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Culturally congruent risk reduction for dementia and related risk factors in Indigenous populations: a scoping review protocol

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ADMINISTRATIVE INFORMATION

Support - Canadian Institute of Health R.

Review Stage at time of this submission - Piloting of the study selection process.

Conflicts of interest - None declared.

INPLASY registration number: INPLASY202650146

Amendments - This protocol was registered with the International Platform of Registered Systematic Review and Meta-Analysis Protocols (INPLASY) on 27 May 2026 and was last updated on 27 May 2026.

INTRODUCTION

Review question / Objective The aim of this international scoping review is to describe peer-reviewed and grey literature on culturally congruent health promotion materials for dementia and dementia risk factors (e.g., diabetes, hypertension) with Indigenous peoples in the countries of Australia, Aotearoa New Zealand, Canada, and the United States of America (USA). These four countries were chosen due to their shared history of British colonization, consistent with the approach used in previous reviews (e.g., Wallace et al., 2026). This review will identify key features of existing health communication resources that support dementia risk reduction with Indigenous communities internationally. Specifically, this review focuses on dementia and the mid- to late life modifiable risk factors as outlined in the 2024 Lancet report (6). The decision to exclude the early-life risk factor of less education is based on the project aim of co-developing health communication materials, which is not readily applicable to education attainment.

This review expands on previous work by Wallace and colleagues (20) by broadening the scope and examining resources for dementia and/or dementia risk factors, regardless of whether the risk is specific to dementia or aging. Furthermore, resources created for any age will be included.

Review Question: What culturally congruent health communication materials exist for dementia and mid- to late life modifiable dementia risk factors with Indigenous populations (Australia, Aotearoa New Zealand, Canada, USA)?

Sub questions

How many resources are available for each risk factor?

Whom are the resources designed with/for? (age, population, setting)

What design approaches have been used (strategies, theories, content, delivery)

Outcomes of Interest:

Identify current health communication guidelines, strategies, and resources focused on dementia risk reduction and related risk factors that are available for Indigenous adults, their caregivers, and their healthcare practitioners

Understand how these resources were designed to inform future co-design of health communication resources.

Background Dementia is a term for several progressive neurodegenerative brain conditions that primarily impact older adults, affecting both cognitive abilities and behaviour (1-4). There are no known cures for dementia, meaning prevention through risk reduction strategies is a public health priority (1, 5). The 2024 report of the Lancet Commission identified 14 potentially modifiable risk factors for dementia that may prevent up to 45% of dementias (6). Public health programs that help reduce modifiable risk factors that contribute to dementia are critically important for preventing or delaying dementia, and promoting brain health throughout life.

Dementia rates across Indigenous populations are higher and more frequently diagnosed at a younger age than in non-Indigenous populations (7-13), with evidence demonstrating that systemic and structural policies and practices resulting from colonization contribute to this difference (14). Similar to the general population, modifiable risk factors are seen to be significant contributors to rates of dementia with Indigenous populations (15). There is an urgent need for health promotion programs and resources that are co-developed, effective, and culturally congruent for Indigenous communities. Despite the known inequities in dementia rates, these types of programs and resources are largely unavailable for Indigenous communities (16-18).

Health communication is a key aspect of high-quality health care, as effective health communication enables access to and comprehension of information, empowering individuals to make informed health decisions (19). However, Indigenous-centred resources that promote culturally appropriate health communication about dementia risk reduction are lacking.

Rationale Without work to develop culturally congruent pathways to improve dementia recognition, health navigation, and risk reduction, the development and translation of culturally valid tools continues to leave Indigenous people at risk of dementia isolated within western/colonial health systems. Development and translation of culturally congruent resources and activities that promote health communication will strengthen relational pathways to improve the health and wellbeing of Indigenous peoples living with, and at risk of, dementia. This scoping review is a key step in mapping resource strengths and needs and

supporting the co-development of culturally congruent resources with community.

METHODS

Strategy of data synthesis We will search all study designs in peer-reviewed and grey literature that reports or outlines a program or resource so that we can extract relevant or helpful information to co-design future resources with Indigenous communities.

Academic peer-reviewed sources will be located by searching Ovid (Medline, Embase, PsycINFO, Healthstar), CINAHL, Informit Indigenous Collection, and Web of Science. Systematic reviews will be excluded from results but will be used for hand searching references. Unpublished and grey literature will be searched using targeted searches of government, public health offices, and regional and Indigenous health authorities in the countries of interest, and a search of clinical practice guidelines via Trip Pro, Dynamed, Guideline Central, and NICE Guidelines. Source results and selection will be managed through the online platform, Covidence.

Search Terms:

- 1 exp Indigenous Populations/
- 2 Indigen*.tw,id.
- 3 exp Inuit/
- 4 Inuit.tw,id.
- 5 Metis.tw,id.
- 6 exp American Indians/
- 7 American indian*.tw,id.
- 8 ((Alaska* or Hawaii*) adj2 native*).tw,id.
- 9 Aborigin*.tw,id.
- 10 First Nation*.tw,id.
- 11 circumpolar.tw,id.
- 12 Maori.tw,id.
- 13 Torres Strait Islander*.tw,id.
- 14 1 or 2 or 3 or 4 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13
- 15 Canad*.tw,id.
- 16 Alberta.tw,id.
- 17 Saskatchewan.tw,id.
- 18 Manitoba.tw,id.
- 19 Ontario.tw,id.
- 20 New Brunswick.tw,id.
- 21 Nova Scotia.tw,id.
- 22 Prince Edward Island.tw,id.
- 23 Newfoundland.tw,id.
- 24 Yukon.tw,id.
- 25 Northwest Territories.tw,id.
- 26 Nunavut.tw,id.
- 27 Australia*.tw,id.
- 28 Queensland.tw,id.
- 29 New South Wales.tw,id.
- 30 Victoria.tw,id.
- 31 Tasmania.tw,id.

- 32 New Zealand.tw,id.
 33 Aotearoa.tw,id.
 34 United States.tw,id.
 35 USA.tw,id.
 36 America*.tw,id.
 37 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36
 38 exp Neurodegenerative Diseases/
 39 exp Neurocognitive Disorders/
 40 dementia.tw,id.
 41 alzheimer*.tw,id.
 42 neurodegenerative.tw,id.
 43 exp Chronic Illness/
 44 chronic.tw,id.
 45 exp Chronic Obstructive Pulmonary Disease/
 46 COPD.tw,id.
 47 exp Chronic Mental Illness/
 48 depressi*.tw,id.
 49 anxi*.tw,id.
 50 traumatic brain injur*.tw,id.
 51 exp Chronic Psychosis/
 52 exp Chronic Pain/
 53 exp Chronic Symptoms/
 54 exp Chronic Stress/
 55 exp Disease Progression/
 56 exp Endocrine Disorders/
 57 exp Metabolism Disorders/
 58 T2D.tw,id.
 59 diabet*.tw,id.
 60 obes*.tw,id.
 61 overweight*.tw,id.
 62 high BMI.tw,id.
 63 high LDL cholesterol.tw,id.
 64 exp Blood Pressure Disorders/
 65 high blood pressure.tw,id.
 66 hypertension.tw,id.
 67 exp Cardiovascular Disorders/
 68 exp Hearing Loss/
 69 hearing loss.tw,id.
 70 exp Vision Disorders/
 71 ((visual or vision) adj2 loss).tw,id.
 72 exp Social Isolation/
 73 social isolation.tw,id.
 74 exp Alcohol Abuse/
 75 alcohol.tw,id.
 76 exp Addiction/
 77 addict*.tw,id.
 78 exp Pollution/
 79 pollution.tw,id.
 80 exp Asthma/
 81 asthma*.tw,id.
 82 exp Tobacco Smoking/
 83 smoking.tw,id.
 84 exp Vaping/
 85 vaping.tw,id.
 86 nicotine.tw,id.
 87 exp Sedentary Behavior/
 88 sedentary.tw,id.
 89 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74 or 75 or 76 or 77 or 78 or 79 or 80 or 81 or 82 or 83 or 84 or 85 or 86 or 87 or 88
 90 exp Harm Reduction/
 91 harm reduction.tw,id.
 92 exp Risk Management/
 93 (risk adj2 (mitigat* or manag* or reduc*)).tw,id.
 94 exp Protective Factors/
 95 protective factor*.tw,id.
 96 exp Prevention/
 97 prevent*.tw,id.
 98 exp Intervention/
 99 intervention*.tw,id.
 100 pilot.tw,id.
 101 exp Prescription Drugs/
 102 prescription*.tw,id.
 103 exp Client Education/
 104 ((patient or client or caregiver or individual or health) adj2 (education or materials)).tw,id.
 105 exp Evidence Based Practice/
 106 evidence based practice.tw,id.
 107 exp Treatment Guidelines/
 108 guideline*.tw,id.
 109 90 or 91 or 92 or 93 or 94 or 95 or 96 or 97 or 98 or 99 or 100 or 101 or 102 or 103 or 104 or 105 or 106 or 107 or 108 1135367
 110 14 and 37 and 89 and 109
 111 limit 110 to yr="2010 -Current".
- Eligibility criteria** The Participant, Concept, Context (PCC) framework (22) was used to create the inclusion criteria and search strategy. Participants. Indigenous people, care partners, and health practitioners working with Indigenous peoples. Concept. Health promotion guidelines, strategies, resources, etc. that support risk reduction for dementia and dementia risk factors (6). Specifically, we are interested in resources designed or adapted with, by and for Indigenous peoples (23). Context. Indigenous peoples in the countries of Australia, Aotearoa New Zealand, Canada, and the USA. The resource may be designed for use in any setting (community, health practitioner's office, long-term care facility). Inclusion: -Dementia and known mid- to late life modifiable dementia risk factors as outlined in the Lancet 2024 report (6): Hearing Loss, High LDL cholesterol, Depression, Traumatic brain injury, Physical inactivity, Diabetes, Smoking, Hypertension, Obesity, Excessive alcohol, Social isolation, Air pollution, Visual loss

- Indigenous populations (Australia/USA/Canada/New Zealand)
 - Health communication materials, guidelines, strategies, resources, etc. for health promotion/risk reduction that have been designed or adapted with, by and for Indigenous peoples (23)
 - Designed for use in any setting (i.e., community, health practitioner's office) by the Indigenous person and/or their supports (e.g., caregiver, health practitioner)
 - Complete paper/report
 - Published since 2010 (20)
- Exclusion:
- Wrong concept: resource is not about dementia or known dementia risk factors
 - Wrong concept: Alcohol-associated dementia, HAD, neurodevelopmental associated dementia, gestational diabetes, studies that focus on suicide without mention of depression or mental illness
 - Wrong population: Non-Indigenous populations
 - Wrong population/country: Indigenous populations in countries other than Australia, USA, Canada or Aotearoa New Zealand
 - Wrong aim: Not health communication/health promotional/risk-reductive/preventative in nature, and/or focused on assessment, screening, post-diagnostic care, management of a condition, or service improvement/access to services
 - Wrong methods: Not developed, designed nor adapted by/with/for Indigenous populations
 - Conference abstracts, books, dissertations, opinion pieces, reviews, protocols
 - Published before 2010.

Source of evidence screening and selection

Abstract and title review for inclusion/exclusion will be managed through Covidence. Two independent reviewers will screen each title and abstract against the scoping review's inclusion criteria. Disagreements between reviewers will be resolved through discussion. An additional reviewer, the lead Indigenous team member and Principal Investigator (PR), will review the source if agreement cannot be achieved. During title and abstract screening, review articles meeting topical relevance will be excluded, but tagged in Covidence for subsequent hand searching. We will retrieve full-text versions of initially included sources and assess during full text screening for final inclusion using the same dual reviewer strategy as was used for title and abstract screening.

Data management Two independent reviewers will use a common data extraction form in Excel. The data extraction form will include information such as title, author, document type, publication year, study design, sample characteristics (region,

age range, Indigenous identity), health condition or risk factor, setting, objective, underlying theory, delivery method, content, and design features/approaches. Disagreements between reviewers will be resolved through discussion. An additional reviewer, the lead Indigenous team member and Principal Investigator (PR), will review the source if agreement cannot be achieved.

Reporting results / Analysis of the evidence We will use the Ways Tried and True (WTT): Aboriginal assessment rubric for public health interventions (24) to assess the extent to which interventions used community-based approaches in its design and delivery. Data will be analysed primarily using descriptive qualitative methods. However, quantitative methods will be used to tabulate number of studies and age range of studies. Qualitative coding will be used to synthesize information on the key characteristics of the resources and design approaches. Results will be presented in a table and supported by a narrative summary.

Presentation of the results Results will be published in an open-access, peer reviewed journal.

Language restriction Articles restricted to English.

Country(ies) involved Canada and Australia.

Other relevant information This scoping review is part of a larger project led by Drs. Pamela Roach and Kate Smith, Co-design of Indigenous dementia Resources in Canada and Australia (CIRCLE): Enhancing health communication for Indigenous peoples along the dementia journey, which is funded by a Canadian Institute of Health Research (CIHR) CCNA Team Grant (Grant Number 02566-000).

The CIRCLE Team is made up of an international group of researchers, community collaborators, and people with lived experience including Dawn Bessarab, Tamara Bodnar, Leon Flicker, Jodie Gawryluk, Lianne Gilchrist, Zahra Goodarzi, Dina LoGiudice, Roslyn Malay, Carrie McAiney, Laura Middleton, Megan O'Connell, Camela Pestell, Sarah Russell, Dallas Seitz, Brittany Skov, Kaitlyn Tate, Jennifer Walker, Sharlene Webkamigad, Reagan Bartel, KD King and Lisa Shepherd.

Keywords Indigenous; Dementia; Risk; Scoping Review; Cultural Safety; Health Communication; Health Equity.

Dissemination plans Findings will be shared with Indigenous communities to inform future co-design of culturally congruent health communication resources as part of the larger CIRCLE project. Results will also be published in an open-access, peer reviewed journal.

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