts, protocol papers, and editorials were also excluded.

2.4 Data coding and extraction

Article screening and coding was conducted using the reference management system Rayyan. Following removal of duplicate citations, two reviewers (HH and JB) independently screened the titles and abstracts of all retrieved studies according to inclusion and exclusion criteria. Discrepancies were resolved through discussion. Two reviewers (HH and JB) then independently undertook full text review of the remaining studies according to inclusion and exclusion criteria, with discrepancies again resolved through discussion. Studies that met all criteria were retained for inclusion.

Two authors (either HH, JB or MF) independently undertook the extraction and synthesis of data. All authors then reviewed the combined data extraction. Any discrepancies between the authors were resolved through discussion, until consensus was reached. For each included study, the following information was extracted: study setting; study design (cross-sectional, qualitative, mixed methods, cohort, case -studies, experimental); the Indigenous group of focus; whether there was Indigenous involvement in guiding the research (e.g., formation of an Indigenous Advisory or Reference Group, partnership with Indigenous community organisations, involvement of Elders in guiding the research, Indigenous research team members or staff) study aims; details about participants (type, number, age, and gender); data collection and analysis and study findings. Broad area of research focus was extracted into the following six domains: (1) prevalence and incidence; (2) risk factors and correlates; (3) diagnosis, including screening; (4) treatment and management, including delivery of healthcare; (5) clinical course and outcomes of dementia; (6) living with dementia, inclusive of the experiences of persons with dementia, their caregivers, and families; and (7) awareness, knowledge, and understandings of dementia. For studies that involved direct participation by Indigenous people with dementia, information about the ethical aspects of the research was extracted, including details about: consent processes (whether individual or proxy consent was sought, how capacity to consent was determined); strategies to facilitate participation in study activities; relationships with Indigenous organisations and communities; ethical approval processes; and ethical and legal governance frameworks (whether the research was guided by specific ethics guidelines or legislation for Indigenous health research). As this review aimed to scope the amount of research conducted and the focus of research, the methodological quality of studies was not assessed.

3 RESULTS

3.1 Search results

An overview of the search results and study coding process is outlined in Figure 1 using the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA)[25] four-phase flow diagram. The initial search yielded 10,976 papers. After removing 5,959 duplicates, 5,017 papers were included in the title and abstract screen. A total of 162 studies were included in the full-text review, of which, 69 met inclusion criteria (see Table 1).

<<TABLE ONE ABOUT HERE>>

3.2 Volume of research over time

The number of publications increased over time, as illustrated in Figure 2. An average of 1.5 papers were published per year in the 10-year period between 2000-2010 (n=15), compared to the average of 5 papers published per year in the 11-year period between 2011-2020 (n=54). This difference was mainly due to the large number of papers published in 2019 (n=11) and 2020 (n=13) relative to other years.

<<FIGURE 1 ABOUT HERE>>

<<FIGURE 2 ABOUT HERE>>

3.3 Scope of research

3.3.1 Indigenous populations of focus

Studies were mostly conducted in Australia with Aboriginal and/or Torres Strait Islander people (n=28). [4-7,26-46] Twenty-one studies were conducted in the United States of America with Native American Indian, Alaskan and Hawaiian people [47-67]; eleven in Canada with Indigenous people including First Nations, Inuit and Metis [8,68-77]; five in New Zealand with Māori people [9,78-81]; two studies in Norway with Sami people [82,83]; one study in Taiwan with Atayal people [84]; and one study in Malaysia with Melanau people[85].

3.3.2 Indigenous leadership and involvement in research

Four studies specified that the research team included an Indigenous researcher or co-researcher.[33,45,81,86] Nine studies reported Indigenous involvement in research through the formation of an Indigenous advisory, steering or reference group, [26,29,33,43,45,72,73,75,77] 24 studies identified partnership or involvement of Indigenous community leaders, community members or organisations,[5,7,26,28,31-38,41,42,44,45,55,68,71,74,75,77,80,86] and eleven studies reported specific involvement of Indigenous elders.[5,6,32,36,38,42,43,70,72,73,79] An additional ten studies identified employment of Indigenous staff or community members for data collection, field work or trial coordination [6,7,30,34,42,44,51,54,60,72] and one study reported using a cultural advisor.[46] No information about Indigenous leadership or involvement were reported for 31 studies.[4,8,9,27,39,40,47-50,52,53,56-59,61-67,76,78,82-85,87,88]

3.3.3 Areas of research focus

Fifteen studies examined the prevalence and/or incidence of dementia or cognitive impairment in Indigenous populations, [4,5,7-9,27,34,46,47,50,52,57,85,86,88] while eight studies examined risk factors for, and correlates of, dementia.[6,31,37,60,63,64,76,87] Fourteen studies focused on dementia diagnosis, including nine studies that explored the development, validation and/or psychometric properties of dementia screening tests for specific populations, [29,35,36,38,41,42,44,66,73] four studies that examined implementation of different methods for assessing dementia, [39,40,61,65] and one study that generated normative data.[32] Seven studies explored treatment and management of dementia. These studies explored health service use and the delivery of dementia care (n=3), [68,81,83] the impact of a tailored dementia awareness resource (n=2),[33,45] the appropriateness of tailored health promotion materials for Indigenous people with dementia (n=1),[77] and the acceptability of a wearable technology for aging in place for Indigenous people living with dementia (n=1).[72] Five studies explored the clinical course and outcomes of dementia, including predictors of mortality, survival, and hospitalisation.[56,58,59,62,78] Twelve studies focused on the lived experience of dementia. These studies explored experiences of caregiving and/or patient experiences and perceptions of living with dementia (n=7), [26,48,53,68,70,71,84] psychiatric disorders and behaviours of nursing home residents with a high prevalence of dementia (n=1),[51] the oral health outcomes of people with dementia (n=1),[80] the unmet needs of those with dementia living in remote communities (n=1),[43] caregiver wellbeing (n=1), [54] and the implementation of a resource designed to support caregivers (n=1). [55] Eight studies explored perspectives, awareness, knowledge, experience and understanding of dementia and aging.[28,30,49,67,74,75,79,82]

3.3.4 Participants

Nineteen studies did not directly recruit participants. In 15 studies, secondary analysis was conducted of datasets that had already been collected [4,8,9,27,47,56-59,62,63,66,76,78,88] and three studies were implementation studies/case studies that did not report on recruitment of participants.[55,65,81] Of the remaining studies, many were comprised of heterogeneous samples of participants. Twenty-five studies recruited individuals with dementia, cognitive impairment, or possible dementia.[5-7,31,32,34-40,42,46,50,52,60,61,64,68-70,80,84,85] Thirteen studies included data from carers or family members of persons with dementia,[26,41,43,48,53,54,69,71,72,75,77,83,84] and thirteen studies included healthcare workers. [43-45,51,67-69,72,75,82-84] Thirteen studies included Indigenous community members without dementia or suspected dementia.[28-30,33,44,45,70,72,74,75,79,86,87]

3.3.5 Study design

Most studies used cross-sectional (n=31) {Carty, 2020 #46;Cotter, 2012 #26;Cullum, 2018 #13;Garvey, 2011 #29;Hocking, 2019 #30;Kirkpatrick, 2019 #51;Lavrencic, 2019 #31;Li, 2014 #8;Lo Giudice, 2011 #34;LoGiudice, 2006 #35;Panegyres, 2020 #87;Petrasek MacDonald, 2015 #75;Pu'un, 2014 #84;Radford, 2019 #36;Radford, 2015 #9;Radford, 2015 #9;Russell, 2019 #38;Russell, 2016 #39;Russell, 2020 #85;Sentell, 2015 #58;Smith, 2016 #40;Smith, 2010 #10;Smith, 2009 #41;Smith, 2008 #11;Verney, 2008 #59;Wadsworth, 2016 #60;Weiner, 2008 #63;White, 2019 #45;Whyte, 2005 #65;Russell, 2019 #38;Weiner, 2011 #64;Jervis, 2007 #49} or qualitative (n=21) [26,33,43-45,48,53,68-

[75,77,79,80,82-84] research designs. Ten studies were cohort studies,[8,34,49,56-58,62,63,78,87] four used mixed methods, [28,29,51,67] and two were case studies.[55,81] Only one study used an experimental design. This study examined the effectiveness of an alternative therapy to reduce stress and depression and improve quality of life for family carers of persons with dementia using a randomised controlled trial design. [54]

3.4 Ethical considerations in studies that directly involved participants with dementia

Ethical considerations identified in studies that involved direct participation by Indigenous people with cognitive impairment are reported in Table 2. Twenty-four studies directly involved Indigenous participants with cognitive impairment or dementia.[5-7,31,32,34-40,42,46,50,52,60,61,64,69,70,80,84,85] Of these studies, 22 (91.6%) commented on consent to participate, briefly stating that individual or proxy consent to participate was obtained either in writing or verbally. [5-7,31,32,34-39,42,46,50,52,60,64,69,70,80,84,85] Five studies additionally stated that where proxy consent was sought, the person with cognitive impairment also gave assent to participate. [5,32,37,38,69] No papers elaborated on the methods or tools used to determine whether individuals had capacity to consent to research. Most studies (n=18, 75%) discussed strategies that supported participation in study activities for people with cognitive impairment. [6,7,31,34,36-40,42,46,50,60,61,70,80,84,85] These strategies included conducting interviews in a familiar location and/or with a carer present. Some strategies to support participation were specifically implemented to address cultural safety and appropriateness, such as the use of culturally adapted study documentation,[31] gifting of tobacco [70] or changes to wording of questionnaires. [50] Five studies stated that language interpreters and/or translated documents were used, ,[6,31,32,36,42] and sixteen studies (66.6%) discussed building relationships with Indigenous organisations and communities to support and/or strengthen research including through co-design approaches, obtaining community consent, negotiating research agreements and formation of advisory groups. [5,7,32,34-38,42,50,52,61,69,70,80,84] All but three studies (n=21, 87.5%) indicated that approval was required from two or more ethics committees and other review bodies, such as an oversight body for research involving Indigenous people. [5-7,31,32,34-40,42,50,52,60,61,64,69,70,85] Ethical and legal governance frameworks were rarely discussed, with only one study mentioning the use of specific First Nations principles to govern collection and use of data.[70] Three studies mentioned compliance with the Declaration of Helsinki,[31] which can be a condition of publication for some journals.

<<TABLE TWO ABOUT HERE>>

4 DISCUSSION

The impacts of dementia experienced by Indigenous people, their carers, and their families is significant. This review serves to summarise the research capacity, areas of focus, and current gaps in knowledge related to Indigenous dementia research globally.

Our findings demonstrate an increase in the volume of scientific output related to Indigenous dementia over the last 10 years. These increases likely reflect both increased prioritisation and investment in both Indigenous health and dementia research more broadly, [89] which have increased the number of researchers working in this space and supported researchers to undertake projects in identified priority areas, including with Indigenous groups. Commitment to Indigenous dementia research is highlighted by the establishment of strategic plans for Aboriginal and Torres Strait Islander dementia research in Australia,[90] and the focus on the distinct needs of Indigenous communities in the Canadian National dementia strategy,[91] and the New Zealand Dementia Action Plan,[92] which will serve to support increased work in this area into the future.

While there was a predominance of studies conducted in Australia with Aboriginal and/or Torres Strait Islander people, the broad representation of different Indigenous populations across nations indicates that dementia in Indigenous populations is attracting global attention. This is critical given the diversity of language, culture, historical experiences, and practices between Indigenous populations and the need for the unique lived experience of dementia within each population to be central to research efforts. A strength of the papers included in this review is that many described strategies for building relationships with Indigenous communities and services, particularly through partnership or involvement of Aboriginal community leaders, community members or organisations and participation of Indigenous elders in the research. This is likely to be reflective of the prominence given to community partnership in ethical guidelines for Indigenous health research and agreed principles for guiding Indigenous health research.[93,94] However, it was difficult to determine the extent to which research has been led by Indigenous people as this was not clearly specified in most papers. As part of improving the transparency and usefulness of Indigenous health research, there is a clear need to implement strategies to document Indigenous authorship and contributorship to research in a common way.

While the predominance of epidemiologic studies exploring prevalence, incidence, risk factors and correlates of disease provides information critical to understand the aetiology of disease across populations, there were few studies examining treatment and management of dementia and perspectives, awareness, knowledge, experience and understanding of dementia and aging. Only one experimental study was identified. [54]. While examination of the methodological quality of the various research designs was not within the scope of this review, consideration of the types of research and their designs allows comment on the quality of data, and inferences able to be drawn from the work conducted to date.

A diagnosis of dementia should not be equated with a lack of capacity to consent to research, [95]] and encouragingly, twenty-four studies utilised data collected directly from Indigenous people with dementia. However, few papers discussed the ethical aspects of involving individuals with cognitive impairment or dementia as participants in research, especially in relation to consent processes. This is despite ethics guidelines typically discussing community relationships and agreement to the research, as well as consent of the individual participant. This finding echoes the results of a systematic review into methods for seeking consent for research with Indigenous populations which found that few publications describe specific methods of seeking informed consent as part of Indigenous research, and even fewer that evaluate a participant's understanding of the consent process.[96] While this may reflect a lack of reporting of the methods used in studies, it highlights the need for researchers to consider and adapt their approaches to determining consent to the population they are working with. Papers should state how capacity to consent to the study was determined, including the use or adaptation of tools that have been specifically developed to assess the decision-making capacity of potential research participants with cognitive impairment.[97] Person-centred consent processes[98] such as the use of culturally adapted consent forms, study information sheets and pictorial flip charts that use pictures, plain English and minimal text, [31] may enhance an individual's capacity to make their own decision about taking part in research.

Overall, there was poor reporting of proxy consent and legal and ethical frameworks that framed research. Proxy consent for dementia research has been examined in non-Indigenous contexts and has identified challenges such as confusion about legal requirements, substandard information provision to inform proxy decisions, and discordance between proxy and participant wishes.[99,100] One paper that included proxy consent justified this approach on the basis that a standardized tool could not adequately assess competence to make an informed decision about research participation, and that competence could change over the course of the study.[69] For dementia research with Indigenous populations, papers should outline local legal and ethical requirements governing proxy consent and how proxy consent and participant assent was facilitated. Papers should also note the legal and ethical frameworks that shaped – positively or negatively – the conduct of dementia research with Indigenous people. Doing so can identify structural barriers and enablers to the involvement of people with cognitive impairment in research.

4.1 Strengths and Limitations

The findings of this review should be considered with regard to its strengths and limitations. Strengths of this review include the systematic literature search that encompassed a wide range of broad search terms and multiple databases. Our search was global and identified studies across multiple countries and Indigenous populations. A limitation of the review is that grey literature, including reports, policy documents, and dissertations were not included. While grey literature contributes important information, it is not peer-reviewed and therefore may not be of suitable quality.

5 CONCLUSIONS

Evidence based policy and healthcare delivery relies on generation of quality research evidence. Although there has been an increase in observational research examining dementia in Indigenous populations, there is a lack of experimental research, and it is unclear how much research has been led by Aboriginal people. There is a clear need for further Indigenous led research and robust experimental studies focusing on the Indigenous populations, to inform the design and deliver services that meet the need of Indigenous peoples, their caregivers, families and wider communities. Additional examination of the methodological quality of research conducted to date will help guide future research. Future research should give explicit consideration and report the ethical aspects of involving Indigenous participants with cognitive impairment in research, including strategies to assess and support participants’ capacity to consent, and the legal and ethical frameworks that shaped the research conduct.

DECLARATIONS

Ethics approval and consent to participate. Not applicable

Consent for publication. Not applicable

Availability of data and materials. The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

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

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Indigenous authorship. Professor Gail Garvey is a Kamilaroi woman from NSW, with over 25 years of leadership and impact in Aboriginal health research, education and capacity building. Professor

Garvey has an internationally recognised research program on Australia’s First Nations Peoples and cancer, emphasising health services research and psychosocial aspects of cancer care.

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Figure 1. PRISMA Four Phase Flow Diagram

Figure 2. Count of publications examining dementia in Indigenous populations by year (2000-2020)

Table 1. Characteristics of included studies (n=69)

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Table 1. Characteristics of included studies (n=69).

Reference	Country, design & Aim	Indigenous group of focus	Indigenous leadership or participation	Participants Group; N; Age; Gender;	Data collection & Analysis	Findings
Arkles 2020	Australia. Qualitative. To explore the experience of dementia caregiving for older Aboriginal and Torres Strait Islander people in urban Australia.	Aboriginal and Torres Strait Islanders living in urban areas.	Aboriginal Advisory Group, partnership with Aboriginal community organisations.	N=5 caregivers, 3 community settings, 1 artist. Age: NR. Gender: NR.	Face-to-face in-depth interviews with community members caring for a family member with memory problems identified by local health workers. Additional data came from "Yarning circles" in a community setting, a fieldwork journal of observations and an artwork. Findings were drawn from the data using a hermeneutic mode of interpretation.	– Importance of the concept of "place" and the struggle to maintain this especially in the context of nursing homes and fear of "placelessness".
Blix 2017	Norway. Qualitative. To explore healthcare providers views of Sami people with dementia, and their perceptions of families' reluctance to seek and accept help from healthcare services.	Sami.	NR.	Healthcare providers involved in providing everyday care for users of local healthcare services. N= 18. Age: NR. Gender: 100% female.	Four focus groups conducted in meeting rooms at local nursing homes or health centres. Narrative context analysis.	– Sami PWD were reluctant to seek and accept help. – Reluctance attributed to macro contexts (socio-historical processes and cultural norms), and micro contexts (individual and interpersonal factors including the healthcare professionals' cultural backgrounds and language competence)
Carty 2020	United States of America. Cross- sectional. To examine AD and related dementias and comorbidities in American Indians across a large geographical region in southwest United States.	American Indians.	NR.	American Indian patients aged ≥55 years in the Banner Health system from 2016-2018. N= 7,090. Age: American Indians (Median =64, IQR 59-71),	Demographic, dementia, and health data was extracted from electronic medical records for American Indians and Non-Hispanic whites and analysed and compared.	– The age-adjusted prevalence of AD and related dementia diagnosis was 6.6% of American Indian patients, compared with 4.4% in non-Hispanic white patients. – Patient age and diagnosis of hypertension, depression, hyperlipidemia, or diabetes were significantly associated with higher

				Non-Hispanic Whites (Median=68, IQR 61-75). Gender: 58.7% female.		risk of AD and related dementia diagnosis in American Indians. Female sex or being married/having a partner were associated with lower risk of AD and related dementia diagnosis. – AD and related dementia risk factors were generally similar between American Indians and non-Hispanic white patients, except for sex and marital status, however, the adjusted risk of AD and related dementia was approximately 49% higher in American Indian patients.
Chen 2020	Taiwan. Qualitative. To explore the experiences of living in the community for older Atayal persons with dementia symptoms.	Atayal.	NR.	N=4 persons with dementia symptoms, N= 3 Family members, N =10 key persons (healthcare providers, community leaders, local government workers). PWD: Age: M= 74.75yrs, SD=5.58. Gender: 25% female.	Face-to-face in-depth interviews with PWD symptoms referred by locals (1st author well known in village). Snowball recruitment of others. Dementia symptoms were confirmed with MMSE. Observation in community also used. Grounded theory approach.	– Low community awareness of dementia. – Supportive family-like environment allowed PWD symptoms to function freely in community (dementia-friendly community). – Barriers to transportation access.
Cotter 2012	Australia Secondary analysis of cross-sectional data. To assess whether Indigenous Australians age prematurely compared with other Australians.	Indigenous Australians.	NR.	Data from national Indigenous and non-Indigenous datasets from 2004-2007.	Data sets: Australian Bureau of Statistics National life tables; Aged care assessment Program National Data repository; Australian Institute of Health and Welfare National Health Morbidity Dataset; Australian Bureau of Statistics National health	– Prevalence of dementia was moderately higher in Indigenous people (rate was ~25/1000 in those 75-84)-acknowledge that dementia is under diagnosed in Indigenous population. – Estimated gap in life expectancy between Indigenous and non-

					survey, and National Aboriginal and Torres Strait Islander Social Survey. Prevalence rates analysed separately for Indigenous and non-Indigenous populations in 10-year age groups.	Indigenous populations was ~6 years in later life, well below 20 years used for policy decisions.
Cox 2019	Australia. Cross-sectional and Qualitative. Investigate community understandings of dementia.	Aboriginal and Torres Strait Islanders.	Aboriginal community leaders, members and organisations.	N= 50 Age: M= 46.44, SD= 16. Gender= 76% male. Of these participants, N=12 also completed an individual interview.	Dementia Knowledge Assessment Scale survey and individual interviews. Descriptive statistics.	– Dementia Knowledge Assessment Scale results were mean score of 27.72 / 54. – Association of dementia with aging, getting older and memory loss. – Knowledge gaps in identification of early dementia symptoms, risk factors and the progressive nature of the disease. – Cultural obligation to care for those with dementia.
Cullum 2018	New Zealand. Cross-sectional. To examine the age and stage of presentation of dementia to clinical services.	Maori.	NR.	N= 142 European, 43 Maori, 126 Pacific, 49 other ethnicities. Age: Maori M=70.2yrs, SD=7.6; Pacific M=74.3yrs, SD=7.6. Gender: Maori (40% male) Pacific (35% male).	Observational study of collected clinical data from a memory service based in a hospital in South Auckland. Descriptive analyses, Chi-squares.	– Pacific peoples tended to have more advanced dementia upon presentation. – Maori and Pacific patients were younger with dementia compared to European patients.
Cullum 2020	New Zealand. Cohort. To examine predictors of mortality in dementia in consecutive referrals to a New Zealand memory service	Maori, Pacific Islander.	NR.	N=559 (new dementia diagnosis). NZ European Age: M=79.9, SD=7.2 Gender: 52% female	Demographic, dementia, and health data was extracted from electronic medical records for patients referred to a memory service based in a hospital in South Auckland with a new diagnosis of dementia. Data was linked to administrative data on	– The risk of death in all people diagnosed with dementia was increased by age and CI and was reduced by use of cholinesterase inhibitors. – The use of antipsychotics increased the risk of death threefold in Maori

	that includes Maori, Pacific Islander, and New Zealand European patients.			Maori Age: M= 71.9, SD= 8.10. Gender: 62% female Pacific Island Age: M=75.5, SD=7.7 Gender: 61% female	mortality, prescribed drug use and hospital contacts.	and Pacific Islanders, compared to New Zealand Europeans.
Derrig 2020	Australia. Longitudinal; Cohort. To: (1) investigate the prevalence and risk factor profiles of mild CI – amnestic and non-amnestic subtypes, in an Aboriginal Australian population and (2) investigate the 6-year outcomes of baseline mild CI diagnoses.	Indigenous Australians.	NR.	N=287 (not diagnosed with dementia or significant cognitive impairment). Age: M= 65.9, SD= 5.6. Gender: 62% Female.	Participants completed a structured interview at baseline. MCI and dementia were diagnosed via cognitive screening, medical assessment, and clinical consensus Associations between life-course factors and baseline MCI subtypes were examined using logistic regression. Conversion to dementia assessed at 6 year follow up.	– Risk factors associated with amnestic mild CI and non-amnestic mild CI were distinct. However, there was no clear difference in the proportion of cases that converted to dementia at follow-up. – In the final model, older age, history of head injury, symptoms of depression, and lower blood pressure remained significant factors associated with amnestic mild CI. – For non- amnestic mild CI, low education, unskilled work history, higher body mass index, and moderate-severe hearing loss remained significant in the final model.
Dingwall 2017	Australia. Cohort; qualitative. To assess the reliability of four cognitive assessment for Indigenous Australians.	Indigenous Australians from Alice Springs.	Aboriginal Reference Group.	N= 84 Cognitive assessment group: Cogstate: N=18 Age: M= 40.65,SD = 12.67, Gender: 33% male	Assessment done at Alice Springs Hospital. T-tests for baseline and retest results.	- No significant differences between baseline and retests except for Story Memory Recall Test which showed improvement from baseline to retest. - PEBL Corsi block-tapping task and CogState had lower retest reliability than Rowland Universal

				PEBL Corsi block-tapping task: N = 19 Age: M= 46.33,SD= 13.22. Gender: 32% male Rowland Universal Dementia Assessment Scale (RUDAS): N= 19 Age: M= 48.45,SD =15.49, Gender: 42% male Story Memory Recall Test (SMRT): N= 17, Age: M= 49.81,SD = 13.18 Gender: 59% male		Dementia Assessment Scale and Story Memory Recall Test, although not statistically significant different. - Rowland Universal Dementia Assessment Scale, CogState and Story Memory Recall Test had retest reliability. - Language may be a source of confusion.
Dudley 2019	New Zealand. Qualitative. To develop a Maori understanding of dementia.	Maori.	Involvement of Maori elders.	N=223 Maori elders in 17 focus groups and 8 families. Age: NR. Gender: NR.	Purposive sampling across 7 locations in New Zealand was used to recruit Maori elders and families. Semi-structured interviews were used in 17 focus groups. A Maori collective qualitative analysis approach was taken.	– Term *mate wareware* preferred to dementia or Alzheimer's which evoked feelings of despair and confusion. – Five key themes identified: causes; protective factors; acceptance of illness and behaviour change; caregiving and dementia services – Important to consider cultural practices and provide support to the family.
Fife 2020	United States of America. Qualitative. To (1) identify stressors experienced by Alaskan native people caring for someone with dementia	Alaskan Native Americans.	NR.	N=21 caregivers of an Alaskan Native with ADRD. Age: M = 53, SD=NR. Gender: 86% female.	An inductive research strategy in which ideas, concepts, and themes emerged from the interview data through a process that began without a priori definitions or hypotheses about what would be	– Alaska Native caregivers reported chronic stressors related to caregiving including poor health, lack of support, and lack of education about dementia. – The use of spiritual practices was identified as a primary resource

	and (2) describe the role of spirituality in coping with those stressors.				discovered was used. Thematic analysis to create meaningful patterns in response to the Explanatory Model of Illness domains.	during challenging caregiving experiences. – Community organizations and health care providers should incorporate spiritual practices as part of the support they provide to American Native dementia caregivers.
Finkelstein 2012	Canada. Qualitative. How dementia care is provided to First Nations.	First Nations in Ontario.	Aboriginal community health centre board of directors and staff members.	N= 7 healthcare providers (5 identified as First Nations). Age: NR. Gender: NR.	In-depth interviews with healthcare providers. Grounded theory.	– Lack of resources in reserves, PWD not accessing care, health care within reserve not collaborating with care outside of reserve. – Healthcare providers reported feeling burnout, affecting their well-being. – Healthcare providers relied on involved of family members for care and had to develop trust with First Nations to provide care. – PWD not seeking dementia care, due to denial and a lack of information
Forbes 2013	Canada. Qualitative. To enhance the understanding of the process of knowledge sharing among healthcare providers, care partners and PWD, and inform the culturally sensitive application of dementia care knowledge-sharing strategies.	First Nations.	First Nations community involvement – detail not specified.	N= 2 PWD, 3 care partners, 2 healthcare providers. Age: NR. Gender: 100% female.	Reports on the sample of First Nations of a larger study, guided interviews. Constructivist grounded theory approach.	– Need to develop trusting relationships with healthcare providers. – PWD supported by family and community, community felt it was a priority – Willing to keep PWD home for long as possible – Conflicts in family with abuse of power and power of attorney – Consistency with care and forming a relationship with care provider was considered important. – Accessing information early is important, however PWD often

						does not feel the need to discuss or seek information. – Difficulty in accessing care.
Garvey 2011	Australia. Cross-sectional. To explore the understanding and knowledge of dementia in Indigenous Australians.	Indigenous Australians.	Involvement of local Indigenous interviewers.	N= 174 (157 in analysis). Age Range: 49% ranged between 25-44 yrs M=NR, SD=NR Gender: 60.3% female.	Cross-sectional survey using a modified version of the Alzheimer's Disease Knowledge Test and open-ended questions. Descriptive statistics, chi-squares.	– Understanding of dementia is poor, significantly in younger populations – Unable to differentiated between dementia and AD. – Indigenous Australians scored lower than non-Indigenous Australians on the Alzheimer's Disease Knowledge Test, particularly in biomedical questions
Gilmour 2016	New Zealand. Qualitative. Understand the oral health issues of those with dementia.	Maori.	Involvement of community workers and partner organisations.	N= 17 (5 PWD, 12 members receiving services from Alzheimer organisations). Age: NR. Gender: NR.	Interviews with PWD. Thematic Analysis.	– Oral health is important to family-centred care. – Lack of professional dental care. – Many of the PWD did not have their own teeth or dentures. – Travelling was an issue. – One participant stated a PWD had trouble using dentures. – Support and care were scarce for PWD. – Poorer oral health status PWD.
Hanssen 2013	Norway. Qualitative. To understand how Sami culture may influence communication and interaction with institutionalised PWD.	Sami.	NR.	N= 8 family members, 9 nursing staff. Age: NR. Gender: NR.	Narrative interviews. Thematic analysis.	– Communication difficult with non-Sami language with carers. – Sami nurses said it is important healthcare providers have Sami background. – Patients happier to eat traditional food. – Religion, spirituality, and traditions important to maintain while in care.

Hocking 2019	Australia. Cross- sectional. To identify the prevalence of factors associated with CI categories in Aboriginal people living in residential aged care facilities.	Aboriginal and Torres Strait Islanders.	Involvement of Aboriginal community services.	N=84 (assessed for eligibility), N= 58 eligible. Age: M=74.3yrs, SD=NR. Gender: 67% female.	Clinical file audit was undertaken for consenting residents of 3 residential aged care facilities in Alice Springs with a diagnosis of dementia or CI indicated by the KICA. Prevalence of associated factors across diagnostic groups was calculated.	– High rates of vascular dementia and dementia due to brain injury were found demonstrating a link between alcohol, traumatic brain injury and dementia. – Hypothyroidism, hypoglycaemia, HTLV-1 and Vitamin D deficiency may also play a role.
Hulko 2010	Canada. Qualitative. To explore the views of elders on memory loss and care in later life.	First Nations.	Involvement of First Nations Elders.	N= 21 elders. Age: NR. Gender: NR.	Narrative interviews and circles. Grounded theory.	– Dementia did not diminish an Elder’s importance. – Attributed memory loss to living off the land and not doing ‘natural stuff’, alcohol drugs, loss of culture, pollution, trauma. – PWD likened to babies due to care.
Jacklin 2013	Canada. Cohort. Reports on the population-level prevalence of First Nations in Alberta.	First Nations	NR.	N=NR. Age: NR. Gender: NR.	Aggregate data from provincial administrative health databases. Linear regression.	– 7.5 per 1,000 for First Nations vs 5.6 per 1000 for non-First Nations. – First Nations people diagnosed with dementia at younger age (60-69, and 70-79). – First Nations males had a disproportionately higher risk of dementia.
Jacklin 2015	Canada. Qualitative. To explore findings and concerns around informal dementia care in Indigenous communities.	First Nations.	Partnership with Indigenous communities.	N= 34 Caregivers. Age: NR. Gender: NR.	Semi-structured in-depth interviews. Critical interpretive analysis from an ethnographic study.	– Want to keep people at home for as long as possible, family, friend and neighbour caregivers, important values for family caregiving. – Reluctant to use mainstream services, distrust of western health care. – Challenges to care was a lack of knowledge of symptoms and progression, inequitable access to medication and support services.
Jacklin 2020	Canada. Qualitative.	First Nations.	Involvement of Indigenous Elder and	N= 15 Indigenous older adults.	Consultations with an Indigenous Elder, a community advisory council, and the KICA authors.	The research resulted in the new Canadian Indigenous Cognitive Assessment.

	To adapt the KICA for use as a brief cognitive test with Anishinaabe populations in Canada.	Community-based participatory research approach.	community advisory council.	Pilot 1 (N=10) Age Range: 45-60 (N=5), 61-80 (N=5) Gender: N=5 males, N=5 females. Pilot 2 (N=5) Age Range: 45-70 Gender: N=3 males, N=2 females N= 7 local health professionals. Age: NR Gender: NR Ad hoc consultations with an Indigenous Elder, a community advisory council, and the KICA authors.	Thematic Analysis.	The KICA was found to be acceptable and readily adapted to North American First Nations peoples. The findings reveal important cultural and linguistic considerations for cross-cultural cognitive assessment in Indigenous contexts.
Jacklin 2020b	Canada. Qualitative. To address inequitable access to supportive technologies that may allow Indigenous older adults to successfully age in place.	First Nations.	Involvement of Indigenous Elders, community researcher and community advisory council.	N=29. Age: NR. Gender: NR.	Informant consultations and focus group interviews in four geographically distinct regions. Thematic Analysis.	-Overall, participants agreed that CareBand would improve caregivers' peace of mind. -Results suggested refinement of the technology is necessary to address the challenges of the rural geography and winter weather, to reconsider aesthetics, address privacy and access, and to consider the unique characteristics of Anishinaabe culture and reserve life.
Jernigan 2020	United States. Cohort.	American Indians and Alaskan Natives.	NR.	N= 438 American Indian and Alaskan Native community members,	Participants who had heard of AD and completed the Alzheimer's Disease Knowledge Test.	– Participants were moderately well informed about AD, but specific knowledge domains call for community outreach and education.

	To quantify the nature and extent of knowledge about AD and dementia and to examine potential variation associated with demographic			N= 431 had heard of AD and included in further analyses Age: M= 43, Range 18-85yrs, SD=NR. Gender: 62% female	Average adjusted predictions and 95% confidence intervals from a linear regression model, used joint F tests.	– Higher scores were associated with education but not with age, sex, or rural versus urban residence. Low scores were observed for items on caregiving and disease risk.
Jervis 2007	United States. Cross-sectional; qualitative To examine the cognitive, psychiatric, and behavioural status of residents in a tribal nursing home.	American Indians.	Involvement of Aboriginal research assistants.	N= 36 staff, 45 residents, 89% American Indian residents. Age: NR. Gender: NR.	Semi-structured interviews and examination of medical records. Descriptive statistics and grounded theory.	– 64% had a dementia diagnosis, higher than the average from national nursing home survey at 41%. – Residents had considerable psychiatric and behavioral morbidity. – Residents had higher prevalence of non-Alzheimer's disease dementia, cognitive impairment, anxious symptomatology, and resistance to care compared to national data.
Jervis 2007b	United States. Cross-sectional. To look at the performance of MMSE and Mattis Dementia Rating Scale among older American Indians.	American Indians.	NR.	N= 137 MMSE and N= 129 Mattis Dementia Rating Scale. Age: M= 69.8, SD=6.4 Gender: 72% female	-Private interviews were conducted in a reservation-based field office. Interviews collected demographic and health-related information and the MMSE and MDRS were administered. -Raw MMSE scores among study participants were compared with a normative population-based database. Descriptive statistics, chi-squares and Fisher's exact test	– Nearly 11% scored more than 2 SD points below performance expectations on the MMSE, as did 27% to 81% on the MDRS. – Complex relationships were found between gender, health conditions (with possible effects on cognitive functioning), and MMSE and MDRS scores.
Kirkpatrick 2019	United States of America. Cross-sectional.	American Indians.	NR.	American Indian veterans. N=60. Age: M= 64 yrs, SD=7.1	American Indian veterans were enrolled as outpatients at Veteran affairs clinic and self-referral, if no prior CI diagnosis and with 2 or more vascular risk factors.	– 44% (95% CI 30-59%) had MoCA score <26. – Of 15 participants further assessed, n=4 normal, n=4 non-

	To determine rates and patterns of memory loss among American Indian veterans from Oklahoma with vascular risk factors.			Gender: 90% male	Initial screening using MoCA and Beck Depression Inventory-II. Further screening if MoCA scores <26. -Descriptive statistics, t-test,chi-square, Fisher's test and Cochrane-Armitage test	amnestic, n=4 mild CI, n=5 vascular mild CI, n=2 vascular dementia. – Rates of undiagnosed CI identified exceeds rates in non-American Indian cohorts.
Korn 2009	United States of America. Experimental (RCT). To compare an alternative therapy, to a control condition to reduce stress and depression and improve quality of life	American Indian from pacific northwest (mainly Salish) and Alaskan Native.	Involvement of tribal liaison and clinical coordinator.	Family carers of PWD. N=42. Age: M=50 yrs, SD=NR. Gender: 90% female.	Carers, identified through health programs, fairs and word of mouth, were randomised to receive polarity therapy or enhanced respite control. Survey of stress (Perceived Stress Scale), depression (Center for Epidemiological Studies-Depression), quality of life (SF36 and Quality of Life-AD (Caregiver Version)), sleep quality (Pittsburgh Sleep Quality Index), worry (Penn State Worry Questionnaire), and health at baseline and post-treatment. T-tests used to evaluate intervention.	– Participants receiving polarity therapy showed significantly improved stress, depression, pain, vitality, and general health compared to control participants. – Delivery of polarity theory is feasible and culturally acceptable.
Lanting 2011	Canada. Qualitative. To understand Aboriginal perceptions of aging and dementia to guide development of culturally appropriate assessment procedures.	Aboriginals from Saskatchewan (Cree, Salteaux, Métis).	Involvement of Aboriginal Grandmothers Group.	Aboriginal Grandmothers group. N=3-4. Age Range: 59-73, M=NR, SD=NR. Gender: 100% female.	Volunteers from a grandmother's group were selected by group facilitator. All had experience as healthcare providers in regional areas. 6 sessions held with all women. Thematic analysis.	– Behaviour and cognitive change seen as normal part of aging process. – Loss of traditional practices such as healthy eating was seen as increasing illness (including dementia) and changing traditional caregiving structures in families and community. – Important that health care is culturally grounded.

Lavrenic 2019	Australia. Cross-sectional. To provide normative data on a range of cognitive tests for Aboriginal Australians.	Aboriginal Australians.	Involvement of Aboriginal community organisation, Elders group, local Aboriginal land council.	Community dwelling Aboriginal Australians. N=104 Control (N=31) Age: M=64.9, SD=4.3 Gender: 48% male MCI (N=38) Age: M=67.7, SD=6.4 Gender: 34% male Dementia (N=35) Age: M=69.6, SD=6.8 Gender: 63% male	Participants were identified through health services and community organisations in 5 communities across New South Wales. Participants were classified for CI using cut-offs on the MMSE, mKICA and RUDAS. Participants undertook a medical assessment and completed a range of cognitive assessments (the Addenbrooke's Cognitive Examination Revised, a digit span task, logical memory, Oral trail marking tests). Test scores were compared between CI categories.	– Normative data is provided. – The control group (no CI) performed better on all tests than the dementia group. – The tests used can differentiate between diagnostic groups in Aboriginal Australians.
Lewis 2020	United States of America. Qualitative. To examine the explanatory models of AD and related dementias held by American Native caregivers and health care providers and explore the differences and similarities in their understanding of AD and related dementias.	Alaska Indian/Alaska Native.	NR.	N = 22 Caregivers Age: M=53, SD=NR. Gender: 86% female N =12 Providers. Age: M= 55, SD=NR. Gender: 83% female.	The data were organized into common themes for comparisons. Direct content analysis to eexamine the major agreements and disagreements between the participants' understandings of AD and related dementias in each of the domains of Kleinman's Explanatory Model of Illness.	– The authors recommend establishing rural outreach and support groups for caregivers, developing an understanding of how American Natives view AD and related dementias to train and educate health care providers, and implement screening early for memory loss during routine medical examinations.
Li 2014	Australia. Cross-sectional. To estimate the prevalence and incidence of dementia in the Northern Territory	Indigenous Australians	NR	4 data sets (NT Hospital Separations, NT Aged Care and Disability, Primary Care Information	Hospital admissions, aged care services, primary care and death registration data from 2008-2011 used to identify clients with diagnosis of dementia.	– Much higher prevalence and incidence of dementia in Northern Territory indigenous population: 3.7 per 100 (6.5 age adjusted) compared to 1.1 per 100 (2.6 age adjusted) in non-Indigenous population.

				System, and NT death registrations) Age Range: 45 and over M=NR, SD=NR.	Log-linear modelling to estimate number of missing cases. Age-adjusted rates calculated.	-Prevalence rate ratios of NT Indigenous to NT non-Indigenous men and women, respectively, were: 6.5 and 5.5 for the 45–64-years age group, 4.0 and 4.1 for those aged 65–74 years and 2.1 and 1.9 for those aged 75 years and over.
Lindeman 2012	Australia. Qualitative. To evaluate the intersectoral collaboration of a dementia awareness resource (DVD) in remote Northern Territory.	Indigenous Australians.	Involvement in Indigenous advisory group, Indigenous researcher and community groups.	Indigenous aged care workers, community members, aged care service users, healthcare providers, and service providers. N=31. Age: NR. Gender: NR.	Focus Groups, individual interviews, and observation after introduction of the DVD resource. DVD “looking out for dementia” in English and 3 Aboriginal languages. Thematic analysis.	– Whole of system perspective needed rather than just aged care services-extend reach of dementia educators. – Strategies to increase number of informed care givers and healthcare providers will lead to better services and earlier detection. – Dementia education delivery needs to be aware of who in community to approach.
LoGiudice 2006	Australia. Cross-sectional. To test the psychometric properties of the KICA-Cog, a tool to assess cognition in older indigenous Australians.	Indigenous Australians in the Kimberley, Western Australia.	Involvement of Indigenous elders and community members.	Indigenous community members from coastal, river and desert areas of the Kimberly. N=70 Age Range: 45 and over, M=72, SD=9.1 Gender: 57% female	Convenience sample of community members of varying cognitive abilities recruited through healthcare providers, aged care services, other community members. Assessed using KICA-Cog as well as DSM-IV and CD-10 criteria and informant history. Interrater and internal reliability determined.	– KICA-Cog is a reliable assessment tool for CI in older Australian Indigenous population living traditionally. – Interrater reliability: κ-value ≥ 0.6 – Internal consistency: $\alpha=0.88$. – Sensitivity and specificity: 90.6% and 92.6%, respectively (using cut-off score of 31/32).
LoGiudice 2011	Australia. Cross-sectional.	Indigenous Australians.	Involvement of Aboriginal communities – detail not specified.	Non-random sample of Indigenous community members from	Convenience sampling of people with a range of CI. Assessed using KICA screen and independent geriatrician review. Sensitivity and specificity calculated.	– 26 (47%) participants had no cognitive impairment, 17 (31%) had Dementia and 12 (22%) had CI not dementia.

	To develop and validate a shorted version of the KICA, the KICA screen.			Northern Queensland. N=55 for validation. Age: 45 and over; M=60.6yrs, SD=11.9 Gender: 55% female.		– 10-item KICA screen valid and acceptable screening tool for Indigenous Australians in remote and rural areas o Sensitivity of 82.4% and specificity of 88.5%, with a cut point of 21/22
Lo Giudice 2016	Australia. Cohort. To determine the incidence of dementia and main risk factors in this population.	Indigenous Australians in remote areas of the Kimberly, Western Australia.	Involvement of Aboriginal communities – detail not specified.	Community members including those living in residential aged care facilities. N=189 followed up (363 at baseline 6 yrs prior) Age Range: 45 and over. M=65.4, SD=10.3 Gender: 60% female.	KICA_Cog scale, health assessments (e.g., body mass index) and semi-structured interviews to get demographics and risk factors e.g., smoking history. Descriptive statistics. Multivariate logistic regression modelling of risk factors.	– Incidence of CI or dementia in Aboriginal Australians is among highest in the world- 52.6 per 1000 person-years over age of 60 – Risk factors were age and head injury.
Martin 2012	New Zealand. Case-study. To describe development of bicultural approach to dementia care in Northland Aotearoa, New Zealand.	Māori people.	Aboriginal co-researcher	Dementia day service in one province of New Zealand which hoped to increase Māori participation. (No study participants)	Description of a model which incorporates Māori principles into dementia services. Social worker, healthcare providers and client interactions observed.	– Potential to increase participation of Māori people with dementia in day service program through model that included Māori principles – Need for health professionals to be committed to cultural inclusiveness
Martindale-Adams 2017	United States of America. Case-study. To describe the implementation of the REACH (Resources for Enhancing Alzheimer's Caregivers Health) in	American Indian and Alaskan Native.	Involvement of Indigenous organisations and community workers.	Caregiving dyads attending healthcare providers serving one of 546 recognised tribes.	Description of adaptations made to the model for this population, challenges and lessons learned during six stages of implementation: exploration and adoption, program installation, initial implementation,	– Need community to recognise problem as a concern – While sharing programs is efficient way to implement care, model does need to be adapted to local community.

	American Indian and Alaska Native communities.			Age: NR. Gender: NR.	full operation, innovation, and sustainability.	
Mayeda 2016	United States of America. Cohort. To compare incidence of dementia in racial/ethnic groups of United States of America.	American Indian and Alaskan Native.	NR.	Data for health care members N=274,283 Age: 60 and over; M=73.4, SD=NR. Gender: 54.6% female.	Demographic and health data obtained for Kaiser Permanente Northern California (health care company) members enrolled in 1996. Data for study was from 2000-2013. Age adjusted Incidence of dementia estimated for each racial group.	– Dementia incidence in United States of America differs by race/ethnicity: higher for African Americans (26.6/1000) and American Indian and Alaskan Natives (22.2) than Lations (19.6), Pacific Islanders (19.6), whites (19.3) and Asian-Americans (15.2).
Mayeda 2017	United States of America. Cohort. To estimate anticipated survival time after a dementia diagnosis in racial/ethnic groups of United States of America.	American Indian and Alaskan Native.	NR.	Data for health care members with a diagnosis of dementia. N=59,494 Age: 60 and over; M age of dementia diagnosis=83.4 Gender: 60% female.	Demographic and health data for KPNC (health care company) members enrolled in 1996. Data for study was from 2000-2013. Kaplan–Meier method used to estimate survival times after dementia diagnosis.	– Survival after diagnosis of dementia in United States of America differs by race/ethnicity: shorter for whites (3.1 years) and American Indian and Alaskan Native (3.4 years) than African Americans (3.7 years), Latinos (4.1 years) and Asian-Americans (4.4 years).
Mehta 2008	United States of America. Cohort. To compare survival rates in non-white and white American patients with AD.	American Indian.	NR.	Patients from 30 AD centres. N=30,916 Age: 65 and over; M=77.6, SD=6.5 Gender: 65% female.	Data from the National Alzheimer's Coordinating Centre from 1984-2005. Cox proportional hazards models with a primary outcome of time to death used to estimate survival. Neuropathologic characteristics were compared were available.	– Median survival was 4.8 years. – American Indian survival was similar to white and Asian-American survival and was shorter than that for Latino and African Americans. – Differences were not explained by neuropathologic characteristics.

Pace 2019	Canada. Qualitative. To understand the role of place and culture in supporting the health of older adults in Newfoundland and Labrador.	Southern Inuit.	Involvement of Aboriginal community council and community members.	Older adults, family caregivers and home care workers. N=14. Age: NR. Gender: 3 males; 11 females.	Participants were older adults, family caregivers and home care workers residing in the same town. Participants took photos that represented their lived experience with aging and dementia and then took part in an interview. A photo story approach was taken.	– Experiences of ageing, dementia prevention and dementia care are connected to place and culture – Need to support ageing in place.
Panegyres 2020	Australia. Cross-sectional. To report the incidence of Creutzfeldt-Jakob disease in Indigenous Australians.	Indigenous Australians.	NR.	Data from national Indigenous and non-Indigenous datasets – 2006 – 2018. N= 8 Indigenous persons identified with Creutzfeldt-Jakob disease. Age Range (at death): 48-80yrs. Gender: 50% female.	Data sets - Australian National Creutzfeldt-Jakob Disease Registry (ANCJDR), ABS Estimates and Projections - Aboriginal and Torres Strait Islander Australians, 2006 to 2031. Incidence rates and standardised mortality ratio analysed for the Indigenous and non-Indigenous populations.	- Overall crude annual rate of Creutzfeldt-Jakob Disease in Indigenous Australians compared to the remainder of the Australian population was not significantly different (0–3.87/million for Indigenous Australians; 0.94–1.83/million for non-Indigenous). - Indirect age-standardised all Creutzfeldt-Jakob Disease mortality ratio for the Indigenous population was 1.49 (95% CI, 0.75–2.98) - not significantly different to the all-resident Australian population.
Petrasek MacDonald 2015	Canada. Cross-sectional. To compare the population attributable risk for AD associated among Indigenous and non-Indigenous peoples and among on- and off-reserve Indigenous peoples in Canada.	Indigenous people of Canada including First Nations, Inuit and Metis.	NR.	-Data for on-reserve Indigenous peoples extracted from 2008–2010 First Nations Regional Health Survey: (N=21,757 people from 216 First Nations communities). -Data for off-reserve Indigenous peoples (First Nations, Inuit,	Statistics Canada data sources were used to extract data on six modifiable risk factors (diabetes mellitus, midlife hypertension, midlife obesity, physical inactivity, smoking, and low educational attainment). Prevalence of each risk factor in the population groups was estimated. Population attributable risk was calculated using relative risks from the literature using the Levin formula.	– Modifiable risk factors responsible for the most AD cases among Indigenous peoples in Canada. – Population attributable risk was higher among Indigenous people and those living on-reserve.

				and Metis) and those who identify as non-Indigenous extracted from the 2010 Statistics Canada Community Health Survey N= NR. Age: NR. Gender: NR.		
Pu'un 2014	Sarawak, Malaysia. Cross-sectional. Determine prevalence of dementia and associated risk factors among elderly Melanau.	Melanau.	NR.	Indigenous community members. N= 344. Age: 60 and over; M=70.4yrs, SD=6.7 Gender: 59.6% female.	Elderly Melanau in 8 villages were screened with the elderly cognitive assessment questionnaire (ECAQ). Clinical interview conducted by trained researcher with individuals who scored <5 to determine dementia diagnosis. Descriptive statistics to evaluate socio-demographic data. Simple linear regression and multiple linear regressions to examine associations.	– N=94 (27.3%) had CI. – N= 36 were diagnosed with dementia. – Overall prevalence of dementia was 10.5%. – Older age, no formal education and presence of 1-5 CVS illnesses were associated with dementia.
Radford 2015	Australia. Cross-sectional. To assess the performance of cognitive screening instruments for the diagnosis of dementia in urban/regional Aboriginal populations.	Aboriginal and Torres strait Islander	Involvement of Aboriginal community organisations and community Elders.	Community members. N=235. Age: 60 and over; M=65.8yrs, SD =5.8 Gender: 60% female.	Sample recruited from 5 urban and regional areas of NSW by local Aboriginal research assistants. Participants were assessed with MMSE; RUDAS; mKICA. Results compared to clinical diagnosis using receiver operating characteristic curve analyses.	– All tests culturally acceptable and had good psychometric properties, with MMSE and mKICA most accurate. – MMSE effective for urban populations. – mKICA useful when literacy, language and cultural considerations present.
Radford 2015b	Australia. Cross-sectional.	Aboriginal and Torres strait Islander.	Involvement of Aboriginal community organisations and	Community members. N=336. Age: 60 and over; M=66.6yrs, SD=6.3	Sample recruited from 5 urban and regional areas of NSW by local Aboriginal research assistants. Detailed history was taken, and participants assessed with MMSE; RUDAS; mKICA. Those scoring below	– High rate of dementia at younger age. – Rate (21% age standardised) is similar to remote Aboriginal populations and threefold higher than overall Australian population.

	To determine the prevalence of dementia in urban/regional Aboriginal populations.		community Elders.	Gender: 60% female.	cut-off values and random sample of those scoring above underwent clinical assessment. A consensus panel made a final decision about CI or dementia diagnosis.	– Alzheimer's disease was most common type diagnosed (44%)
Radford 2019	Australia. Cross-sectional. To examine the risk factors for dementia in Aboriginal Australians.	Aboriginal and Torres strait Islander.	Involvement of Aboriginal community organisations and local community members.	Community members. N=331. Dementia N=45 Age: 71.3, SD=8.2 Gender: 53% male. No Dementia N=286 Age: M=66, SD=5.6 Gender: 38% male.	Representative sample from 5 urban and regional areas of NSW. Participants were assessed for dementia or possible AD by clinicians. Risk factor data collected by interview. Logistic regression analysis conducted.	– Age, childhood trauma, unskilled work, stroke, and head injury were risk factors for dementia. – Comorbidities of dementia included functional impairment, incontinence, recent hospital admission, low body mass index, living in residential care, depression, current high-risk alcohol use, social isolation, and low physical activity levels. – These factors should be considered when designing appropriate interventions.
Russell 2016	Australia. Cross-sectional. To pilot a method of assessing dementia and CI in Torres Strait Islander populations.	Torres Strait Islanders.	NR.	Residents of one Torres Strait community. N=20. Age: 45 and over; M=65.8 yrs, SD=9.5 Gender: 11 women, 9 men.	Participants, recruited by healthcare providers, underwent a geriatrician clinical examination including semi-structured interview, cognitive testing, informant history and review of medical records.	– One participant diagnosed with AD. – Four participants diagnosed with Cognitive Impairment. – High rate (80%) of vascular risk factors. – Methodology was appropriate for population.
Russell 2019	Australia. Cross-sectional. To examine the utility of using a culturally appropriate dementia screening tool (KICA-screen) in a telehealth setting.	Aboriginal and Torres Strait Islanders.	NR.	Convenience sample of Aboriginal and Torres Strait Islander people. N= 33. Age: M= 62.9 yrs, SD=9.8 Gender: NR	Participants were recruited from two rural healthcare settings. The KICA-screen was administered to each participant twice, once face-to-face and once using either videoconference equipment or iPads. Order of testing was randomised.	– Comparison of face-to-face and telehealth administered KICA showed good correlation (Pearson's r=0.851; p<0.01) and good agreement (intraclass correlation coefficient=0.85; p<0.01).

Russell 2020	Australia. Cross-sectional. To examine the prevalence of dementia and problems associated with ageing in the Torres Strait.	Torres Strait Islanders.	Involvement of community members and Aboriginal researcher.	N= 274 Aboriginal and/or Torres Strait Islander residents, N= 40 non-Indigenous Torres Strait Island residents. Age: M=65.1, SD=10.8 (range 45-93) Gender: 65.7% female	Participants underwent a comprehensive health assessment and a Geriatrician assessment, which were used to establish consensus diagnoses.	– The prevalence of dementia in the sample was 14.2%, which was 2.87 times higher than the wider Australian population.
Sentell 2015	United States of America. Cross-sectional. To compare rates of hospitalization of people with dementia in Native Hawaiian, Asian-American and white populations in Hawaii.	Native Hawaiian.	NR.	Data on inpatients with dementia in Hawaii. N=13,465 Age: 18 and over M=NR, SD=NR. Gender Chinese: 60% female Filipino: 50% female Japanese: 61% female Native Hawaiian: 61% female White: 57% female.	Data on race, ethnicity, age, sex, and dementia diagnosis extracted from Hawaii Health Information Corporation data for hospitalisations between 2006-2010. Rates of inpatients with a dementia diagnosis were compared between racial and ethnic groups. Rates were calculated using population size denominators derived from the U.S. Census.	– Native Hawaiians had highest rates of inpatients with dementia and at younger ages than other racial and ethnic groups. – Native Hawaiians had an adjusted dementia relative risk of 1.5-2.53 compared to white people
Smith 2007	Australia. Qualitative. To describe the process of developing an instrument to assess cognition in an Indigenous community from the Kimberley region of western Australia.	Indigenous Australians	Involvement Indigenous organisations, community council, local Indigenous workers and community members.	Community members, Indigenous councils, healthcare providers. N= NR. Age: NR. Gender: NR.	Consultation with a range of people within a community in the Kimberley region of Western Australia led to the drafting of the KICA tool. Draft questions were trialled with Indigenous community members over age 45 years.	– Questions were developed and incorporated into the KICA survey – the first specific tool for assessing CI in Indigenous Australians.

Smith 2008	Australia. Cross-sectional. To determine the prevalence of dementia and CI in older Indigenous Australians from the Kimberley region of Western Australia.	Indigenous Australians.	Involvement of local Indigenous workers and community members.	Indigenous community members. N=363. Age: 45 and older; M=60.7yrs, SD=11.9 Gender: 55% women.	Semi-purposeful sampling used to recruit eligible people identified from lists provided by healthcare providers and local community workers across 6 communities and 1 town in the Kimberley region of Western Australia. Participants were assessed with KICA and a sample of those below and above cut off underwent clinical review by specialist clinicians.	– Prevalence of dementia of 12.4% in Indigenous population over 45 years, substantially higher than in non-Indigenous population and other studied populations. – Prevalence of CI not dementia was 8%.
Smith 2009	Australia. Cross-sectional. To re-evaluate the psychometric properties of the KICA-Cog in 2 remote or rural areas populations: Kimberley, Western Australia, and Northern Territory.	Indigenous Australians	Involvement of local Indigenous workers, community council, Elders and community members.	Indigenous community members. N=52 (Northern Territory); 363 (Western Australia). Age Range: 45 and older. M=NR, SD=NR. Gender: 73% female (Northern Territory); 55% female (Western Australia).	In Northern Territory participants recruited by convenience sampling of people with a range of CI through healthcare providers and aged care services. In the Kimberley participants recruited by semi-purposeful sampling through lists provided by healthcare providers and local community workers in 6 communities and 1 town. Assessed using the KICA and independent geriatrician review. Sensitivity, specificity, and cut-off scores calculated using ROC curves.	– KICA-Cog is valid screening tool for dementia in Indigenous Australians living in remote or rural areas – KICA-Cog was most reliable at a cut-off of 33 out of a possible 39. – NT sample: Sensitivity was 82.4% and specificity was 87.5% for diagnosis of dementia – Kimberley sample: Sensitivity was 93.3% and specificity was 98.4%
Smith 2010	Australia. Cross- sectional. To determine the factors (demographic, lifestyle and clinical) associated with dementia in Indigenous Australians from the Kimberley region of Western Australia.	Indigenous Australians.	Involvement of Aboriginal community council, community members and local workers.	Indigenous community members. N=363. Age: 45 and older, M= 60.7yrs, SD=11.9 Gender: 55% women.	Semi-purposeful sampling was used to recruit eligible people identified from lists provided by healthcare providers and local community workers across 6 communities and 1 town in the Kimberley region, WA. Participants assessed with KICA and specialist clinical review for those scoring below cut off and a sample of those above. Demographic, lifestyle, and clinical factors were	– Older age, male gender, no formal education associated with dementia diagnosis. – Other factors associated with dementia included: current smoking, previous stroke, epilepsy, head injury, falls, poor mobility, and urinary incontinence. – Interventions to better manage preventable risk factors are needed.

					collected during the KICA screen from participants and informants. Factors associated with dementia assessed by univariate and multivariate logistic regression.	
Smith 2011	Australia. Qualitative. To identify the unmet needs of PWD living in a remote community in the Kimberley region of Western Australia and identify ways to improve the delivery of services.	Indigenous Australians.	Steering Committee of Aboriginal caregivers, service providers and Aboriginal community council.	Service providers (n=42), community care workers and caregivers of Indigenous PWD (n=31) and community representatives. Age: NR Gender: NR.	An Aboriginal researcher conducted in-depth interviews with those involved in the care and delivery of services to Indigenous PWD living in remote communities of the Kimberly. Initial interviews informed the themes discussed at 4 focus groups with community representatives and care workers. Thematic analysis.	– Barriers to accessing quality care included availability of community-based culturally safe services, communication between services, lack of interpreters, and factors associated with remote location (e.g., high living costs, lack of transport options, overcrowded houses). – Recommendations to address unmet needs included having genuine community engagement, having an Aboriginal workforce and community, caregiver and client education, and staff and external service provider training about dementia.
Smith 2016	Australia. Cross-sectional. To develop and adapt the KICA Carer tool.	Indigenous Australians	Involvement Indigenous organisations, community council, local Indigenous workers and community members.	Nominated informants from the Kimberley region of Western Australia. N=349. Age: NR. Gender: NR.	Informants were nominated by Indigenous PWD. The PWD were identified from lists provided by healthcare providers and local community workers across 6 communities and 1 town in the Kimberley region, Western Australia. The informant's KICA Carer results were reviewed by a specialist psychiatrist or geriatrician blinded to the PWD's KICA results. Sensitivity, specificity, and cut-off scores calculated using ROC curves.	– KICA Carer is a useful tool to screen dementia when the KICA Cog is unable to be used. – KICA Carer was most reliable at a cut-off of ≥3 out of a possible 16. – KICA Carer is acceptable to carers. – KICA Carer score of >=3/16 gave optimum sensitivity (76.2%) and specificity (81.4%) – A KICA Cog score of <=33/39 gave a sensitivity of 92.9% and specificity of 89.9% – Cut-off scores of KICA Cog <= 33/39 and KICA Carer >= 2/16 in series indicate possible dementia,

						with sensitivity of 90.5% and specificity of 93.5%.
Taylor 2012	Australia. Qualitative. To evaluate a dementia awareness resource developed by Alzheimer's Australia in the Northern Territory in English and 3 Aboriginal Languages.	Aboriginal Australians	Involvement of Aboriginal community members, Indigenous researcher and advisory group.	Community members, aged care workers (N=26), and healthcare providers (N=5). Age= NR. Gender = NR.	Focus groups, individual interviews and observation of the resources were conducted across 4 communities in NT. Cross-case and thematic analysis conducted.	– Resources was able to change attitudes, awareness and understanding of dementia. – Effective elements included involvement of Aboriginal people at all stages of development, skilled facilitation, a clear implementation strategy, use of local languages and images and specific vocabulary to discuss dementia.
Verney 2008	United States of America. Cross- sectional. To investigate the relationship between depressive symptoms and CI in older American Indians.	American Indians (Northern Plains).	Involvement of Indigenous field staff.	Community members receiving nutrition programme. N= 140. Age: 60 and older; M=69 yrs (depression symptoms), M=70yrs (no depression symptoms) SD= NR. Gender: 71% female	Older American Indians were recruited through 10 nutrition programme sites. Participants completed an interview and were assessed using a depression screen (derived from the composite international diagnostic instrument), MMSE and Mattis Dementia Rating Scale. Assessed statistical differences in demographic and health factors according to depression symptom status with t-tests and chi-squared tests. Regression methods to re-examine the association between depression symptoms and each of our cognitive functioning measures after adjusting for sociodemographic and health factors.	– Depression screen not associated with total MMSE or Mattis Dementia Rating Scale scores. – Those with depressive symptoms did score lower on Mattis Dementia Rating Scale conceptualization subscale than those without depressive symptoms when sociodemographic and health factors were accounted for. – Combined effect likely to adversely impact health and welfare.

Wadsworth 2016	United States of America. Cross- sectional. To determine the feasibility and reliability of administering standard neuro-psychological tests via video teleconference to rural Native Americans.	Native Americans.	NR.	Patient of healthcare provider. N= 84 Age: M=64.89yrs, SD=9.7 Gender: 63% female.	Participants with and without dementia or CI were recruited through an AD centre in Oklahoma. Each participant completed a battery of tests, including the MMSE and Clock Drawing, both face-to-face and via video conferencing. Intraclass correlation coefficients were compared.	– Scores measured face-to-face and via video teleconference were similar. – Video teleconferencing is a feasible and reliable way to screen individuals living in rural locations.
Webkamigad 2019	Canada. Qualitative. To explore the appropriateness of nationally developed health promotion materials about dementia for Indigenous people living in urban communities in Northern Ontario.	Indigenous people of Northern Ontario.	Involvement of local Indigenous advisory group and partnership with community health centre.	Informal caregivers and community members. N=12. Age: community members 55yrs or older; caregivers over 16 yrs. M=NR, SD=NR. Gender: 8 females; 4 males.	Snowball sampling and advertisements were used in one city to recruit indigenous adults including those who provided care to a family member, friend, or neighbour with dementia. Participants were provided with two dementia fact sheets developed nationally and took part in focus groups or interviews to discuss these. Qualitative thematic analysis was conducted.	– It is important to provide locally and culturally relevant health information to improve uptake and effectiveness.
Weiner 2003	United States of America. Cohort. To compare the medical history and initial clinical presentation of Native Americans and Whites diagnosed with possible or probable AD.	Native Americans.	NR.	Patients of University of Texas Southwestern medical centre or outreach clinics in Oklahoma. N=91 Native Americans; 509 whites Age: M at evaluation= 75.6yrs (Native American); 73.3yrs (Whites).	Data extracted from database held by the University of Texas Southwestern AD Centre for Native American and White patients diagnosed with possible or probable AD between 1993 and 2002. Characteristics of the two groups were compared with standard statistical tests.	– AD in Native Americans followed similar course to in Whites in terms of survival time after diagnosis and MMSE score at evaluation. – Age of onset of symptoms slightly lower in Whites. – Lower education level, greater prevalence of depression and cardiovascular risk factors in Native Americans.

				Gender: 64% female (Native Americans); 66% (Whites). SD=NR.		
Weiner 2007	United States of America. Cohort. To compare the course of AD in Native Americans, whites and African Americans.	Native Americans/ Alaska natives.	NR.	Population based. N= 30,993 Age (at initial visit) Indian: M =75.8, SD=9.4 Gender: 66% female. White: M= 75.3, SD=8.7 Gender: 62% female. African American: M= 76.7, SD=8.3 Gender: 74% female.	Data was extracted from the national Alzheimer's Coordinating centre database for Native Americans / Alaska Natives, whites, and African Americans. Demographic and clinical factors including education, family history of dementia, age at symptom onset and evaluation, MMSE scores comorbidities and duration of illness were compared using standard statistical tests.	– No clinically significant differences between groups in the course of AD. – Native Americans had lowest proportion with affected first-degree relatives, depression, and extrapyramidal symptoms. – Whites had the highest proportion with affected first-degree relatives and depression, but the lowest history of stroke. – African Americans had the highest proportion with history of stroke and extrapyramidal symptoms.
Weiner 2008	United States of America. Cross- sectional. To examine the prevalence of Atherosclerosis risk factors in American Indians with AD.	Native Americans.	NR.	Patients of University of Texas Southwestern medical centre outreach clinic in Oklahoma. American Indian AD Group: N=34, Age: Median= 78 M=NR, SD=NR. Gender: 62% female	American Indian participants with AD were recruited from the University of Texas Southwestern medical centre outreach clinics in Oklahoma. Age-matched control American Indians without AD were recruited through patients and at health fairs. Data for age-matched whites with AD was taken from the centre's database. Prevalence of hypertension, myocardial infarction, stroke, diabetes,	– History of hypertension and diabetes was significantly more common among American Indian AD patients than Indian controls or whites with AD. – The 3 groups did not differ in history of stroke or myocardial infarction. – Body mass index was significantly greater in both Indian groups than the white AD group.

				American Indian Control Group: N=34, Age: Median=75.5 M=NR, SD=NR. Gender: 68% female White AD Group: N=34, Age: Median=76.5 M=NR, SD=NR. Gender: 41% female	and high cholesterol, weight, and blood factors were compared using standard statistical tests.	– Preliminary evidence of association between history of hypertension and diabetes and AD in American Indians.
Weiner 2011	United States of America. Cross- sectional. To examine the use of videoconference technology in diagnosing and treating those with symptoms of CI.	Native Americans.	NR.	Patients of the Choctaw Nation Healthcare Centre. N=85 patients (171 appointments). Age: M at first visit=69.67yrs, SD=12.8 Gender: 53% female	Descriptive analysis of data collected routinely by the video conference clinic including diagnosis at initial consultation, number of follow-up visits, attendance, staff time and costs.	– 55% were diagnosed with dementia at initial consultation. – Videoconference diagnosis/treatment was feasible and acceptable. – Barriers to the use of videoconference appointments included patients travel to clinic still needed, cultural issues and high running costs. – Aspects that worked well included hiring Native Americans people at the clinic and reminders of appointments.
White 2019	Australia. Cross-sectional. To estimate the prevalence of CI among homeless people in Cairns, Queensland.	Aboriginal and Torres Strait Islander.	Involvement of a cultural advisor.	Residents of homeless shelter, 75% of which were Aboriginal or Torres Strait Islander people. N=60. Age Range: 15-60+ M=NR, SD=NR. Gender: 33% female	Opportunistic sample of residents of a homeless shelter were interviewed and screened with the KICA-Cog, clinical assessment, and WHO Disability Assessment Schedule. Descriptive statistics and test for correlation (pearson's correlation coefficient).	– 35.3% of participants who completed KICA-Cog scored below 33, indicative of screening positive for dementia or global CI. – 70% presented with clinically significant CI. – Indicated dementia or global CI was correlated with greater difficulties in understanding, communicating, self-care and life activities.

Whyte 2005	United States of America. Cross-sectional. To determine if the Consortium to Establish a Registry for Alzheimer's Disease Neuropsychological Battery is affected by cultural difference between Native Americans and Caucasians.	Native Americans.	NR.	Native American and Caucasian clients of a Medical Center and outreach clinics. Native Americans N=40 Age: M=76.04, SD=7.4 Gender: 73% female. Caucasians N=40 Age: M=75.69, SD=7.1 Gender: 73% female.	Participants were patients at a southwestern medical centre or an outreach clinic. Caucasian participants were matched for demographic characteristics to Native American participants. All were administered the Consortium to Establish a Registry for Alzheimer's Disease Neuropsychological Battery. Groups were compared using independent samples t tests.	– No difference between Native Americans and Caucasians on the Consortium to Establish a Registry for Alzheimer's Disease Neuropsychological Battery. – Consortium to Establish a Registry for Alzheimer's Disease Neuropsychological Battery is therefore efficient cognitive screening assessment in English-speaking Native Americans.
Wiese 2020	United States of America. Parallel mixed methods. To examine Appalachian stakeholder attitudes toward routine memory screening, and to compare results from a similar study conducted in an ethnically diverse rural Florida cohort.	Rural Appalachian location – Indigenous group/s not specified	NR.	N = 22 Appalachian, rural stakeholders (residents, health providers, administrators). Age: M=64, SD=2.1 Gender: 73% female	Semi-structured interviews, measurements of health literacy using the Rapid Estimate of Adult Literacy in Medicine—Short Form, socio-demographics and cognitive screening perceptions using the Perceptions Regarding Investigational Screening for Memory in Primary Care to examine beliefs about memory screening.	– 90% of participants were highly supportive of earlier dementia detection through routine screening. – 50% of those interviewed were doubtful that provider care or assistance would be adequate for this illness.

Table 2. Ethical aspects of involving participants with cognitive impairment in research (n=24).

Reference	Inclusion/exclusion of participants with CI or dementia	Consent to participate	Strategies to support participation	Relationship with Indigenous organisations & communities	Ethical approval processes	Ethical and legal governance frameworks
Chen 2019	Inclusion: aged >55 years, able to communicate verbally. Exclusion: unable to communicate verbally; unable to leave home – these criteria excluded people with "late-stage dementia".	"Participants agreed to participate and signed a written informed consent".	- Some interviews done in person's home and with translator.	First author a manager for a long-term care project in the Aboriginal community and had pre-existing trusting relationships with tribal persons.	Approval from 1 ethics committee (hospital).	Not reported.
Forbes 2013	Inclusion: speak English; have dementia diagnosis.	Consent sought from a proxy (e.g., care partner) and assent from person with dementia.	- Not reported.	Administrators and frontline staff from community health centre involved in study design.	Approval from: 2 ethics committees (university and health service provider); Chief and Band Council of the participating First Nations community.	Not reported.
Gilmour 2016	Inclusion: ability to consent, verbally communicate their experience, and indicate that	"Participants consented to be interviewed".	- People with dementia interviewed with care partner.	Research was carried out as a partnership between Te Rōpū Rangahau Hauora	Approval from 1 ethics committee (described as	Not reported.

Reference	Inclusion/exclusion of participants with CI or dementia	Consent to participate	Strategies to support participation	Relationship with Indigenous organisations & communities	Ethical approval processes	Ethical and legal governance frameworks
	they understood the purpose of the study.			a Eru Pōmare and Alzheimer's New Zealand	'multi-region' committee).	
Hocking 2019	Inclusion: Aged 45 years or older Exclusion: No legal guardian to provide consent.	"Consent was obtained from the individual or legal guardian".	- Culturally adapted consent forms, study information sheets and a pictorial flip chart that used pictures, plain English and minimal text were used. - Interpreter services used for most cognitive screening interviews which covered six different Central Australian languages. - Interviews were conducted in participant's room or quiet place in aged care facility.	None reported.	Approval from 2 ethics committees (NT Health and Central Australian HREC).	Complied with ethical standards of the relevant national and institutional committees and with the Helsinki Declaration of 1975.
Hulko 2010	Inclusion: Older person with memory loss or dementia. No further details provided.	"Attainment of informed consent (oral or written)".	- Data collected via sharing circles and in-home interviews. Process included refreshments, discussion of ethics protocol, consent, discussion to collect data, gifting of tobacco pouches and honorarium. - Interviews involved photo elicitation and third party questioning which was considered a culturally safe approach.	First Nations elders were advisors for the project and research agreements were negotiated and signed with each community.	Approval from 2 ethics committees (university and health authority), after negotiation of ethical protocol with communities.	First Nations principles of OCAP (ownership, control, access, and possession) were respected.
Jervis 2007	Inclusion: Aged 60 years or older.	"All participants signed approved consent forms."	- Focus groups were conducted on the reservation. - Slight modifications were made to language (e.g., On Mini Mental State Exam, spell WORLD changed	Participating tribe not named due to confidentiality agreement with tribe.	Approval from 2 ethics committees (state and Indian Health Service), as well	Not reported.

Reference	Inclusion/exclusion of participants with CI or dementia	Consent to participate	Strategies to support participation	Relationship with Indigenous organisations & communities	Ethical approval processes	Ethical and legal governance frameworks
			to spell TRIBE. For Mattis Dementia Rating Scale, "Stick out tongue and raise hand" changed to "Smile and raise hand" to avoid cultural offensiveness.)		as additional approval from tribal government.	
Kirkpatrick 2019	Inclusion criteria: Self- identified American Indian race, at least two vascular risk factors, and willingness to participate. Exclusion criteria: prior diagnosis of CI, use of memory loss medications, stroke in last 6 months, self-reported intake of narcotic medications, sedatives, alcohol, or illicit drugs within 2 h before cognitive screening.	"Individual informed consent was obtained for all study participants."	- Not reported.	Research team collaborated with a Native American Navigator Program through the state Veterans Affairs healthcare system.	Approval from 2 committees (university ethics committee and local Veterans Affairs Research and Development Committee).	Complied with Veterans Affairs Research and Development Committee rules and the Helsinki Declaration.
Lavrencic 2018	Inclusion: aged 60 years and older, living in the five study catchment areas for at least 6 months.	"Participants provided written informed consent or, when unable to provide written consent, gave verbal assent with written consent obtained from the appropriate relative/caregiver."	- Not reported.	Research team had established relationships Aboriginal organisations and authorities in participating communities. A guidance group for the study included community Elders.	Approval from 3 ethics committees (Aboriginal Health & Medical Research Council, university, and NSW Health).	Not reported.

Reference	Inclusion/exclusion of participants with CI or dementia	Consent to participate	Strategies to support participation	Relationship with Indigenous organisations & communities	Ethical approval processes	Ethical and legal governance frameworks
LoGiudice 2006	Recruitment focused on people with memory problems and possible dementia.	Individual consent determined from participants and/or family members, for those taking part in inter-rater reliability assessment and development and testing of KICA-Cog.	- Interpreters were used when required. - The KICA-Cog was translated and back-translated from English to the Walmajarri language to ensure that all questions were clear in their meaning.	Consent from individual communities was obtained. Research occurred in collaboration with various Aboriginal community councils, health and community service organisations, a language resource centre, and an interpreting service.	Approval from 3 ethics committees (Aboriginal Medical Services Council, state Aboriginal HREC, and University HREC).	Not reported.
LoGiudice 2011	Inclusion: Residents over the age of 45 years living in six remote Aboriginal communities.	Each participant or family member and carer provided informed consent.	- Not reported.	Not reported.	Approval from 3 committees (state Aboriginal HREC, University HREC, Health service district HREC) as well as the District Managers from three health services.	Not reported.
Lo Giudice 2016	All eligible Indigenous people aged 45 years or over living in six communities and a random sample of one third of eligible Indigenous people in another community.	"All participants provided written informed consent."	- Cognitive assessment tools used were developed and validated specifically for this Aboriginal population.	Approval to complete study negotiated with each participating community and regional organisations.	Approval from 2 ethics committees (state Aboriginal HREC and University HREC) and 3 regional organisations (Aboriginal	Statement that research complied with Helsinki Declaration.

Reference	Inclusion/exclusion of participants with CI or dementia	Consent to participate	Strategies to support participation	Relationship with Indigenous organisations & communities	Ethical approval processes	Ethical and legal governance frameworks
					Medical Services Council, Aged & Community Services; Aboriginal Health Planning Research Subcommittee)	
Pu'un 2014	Inclusion: Aged 60 and over, able to consent. Exclusion: if "mental retardation, severe sensory impairment or debilitating physical illness which might hinder proper interview and assessment"	Statement that participants needed to be able to consent.	- Data collected by house-to-house visits in villages. - First author familiar with the indigenous culture and language (however eligible participants had to speak Malay or English).	Not reported.	Approval from 2 ethics committees (university HREC and government health)	Not reported.
Radford 2015	Inclusion: Aboriginal or Torres Strait Islander people aged 60 years and older, living in one of the five catchment areas for 6 months or longer. Exclusion: Current incarceration or stroke within the past 3 months.	All participants gave written informed consent or, in the case of reduced capacity to consent, gave their assent and proxy informed consent was obtained.	- Data were collected at the participant's place of residence or at local community health or research centres. - Aboriginal research assistants from the local community were present for data collection.	Partnership with ACCHSs, and under the guidance of local community Elders and a study-specific Aboriginal reference group. Study recruitment was facilitated through local Aboriginal research assistants, with the support of community organizations and local guidance groups.	Approval from 3 ethics committees (1 state based Aboriginal HREC, 1 university HREC and one state-based population health HREC).	Not reported.

Reference	Inclusion/exclusion of participants with CI or dementia	Consent to participate	Strategies to support participation	Relationship with Indigenous organisations & communities	Ethical approval processes	Ethical and legal governance frameworks
Radford 2015	Inclusion: Aboriginal and/or Torres Strait Islander, age 60 years and older at the time of study enrolment, residing in the study site for at least 6 months. Exclusion: Current incarceration or stroke within the past 3 months	All participants gave written informed consent or, in cases when capacity to consent was lacking, gave verbal assent and written informed consent was obtained from an appropriate relative or a caregiver.	- Not reported.	Study undertaken in collaboration with local ACCHSs and local Elders across five Aboriginal communities.	Approval from 3 ethics committees (1 stated based Aboriginal HREC, 1 university HREC and one state-based population health HREC).	Not reported.
Radford 2019	Inclusion: Aboriginal and/or Torres Strait Islander identification, age 60 years and older at the time of study enrolment, and residing in the study site for at least 6 months Exclusion: Current incarceration or stroke within the past 3 months	Participants gave written informed consent or, in cases where capacity to consent was lacking, gave verbal assent and written informed consent was obtained from an appropriate relative or a caregiver.	- Employed local community members to support recruitment, data collection, feedback, and culturally safe engagement with participants	Partnership with local Aboriginal Community Controlled Health Organizations (ACCHOs) and other key community organizations	Approval from 3 ethics committees (Aboriginal, university and HREC).	Not reported.
Russell 2016	Inclusion: Residents aged 45 years and over living on Hammond Island in the Torres Strait	Not reported.	- Potential participants were approached by the local primary health care staff.	Not reported.	Approval from 2 ethics committees (1 University HREC,	Not reported.

Reference	Inclusion/exclusion of participants with CI or dementia	Consent to participate	Strategies to support participation	Relationship with Indigenous organisations & communities	Ethical approval processes	Ethical and legal governance frameworks
			- Assessments were conducted in the participant's home or at the local council office.		1 state based HREC).	
Russell 2019	Inclusion: Aboriginal and Torres Strait Islander people aged 45 years and older attending two local rural healthcare settings (memory outreach clinic or local hospital). Exclusion: Severe hearing or visual impairment or medically unstable.	Each participant provided informed consent.	- An assistant sat in the room during the telehealth assessments to hand participants a pencil and paper for the praxis task and to ensure that vision and hearing aids were used when necessary. The assistant did not assist with the assessment.	Not reported.	Approval from 2 ethics committees (HREC and University).	Not reported.
Smith 2008	Inclusion: All eligible Indigenous people aged 45 years or over living in six communities and a random sample of one third of eligible Indigenous people in another community.	Each participant (and carer where relevant) provided informed consent.	- Indigenous men and women were employed in each community to assist with data collection.	Indigenous men and women were employed in each community to assist with data collection. Individual community council approval was obtained from each community.	Approval from 2 ethics committees (HREC and University).	Not reported.
Smith 2009	Inclusion: Indigenous Australians aged ≥45 years	Informed consent was sought from and provided by each participant and/or their carer where there was prior evidence of CI or dementia.	- The information on the cover sheet was read to participants by the researchers with the use of interpreters when required. - The cover sheet was given to each participant or, in cases in which they were not literate, to the informant or a literate family member.	Community consultation occurred at the remote community level with councils, interested elders and community members, Community Development and Employment Project coordinators and administrators. Ongoing consultation occurred with	Approval from 3 ethics committees (two Aboriginal state based HRECs and 1 University HREC).	Not reported.

Reference	Inclusion/exclusion of participants with CI or dementia	Consent to participate	Strategies to support participation	Relationship with Indigenous organisations & communities	Ethical approval processes	Ethical and legal governance frameworks
			- When participants were unable to sign their name, they signed with a cross.	local services. Council approval was obtained from each community.		
Smith 2010	<u>Inclusion</u>: All Aboriginal community members aged > 45 years living in the communities at least 6 months of the year. People living in residential care that were originally from community were also eligible.	Community council and individual approval was sought and gained, with assistance from paid interpreters or Aboriginal community workers.	- Aboriginal community workers were trained in study procedures and undertook data collection. - Interpreters were employed as required.	Collaborated with local health services and community office for recruitment of participants.	Approval from 2 ethics committees (HREC and Uni).	Not reported.
Verney 2008	<u>Inclusion:</u> Clients aged 60 and older, American Indian and living within a five-mile-radius of a senior nutrition centre and attending that centre.	Not reported.	- Recruitment was conducted by trained field staff who were themselves tribal members.	Not reported.	Approval from 3 entities (the Indian Health Service, the Colorado Multiple Institutional Review Board, and the tribal government).	Not reported.
Wadsworth 2016	Not reported.	"Each participant provided written informed consent prior to participating"	- Authors noted that no special assistance was required even among individuals with CI.	Project was approved by the Choctaw Nation	Approval from 2 ethics committees (university and Choctaw Nation)	Not reported.

Reference	Inclusion/exclusion of participants with CI or dementia	Consent to participate	Strategies to support participation	Relationship with Indigenous organisations & communities	Ethical approval processes	Ethical and legal governance frameworks
Weiner 2008	Inclusion criteria: Indians with probable and possible dementia, white people with probable dementia and Indians without dementia with specified data available.	All Indian participants with dementia and their caregivers signed informed consent documents approved by the UT Southwestern Institutional Review Board and the Choctaw nation Institutional Review Board. Indian participants without dementia also signed informed consent.	- Not reported.	Not reported.	Approval from 2 institutional review boards.	Not reported.
White 2019	Inclusion: Individuals using a homeless shelter on any night during a 12-week assessment phase during study period.	Individuals provided consent to participate.	- Cultural Advisors spent 12 weeks at the shelter developing rapport and trust with shelter occupants. Over time the Cultural Advisor and the Research Team were able to discuss the project and its methodology with the occupants and engaged in a range of cultural ceremonies to allow the team to commence the project. - Participants were offered a culturally safe and appropriate clinical cognitive assessment.	Not reported.	Approval from 1 ethics committee (FNQ HREC).	Not reported.