



## RESEARCH ARTICLE OPEN ACCESS

# Prevalence of Dementia in European, Chinese and Indian/Fijian-Indian Populations in Aotearoa New Zealand: A Protocol

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## ABSTRACT

**Objectives:** Aotearoa New Zealand (NZ) is a bicultural nation (Māori and European) with a growing population of Asian and Pacific peoples. Recent analysis of national routinely collected data suggests dementia prevalence is higher in Māori and Pacific peoples when compared with European and Asian, and that inequities in dementia care for Māori, Asian, and Pacific people with dementia exist. A population-based dementia prevalence study is needed to confirm these findings. The aim of this protocol is to describe a dementia prevalence study focussing on the European, Chinese and Indian populations in NZ. The findings will be compared to a separate study on Māori populations using a similar study design.

**Methods:** This is a cross-sectional screen-interview survey of people aged  $\geq 65$  from European, Chinese and Indian/Fijian-Indian backgrounds in sampled meshblocks within two regions of NZ. Stage 1 involves screening eligible participants at the door using the brief cognitive scale of the Community Screening Instrument for Dementia (CSI-D). Stage 2 involves interviewing random samples of screen positive and negative participants using the 10/66 dementia protocol. With a margin of error of approximately 3%, and a confidence level of 5%, a total of 485 European, 410 Chinese and 425 Indian/Fijian-Indian people will be interviewed with the 10/66 protocol. Age-standardised prevalence estimates of 10/66 dementia will be back-weighted for study design.

**Conclusion:** This study will provide evidence for suspected ethnic inequalities in dementia, inform new culturally appropriate dementia management strategies, and contribute to improved outcomes for people with dementia in NZ.

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## Summary

- This is a protocol describing the methods to measure the prevalence of dementia in European, Chinese and Indian/Fijian-Indian populations in Aotearoa New Zealand.
- We will use a cross-sectional screen-interview survey of people aged  $\geq 65$  in sampled meshblocks within the two regions of New Zealand. A total of 485 European, 410 Chinese and 425 Indian/Fijian-Indian people will be interviewed with the 10/66 protocol.
- The findings will be compared to a separate study in the NZ Māori population using a similar study design in order to examine evidence for suspected ethnic disparities in dementia prevalence and inequities in dementia care.

## 1 | Introduction

Dementia is a global health priority. The prevalence of dementia varies in different populations but generally lies between 5.6% and 7.6% in people aged 60 years and over [1]. Governments across the world are developing policy and planning services to manage the rapid rise in dementia with demographic ageing. The population of Aotearoa New Zealand (NZ) is ageing and the number of people living with dementia increasing. In 2020, an estimated 70,000 people living with dementia in NZ is projected to reach 170,000 by 2050 [2]. However, these figures are estimates extrapolated from meta-analyses of other countries' statistics [1, 3] and do not consider the ethnic diversity and associated differential dementia risk of the NZ population.

Officially recognized as a bicultural nation (Māori and European), NZ is becoming more diverse in its ethnic make-up. Māori, NZ's Indigenous people, arrived from East Polynesia in the 12<sup>th</sup> and 13<sup>th</sup> centuries. Following European settlements throughout the 18<sup>th</sup> and 19<sup>th</sup> centuries, the Māori population was decimated by land seizures and sickness, and only in the late 20<sup>th</sup> century did population numbers recover to the current 19.6% of NZ's population, while people of European background comprise 68% of the population [4]. The fastest growing ethnicity in NZ is Asian, comprising 17.3% with Chinese and Indian/Fijian-Indian being the largest groups. The earliest documentation of Indian presence in NZ dates to the mid-18<sup>th</sup> century, while Chinese arrived during the gold rush in the late 19<sup>th</sup> century. In the late 20<sup>th</sup> century there were a number of coups in Fiji, leading to a rise in Fijian-Indians relocating to NZ. Indians first arrived in Fiji as indentured labour in the 18<sup>th</sup> and 19<sup>th</sup> centuries and as free agents from the early 1900s. Culturally they have retained elements of the Indian language and culture, and are distinct from the Fijian Indigenous people. They are categorised under Indian ethnicity by Statistics New Zealand (Stats NZ).

### 1.1 | Disparity in Dementia Prevalence

Health inequities exist in NZ [5]. A recent study examined national datasets and reported that the age-standardised

prevalence of *diagnosed* dementia in people aged  $\geq 65$  was higher in Māori and Pacific peoples compared to that for people of European and Asian backgrounds [6–8], likely due to the inequities in prevalence of risk factors for dementia [9]. The data for the Asian population were not disaggregated to specific ethnic groups; however, we would expect dementia prevalence to be higher in the Indian/Fijian-Indian populations but lower in the Chinese population due to differences in prevalence of dementia risk factors [5]. On the other hand, lower prevalence of diagnosed dementia in Asians may be explained by inequity of access to diagnostic services or increased dementia stigma; Asians have almost twice the risk of undetected dementia [10]. A community-based prevalence study is required to answer these issues.

### 1.2 | Inequity in Dementia Care

In addition to the extent of dementia, we also require data on the impact of dementia on health and social care sectors as well as families. Compared to NZ Europeans, Asian people living with dementia utilise half the social care resources, resulting in a higher cost of unpaid care for families [2, 12]. In 2020 social care cost per person living with dementia was higher for European (\$20,530) than for Asian peoples (\$10,090), mostly due to higher rates of European utilisation of aged residential care [2]. The limited research evidence for Chinese [13] and Indian/Fijian-Indian [14] communities living in NZ suggests that care is mostly provided by families due to a lack of culturally and linguistically appropriate social care. Caring at home means that family members must negotiate their working hours and employment to fulfil these obligations [2].

### 1.3 | Feasibility of an NZ Community-Based Dementia Prevalence Study

Culturally appropriate and responsive services for dementia can only be developed in an efficient and informed manner if the true prevalence of dementia and social and economic impacts of dementia are known, with all major ethnic groups included. Over the past 5 years our research group 'Living with Dementia in Aotearoa (LiDiA)' [15] has developed and built capacity for dementia research that represents NZ's main ethnic groups. Our research has laid the groundwork for the first ever nationally representative dementia prevalence studies that might demonstrate the true disparities in dementia prevalence [16].

### 1.4 | Cultural Adaptation of the 10/66 Protocol

Recognising the need for a culture-fair and education-fair cross-cultural dementia diagnostic instrument, the 10/66 dementia protocol developed by the 10/66 Dementia Research Group was chosen [17], as it is considered the global gold standard for dementia epidemiology in multicultural settings [18]. Prevalence studies have been conducted in many countries using adapted versions of the protocol including Central and South America, India, China and Singapore [19, 20]. The protocol includes a diagnostic dementia assessment and cognitive

testing, health history and physical assessment for risk factors, information about household makeup, assessment and cost of care arrangements, caregiver burden, and a family respondent (or other support person) interview [21]. In NZ the original and short versions of the 10/66 protocol [22] were adapted and tested for diagnostic accuracy in Māori and in Hindi-speaking Fijian-Indians [23, 24]. The English and Chinese versions had already been validated overseas [18, 20].

### 1.5 | Feasibility of Sampling Strategy

Feasibility was proven for a fully powered population-based dementia prevalence study using the 10/66 protocol in Māori, Chinese, Indian/Fijian-Indian and European communities [25, 26]. A probability sampling strategy using census data and meshblock sampling was accurate and all ethnic groups were sampled effectively. A multi-ethnic workforce of lay interviewers was trained and administered the 10/66 protocol. Door-to-door knocking in selected meshblocks resulted in 80% of doors answered, 24% of responders were people aged  $\geq 65$  years, and 75% of these agreed to be contacted for further interview. Attrition at the full interview stage was high and only 25.2% of the original sample received the 10/66 protocol; however, this may have been partly due to COVID-19 restrictions at the time of the study. Participants found the door knocking recruitment and the process and content of the interviews to be acceptable [26].

The method of recruitment was not feasible for Pacific communities. More work is ongoing with Pacific researchers developing ways of using 10/66 questionnaire in Pacific communities (Tongan, Samoan, Cook Island Māori and Niuean) with church and community engagement (<https://www.hrc.govt.nz/resources/research-repository/what-does-dementia-mean-pacific-communities-new-zealand>).

## 2 | Aim

The aim of this paper is to describe the protocol for a population-based dementia prevalence study for European, Chinese and Indian/Fijian-Indian communities in NZ. A parallel independent dementia prevalence study for Māori ‘*He rapunga hauora mo te mate wareware: a prevalence study*’ (<https://www.hrc.govt.nz/resources/research-repository/he-rapunga-hauora-mo-te-mate-wareware-prevalence-study>) is already underway in five regions across NZ (not reported here) that will also use the 10/66 protocol to enable comparisons.

The major impact of these studies is the creation of new knowledge about the community prevalence of dementia in NZ.

## 3 | Materials and Methods

### 3.1 | Study Design

This is a cross-sectional *screen-interview* survey of people from Chinese, Indian/Fijian-Indian and European backgrounds aged

$\geq 65$  in two territorial authorities—Auckland and Canterbury, two of the largest regions in NZ. The study procedure and recruitment flow are outlined in Figure 1.

### 3.2 | Sample Size Calculation

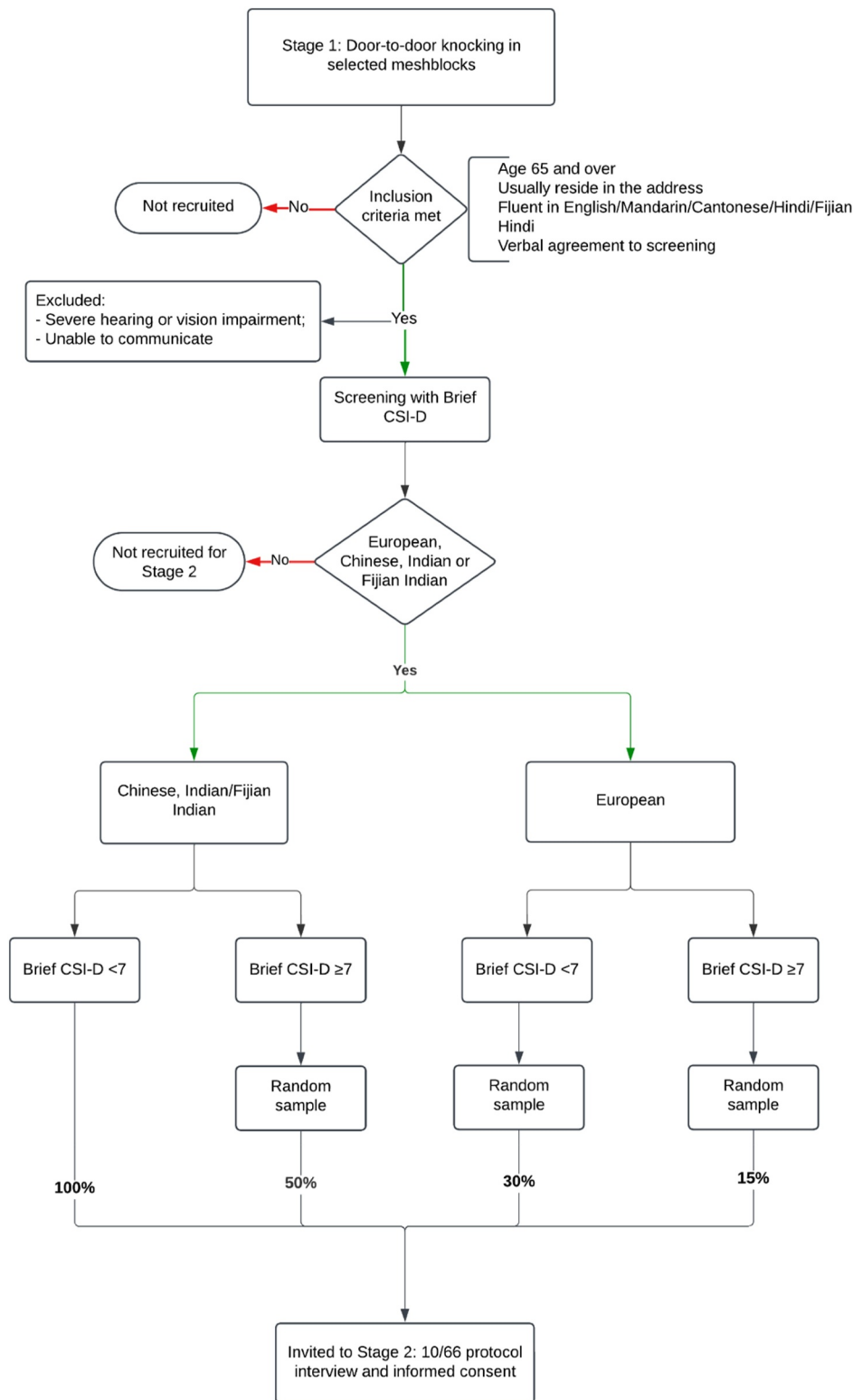
Using local data [2], we estimated an overall dementia prevalence of 8% in populations aged  $\geq 65$  years. With a margin of error of approximately 3%, and a confidence level of 5%, sample sizes of 425 Indian/Fijian-Indian, 485 European and 410 Chinese people (total 1320 people) are required to receive the 10/66 protocol. Based on a projected 50% consent rate from the feasibility study findings [26], the weighted sampling strategy and the performance of the cognitive test (see below), we expect to screen approximately 4000 people aged  $\geq 65$  in the specific ethnic groups to be able to interview 1320 people. The total number of households to be door-knocked will depend upon the projected percentage of residents aged  $\geq 65$  and the ethnic breakdown of the selected meshblocks; based on the feasibility study findings this will likely exceed 40,000 houses.

### 3.3 | Meshblock Sampling

Meshblocks are defined as ‘the smallest geographic unit for which Stats NZ has demographic information’ (approximately 100 people) [27]. The population-based sampling procedure has four phases. The *first* phase consists of selecting census territorial authorities in Auckland and Canterbury: Auckland, Christchurch, Selwyn, and Waimakariri. In the *second* phase, a stratified sample of areas is determined, considering factors such as district and rurality, and proportional representation to the density of the population aged  $\geq 65$  from the Indian/Fijian-Indian and Chinese communities. The *third* phase involves sampling meshblocks within the selected areas, utilising an inverse proportional strategy based on the size (in square kilometres) of the meshblocks. The number of sampled meshblocks within each area is proportionate to the total number of meshblocks present, ensuring a comprehensive and representative selection of areas for the study. In areas with high density of Chinese and Indian/Fijian-Indian people aged  $\geq 65$ , all meshblocks are selected. The *fourth* phase consists of recruitment of participants within the meshblocks selected at phase three.

### 3.4 | Community Engagement

Prior to study commencement, we have engaged European, Chinese and Indian community organisations (e.g. churches, ethnic specific community associations, and social programmes for older people), as well as through local media (e.g. language-specific television/radio and editorials) and continuous community outreach events (e.g. existing community group meetings/events). Community leaders freely gave advice and repeat visits to these community groups, including providing brain health seminars, are planned to ensure two-way communication throughout the project.



**FIGURE 1** | Recruitment flow.

### 3.5 | Interviewer Training and Fieldwork Procedures

We have produced a NZ and ethnic-specific training programme that includes approach, consent procedures, questionnaire administration, ethnic-specific protocols for offering gifts as

appreciation for participation, and data administration, plus training in specific language/cultural practices including English, Mandarin, Cantonese, Hindi or Fijian-Hindi. All data collection will be conducted by pairs of interviewers to ensure their safety. Training procedures have been adapted and optimised in the feasibility study [26] and we will re-test our

fieldwork protocol including verification of ineligible/refusal cases, contact with families/support people to ensure correct protocol is followed, quality control of data, and observation of interviews. Interviewers will feedback problems that they encounter and will use this information to continuously refine recruitment, training procedures, and fieldwork monitoring.

4 | Stage 1: Door-Knocking Procedures

Flyers will be distributed in the selected meshblock 3–4 weeks prior to door knocking, featuring contact information, introducing the project in different languages (English, Mandarin, Cantonese, Hindi, and Fijian-Hindi) and names of the local door-knocking team. The second round of flyer distribution will occur in the chosen meshblock 1 week prior to door-knocking. This approach was successful in the feasibility study and aims to involve local communities throughout the study, enhance transparency and enable community members to easily identify the door-knockers and understand the purpose of their visit.

Trained bilingual (Hindi/Fijian-Hindi/Mandarin/Cantonese/English) research interviewers will conduct door-to-door visits in the chosen meshblocks and offer screening questions in those languages if preferred. If no-one is at home, three further attempts will be made, including contacts outside of working hours and at weekends.

People who answer the door will be asked to identify any persons living at that residence who are age ≥ 65. For these individuals, screening questions to determine their eligibility to participate in Stage 2 of the study will be asked, see Box 1.

BOX 1 | Screening questions at the door.

Initial eligibility questions

Would you be willing to answer a few questions? It should not take more than a few minutes.

- 1. As I said, we are planning to do a survey of the health of people aged 65 and over living in this area. Is there anyone over the age of 65 living in the house?
- 2. Do you mind telling me how many people aged ≥ 65 live here?
- 3. Do you usually live here?  
*If 'No', then please ask the following questions:*
  - a. Are you visiting NZ or recently moved to NZ?
  - b. Have you been in NZ for 3 months or are you going to stay here for 3 months?
  - c. Is this one of the places you usually stay or live?*Participants can choose 'Refuse to answer' to any of these questions.*
- 4. Do you think they/you might be willing to answer a few screening questions about brain health with our interviewers?
- 5. Do you prefer to speak in Hindi/Fijian Hindi/Mandarin/Cantonese? (English is default language)

Sociodemographic questions:

What is your gender? (participant self-identified gender)

- 1. Female
- 2. Male
- 3. Another gender, please state:

Age reported by participant:

Which ethnic group do you belong to? (select all that apply)

- 1. European
- 2. Māori
- 3. Pacific Peoples
- 4. Asian
- 5. Middle Eastern/Latin American/African
- 6. Other Ethnicity

How much schooling have you had?

- 1. None
- 2. Some, but did not complete primary
- 3. Completed Primary
- 4. Completed Secondary (metric)
- 5. Completed Tertiary (college)/further education

Cognitive screening:

Now I am going to tell you three words and I would like you to repeat them after me: Boat; House; Fish. Repeat the three words, up to a maximum of six times. or until the person has remembered them all correctly. Then say: 'Very good, now try to remember these words because I will be asking you later.'

CSI-D questions (score 0/1)

- 1. (Interviewer points to their elbow) What do we call this?
- 2. What do you do with a hammer? *Acceptable answer 'To drive a nail into something'*
- 3. Where is the local market/local store?
- 4. What day of the week is it?
- 5. What is the season?
- 6. Please point first to the window and then to the door
- 7. Do you remember the three words I told you a few minutes ago?  
Boat; House; Fish (1 point each)

**TOTAL SCORE** (Maximum = 9): cut-point for dementia 6/7 [28].

4.1 | Screening

The brief cognitive scale of the Community Screening Instrument for Dementia (CSI-D) will be used to screen for eligibility [28]. The recommended optimal cutpoint on the 10-point scale is 6/7 (sensitivity 90%, specificity 80%) [28]. With an expected 10/66 dementia prevalence of approximately 8% in the included populations (aged ≥ 65), we would expect 25/100 to screen positive, of which 7/25 will be true positives and 1/75 will be a false negative (see Table 1). As dementia prevalence could be



**TABLE 1** | Expected performance of brief cognitive scale CSI-D screening.

	Dementia	No dementia	Total
Screen < 7*	7	18	25
Screen > 6	1	74	75
	8	92	100

\*Sensitivity 90% and specificity 80% at the recommended cutpoint of 6/7; prevalence 8%.

different across Indian, Chinese and European populations, and screening scale characteristics may be prevalence sensitive, the sensitivity and specificity in each population will be recalculated at study end. False positive and false negative rates will be reported, considered in weightings and the precision of the prevalence estimate reported in each group.

Potential participants who are unable to engage due to severe hearing, visual and communication impairment will be excluded. Participants will receive a small gift after the screening questions.

5 | Stage 2: 10/66 Protocol Interview

5.1 | Eligibility for Stage 2

Adults aged ≥ 65 years are potentially eligible for the 10/66 protocol interview if they live in private residences; self-identify as Chinese, Indian/Fijian-Indian or European on the screening questionnaire, and speak either English, Chinese (Mandarin or Cantonese), Hindi or Fijian Hindi. If a potential participant self-identifies with more than one ethnicity, they will be included if at least one of their ethnicities is Chinese, Indian/Fijian-Indian or European. If a potential participant primarily identifies as Māori or Pacific, they will be excluded.

5.2 | Sampling

Eligible participants from Stage 1 will be randomly sampled and invited to complete the 10/66 protocol as described above and in Figure 1. We estimate that this randomisation procedure (using traditional randomisation tables administered by a distant researcher on telephone contact) will achieve similar final sample sizes across ethnicities.

At the door-knocking stage, a two-phase approach using cognitive screening with oversampling of individuals with low scores was seen as efficient and has been commonly used in dementia prevalence studies—sampling 100% of those with low scores (likely dementia) and 50% of those with high scores [29]. Additionally, based on expected proportions from census numbers in the selected meshblocks, a mechanism was implemented to manage the larger European population (76% of those aged ≥ 65). By sampling a lower proportion of Europeans, the sample size grows consistently across ethnicities. Simulations were used and results indicated that selecting 100% of Indian and Chinese individuals and 30% of Europeans yielded the most representative sample, with approximately 400 individuals from

each ethnic group. The final random selection rule was: 100% of Indian/Chinese and 30% of Europeans with low scores, and 50% of Indian/Chinese and 15% of Europeans with high scores. The prevalence estimates will be adjusted for screening over-sampling using sampling weights, including screening weights.

5.3 | Recruitment

The interviewer will explain Stage 2 of the study to eligible participants, including the household/family decision maker and identified support person. If possible, the 10/66 protocol will be conducted on the same day. For those who are unavailable, the interviewer will re-schedule. If the support person is not available for face-to-face interview on the same day as the participant, we will attempt to contact them and interview by any means possible for example, face to face, phone or online.

5.4 | Interview

We will use the short version of the 10/66 protocol interview [22] conducted in English, Mandarin, Cantonese, Hindi or Fijian-Hindi. The interview includes a participant questionnaire, a support person questionnaire: and a household questionnaire. The specific instruments used are presented in Box 2. At the end of the interview, participants will receive a supermarket or fuel voucher.

**BOX 2** | Instruments used in the 10/66 dementia protocol.

Questionnaire	Section	Instruments used
Participant	Cognitive test battery	CSI-D participant version [28, 32]
		CERAD word list memory test (immediate and delayed recall) [33]
		Neurological examination—Palm-fist-hand test from the Luria battery of frontal lobe tasks [38]
		EURO-D depression scale [34]
	Sociodemographic status	Sociodemographic and risk factors questionnaire (participant version) [18, 19]
Support person	Support person interview	Brief informant history from the CSI-D [28, 32]
		Client service receipt inventory or CSRI [35]

(Continues)

(Continued)

Questionnaire	Section	Instruments used
		Self-reported questionnaire [39, 40]
		The Zarit burden Interview [41–43]
		History and aetiology schedule [44]
		Neuropsychiatric inventory questionnaire or NPI-Q [45]
	Sociodemographic status	Sociodemographic and risk factors questionnaire (proxy version) <sup>a</sup> [18, 19]
Household	Head of household questionnaire	Questions about house and family income [18, 19]

Abbreviations: CERAD = Consortium to Establish a Registry for Alzheimer's Disease; CSI-D = Community Screening Interview for Dementia; DSM = Diagnostic and Statistical Manual of Mental Disorders; GMS = Geriatric Mental State; ICD = International Classification of Diseases; NPI-Q = Neuropsychiatric Inventory Questionnaire.

<sup>a</sup>Proxy version was used if the main participant could not complete the participant version of the sociodemographic and risk factors questionnaire.

## 5.5 | Informed Consent

Verbal agreement for screening will be sought at the door. No personal information is recorded for those that are not eligible for the full interview and this component is considered as establishing eligibility for the study for consenting purposes.

If potential participants agree to participate and are eligible after screening, informed consent will be sought from the participant, the support person, and the household/family decision maker. Based on our feasibility study [26] most participants (96%) had capacity to consent and will give informed consent. We will follow the NZ Health and Disability Code of Right 7(4) when a potential participant lacks capacity to consent [30] by discussing with the potential participant's family/support person who will determine whether they believe participation is in the participant's best interest and consistent with their prior wishes. The research team will make the final decision regarding participation after appropriate consultation with the participant and their family/support person.

## 5.6 | Safety Issues

If a participant reports suicidal ideation or significant anxiety/depression, the interviewer will discuss this with the participant and the research team clinicians. All interviewers will be

supported by research team clinicians who are experienced in working with distressed participants. The research team will liaise with the participant's general practitioner (GP) or other usual health provider to arrange ongoing support for them. Our research team clinicians are skilled in community geriatric and mental health practice and understand referral pathways and medicolegal framework for supporting vulnerable older people.

## 6 | Participant and Community Involvement

General feedback on Stage 1 will be provided to participants if they wish to know their cognitive screening results, including information about brain health and recommendations to see their usual health providers if they have concerns. The Stage 2 cognition and depression scores will be sent to participants' GPs with general advice. We will also disseminate the general study findings to participants, communities and non-governmental organisations (NGOs) throughout the study and at the end, along with presenting our findings at events in collaboration with the communities involved with the study. An advisory group, including community members will meet 6-monthly to provide guidance, and community and health providers will be involved in co-creations groups throughout the study to receive information from the prevalence study and provide input to solution strategies.

## 7 | Statistical Analyses

Data will be collected and stored in the secure web-based database REDCap, hosted by The University of Auckland. Only de-identified datasets are downloaded for analysis. Descriptive analysis will report overall findings and by main ethnic groups: European, Chinese, and Indian/Fijian-Indian. Statistical analyses will be performed using R [31].

We will use the algorithm developed by Stewart et al. [22] and used in our feasibility study [26] to generate the 10/66 dementia diagnosis. The algorithm organises the output as "10/66 dementia" or "10/66 no dementia", depending on the score obtained from the logistic regression equation developed in the 10/66 international pilot study [18]. The equation uses coefficients obtained from the analysis of the three sub-components: CSI-D (participant and support person) [28, 32], 10-word list learning (delayed recall) [33], and EURO-D [34]. For those with no support person (and therefore incomplete CSI-D) a combination of clinician review of data and predictive modelling will estimate likelihood of dementia presence. Prevalence estimates of 10/66 dementia and corresponding 95% confidence intervals will utilize inverse probability weights to achieve representation of the sampling frame. We will report crude prevalence by ethnic group and also adjusted by age and socioeconomic class.

The cost of dementia will be analysed from a societal perspective. A well-recognised instrument will be used to collect costing data (Client Service Receipt Inventory) as part of the 10/66 protocol [35]. The health and social care utilisation data will be costed and summed. The approach to economic analyses is

being developed with input from the relevant communities and a health economist (BTA) and will involve age-standardisation according to the sample engaged. Equity for Chinese, Indian and Fijian-Indian communities will be established by comparing total utilisation and costs of health and social care with those of European as the reference.

## 8 | Ethics Statement

NZ Health and Disability Ethics Committee approved the study, 2024 FULL 19556, 23 Feb 2024. The ethics review process includes community members on the committee, and includes assessment by the Indigenous community.

## 9 | Discussion

This study and the parallel Māori dementia prevalence study will measure the true extent of dementia in NZ and examine differences between four different ethnic groups within one country. New health-related knowledge will examine suspected ethnic inequalities in dementia and be used to inform new culturally appropriate dementia management strategies. The data collected using the 10/66 protocol will also allow us to (1) examine risk factor profiles in each ethnic group, (2) measure care arrangements and caregiver burden in families living with dementia, and (3) determine costs related to dementia. Furthermore the information can be used by the Ministry of Health to direct relevant resources towards earlier identification and diagnosis of dementia, and implementation of NZ's dementia action plan [36], contributing to improved dementia care services, and outcomes for individuals and families living with dementia.

Only a handful of countries have previously examined inter-ethnic differences in dementia prevalence between ethnic groups living in one country, and most of these were conducted in the United States. Shiekh et al. [37] published a systematic review and meta-analysis in 2021 and reported significant ethnic differences in the prevalence of dementia, primarily noting an increase in dementia prevalence among minority ethnic groups across all studied regions when compared to major ethnic groups. We will compare the findings of our proposed fully powered dementia prevalence study with these and other inter-ethnic dementia prevalence studies published since the review.

The strength of our protocol is inclusivity and potentially retention, both in our sampling strategy and our culturally safe processes. Due to the significant attrition in our feasibility study [26], we have adapted our study design to maximise the information collected at first contact. A brief cognitive screening tool will be used so that if the participants decline the invitation for the 10/66 protocol interview, we still have some population data to estimate cognitive function from the screening interview. We have not included participants living in aged residential care or retirement village settings, which will lower our prevalence estimate of dementia in the NZ population. However, our intention is to sample these settings in separate studies using the

same 10/66 protocol. Neither this study or the Māori dementia prevalence study can directly investigate the prevalence and burden of dementia in Pacific peoples, the fourth largest ethnic group in NZ, but this work is being developed by a Pacific-led research team. We will work in partnership with the Māori research team to evaluate potential disparities and inequities between Māori and other populations.

## 10 | Conclusion

In 2012, the World Health Assembly recommended its member nations develop national dementia plans by 2025 to address the dementia challenges that every country will face. Currently in 2024 only 39 countries have dementia plans. A national dementia plan for NZ was announced in 2022 [36] but only \$12 million NZD over 4 years was allocated for piloting initiatives primarily for Māori and Pacific peoples and respite options. Like many countries, NZ is facing financial constraints, but the numbers of people living with dementia will continue to increase, particularly in non-European ethnic groups who are still served by largely Eurocentric services.

We hope that by collating a comprehensive dataset and creating knowledge about the extent, impact and costs of dementia in NZ's diverse communities, we will be able to co-design solutions with those communities to address the expected disparities in prevalence and inequities in dementia care, see figure S1. These findings will inform the development and delivery of innovative services that will help to provide appropriate care and mitigate the impacts of dementia for people and families living in NZ.

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### Conflicts of Interest

The authors declare no conflicts of interest.

### Data Availability Statement

Data sharing not applicable to this article as no datasets were generated or analysed during the current study.

### References

1. M. Prince, A. Wimo, M. Guerchet, G.-C. Ali, Y.-T. Wu, and M. Prina, "World Alzheimer Report 2015. The Global Impact of Dementia," *An Analysis of Prevalence, Incidence, Cost and Trends* (2015).



2. E. Ma'u, S. Cullum, S. Yates, et al., *Dementia Economic Impact Report 2020 in Aotearoa New Zealand* (University of Auckland, 2021).
3. GBD 2019. "Dementia Forecasting Collaborators. Estimation of the Global Prevalence of Dementia in 2019 and Forecasted Prevalence in 2050: An Analysis for the Global Burden of Disease Study 2019," *Lancet Public Health* 7, no. 2 (February 2022): e105–e125; PMID: 34998485; PMCID: PMC8810394, [https://doi.org/10.1016/S2468-2667\(21\)00249-8](https://doi.org/10.1016/S2468-2667(21)00249-8).
4. NZ Census. "2023 Census Population Counts (By Ethnic Group, Age, and Māori Descent) and Dwelling Counts," *Stats NZ* (2023).
5. Ministry of Health. *Health and Independence Report: The Director-General of Health's Annual Report on the State of Public Health* (Ministry of Health, 2018).
6. G. Cheung, E. To, C. Rivera-Rodriguez, et al. "Dementia Prevalence Estimation Among the Main Ethnic Groups in New Zealand: A Population-Based Descriptive Study of Routinely Collected Health Data," *BMJ Open* 12, no. 9 (2022): e062304, <https://doi.org/10.1136/bmjopen-2022-062304>.
7. B. Ryan, E. To, E. Ma'u, et al. "Prevalence of Young-Onset Dementia: Nationwide Analysis of Routinely Collected Data," *Journal of Neurology, Neurosurgery & Psychiatry* 93, no. 10 (2022): 1066–1073, <https://doi.org/10.1136/jnnp-2022-329126>.
8. E. Ma'u, S. Cullum, N. Mukadam, D. Davis, C. Rivera-Rodriguez, and G. Cheung, "Estimating the Prevalence of Dementia in New Zealand Using Capture-Recapture Analysis on Routinely Collected Health Data," *International Journal of Geriatric Psychiatry* 39, no. 8 (2024): e6131, <https://doi.org/10.1002/gps.6131>.
9. E. Ma'u, S. Cullum, G. Cheung, G. Livingston, and N. Mukadam, "Differences in the Potential for Dementia Prevention Between Major Ethnic Groups Within One Country: A Cross Sectional Analysis of Population Attributable Fraction of Potentially Modifiable Risk Factors in New Zealand," *Lancet Regional Health-Western Pacific* 13 (2021): 100191, <https://doi.org/10.1016/j.lanwpc.2021.100191>.
10. A. Martinez-Ruiz, Y. Huang, S. Gee, H. Jamieson, and G. Cheung, "Individual Risk Factors for Possible Undetected Dementia Amongst Community-Dwelling Older People in New Zealand," *Dementia* 19, no. 3 (2020): 750–765, <https://doi.org/10.1177/1471301218786277>.
11. E. Ma'u, F. Saeed, O. B. Yates, et al. "Do Māori and Pacific Peoples Living With Dementia in New Zealand Receive Equitable Long-Term Care Compared With New Zealand Europeans?," *Journal of Long-Term Care*. (2022): 222–233, <https://doi.org/10.31389/jltc.148>.
12. G. Cheung, A. Su, K. Wu, et al. "The Understanding and Experiences of Living With Dementia in Chinese New Zealanders," *International Journal of Environmental Research and Public Health* 19, no. 3 (2022): 1280, <https://doi.org/10.3390/ijerph19031280>.
13. R. Krishnamurthi, E. Dahiya, R. Bala, G. Cheung, S. Yates, and S. Cullum, "Lived Experience of Dementia in the New Zealand Indian Community: A Qualitative Study With Family Care Givers and People Living With Dementia," *International Journal of Environmental Research and Public Health* 19, no. 3 (2022): 1432, <https://doi.org/10.3390/ijerph19031432>.
14. S. Cullum, M. Dudley, and G. Cheung, "Living With Dementia in Aotearoa: Background and Methods," *Australia and New Zealand Journal of Psychiatry* 52 (2018): 60.
15. S. Cullum, M. Dudley, and N. Kerse, "The Case for a Bicultural Dementia Prevalence Study in Aotearoa New Zealand," *New Zealand Medical Journal* 133, no. 1524 (October 2020): 119–125; PMID: 33119575.
16. M. Prince, C. P. Ferri, D. Acosta, et al. "The Protocols for the 10/66 Dementia Research Group Population-Based Research Programme," *BMC Public Health* 7, no. 1 (2007): 165, <https://doi.org/10.1186/1471-2458-7-165>.
17. M. Prince, D. Acosta, H. Chiu, M. Scazufca, M. Varghese, and G. Dementia Research, "Dementia Diagnosis in Developing Countries: A Cross-Cultural Validation Study," *Lancet* 361, no. 9361 (2003): 909–917, [https://doi.org/10.1016/S0140-6736\(03\)12772-9](https://doi.org/10.1016/S0140-6736(03)12772-9).
18. M. J. Prince, "The 10/66 Dementia Research Group—10 Years on," *Indian Journal of Psychiatry* 51, no. Suppl1 (2009): S8–S15.
19. M. Subramaniam, S. A. Chong, J. A. Vaingankar, et al. "Prevalence of Dementia in People Aged 60 Years and above: Results from the WiSE Study," *Journal of Alzheimer's Disease* 45, no. 4 (2015): 1127–1138, <https://doi.org/10.3233/jad-142769>.
20. M. Prince, C. P. Ferri, D. Acosta, et al. "The Protocols for the 10/66 Dementia Research Group Population-Based Research Programme," *BMC Public Health* 7, no. 1 (2007): 165, <https://doi.org/10.1186/1471-2458-7-165>.
21. R. Stewart, M. Guerchet, and M. Prince, "Development of a Brief Assessment and Algorithm for Ascertaining Dementia in Low-Income and Middle-Income Countries: The 10/66 Short Dementia Diagnostic Schedule," *BMJ Open* 6, no. 5 (2016): e010712, <https://doi.org/10.1136/bmjopen-2015-010712>.
22. A. Martinez-Ruiz, S. Cullum, G. Cheung, et al. "Diagnostic Accuracy of 10/66 Dementia Protocol in Māori Kaumātua (Elders) Living in Aotearoa New Zealand," *New Zealand Medical Journal* 135, no. 1548 (January 2022): 42–53.
23. A. Martinez-Ruiz, R. Krishnamurthi, E. S. Dahiya, et al. "Diagnostic Accuracy of 10/66 Dementia Protocol in Fijian-Indian Elders Living in New Zealand," *International Journal of Environmental Research and Public Health* 18, no. 9 (2021): 4870, <https://doi.org/10.3390/ijerph18094870>.
24. A. Martinez-Ruiz, S. Yates, G. Cheung, et al. "Living With Dementia in Aotearoa (LiDiA): A Cross-Sectional Feasibility Study Protocol for a Multiethnic Dementia Prevalence Study in Aotearoa/New Zealand," *BMJ Open* 11, no. 5 (2021): e046143, <https://doi.org/10.1136/bmjopen-2020-046143>.
25. A. Martinez-Ruiz, S. Yates, G. Cheung, et al., "Living With Dementia in Aotearoa (LiDiA): A Feasibility Study for a Dementia Prevalence Study in Māori and Non-māori Living in New Zealand," *Dementia* (2023): 147130122311730.
26. N. Z. Stats, "Statistical Standard for Meshblock," 2016, <https://www.stats.govt.nz/assets/Uploads/Retirement-of-archive-website-project-files/Methods/Statistical-standard-for-meshblock/stats-std-meshblock.pdf>.
27. M. Prince, D. Acosta, C. P. Ferri, et al. "A Brief Dementia Screener Suitable for Use by Non-specialists in Resource Poor Settings—The Cross-cultural Derivation and Validation of the Brief Community Screening Instrument for Dementia," *International Journal of Geriatric Psychiatry* 26, no. 9 (2011): 899–907, <https://doi.org/10.1002/gps.2622>.
28. C. Brayne and Y. T. Wu, "Population-Based Studies in Dementia and Ageing Research: A Local and National Experience in Cambridgeshire and the UK," *American Journal of Alzheimer's Disease and Other Dementias* 37 (January–December 2022): 15333175221104347; PMID: 36000966; PMCID: PMC10581148, <https://doi.org/10.1177/15333175221104347>.
29. Code of Health and Disability Services Consumers' Rights—Health & Disability Commissioner
30. R Core Team. *R: A Language and Environment for Statistical Computing* (R Foundation for Statistical Computing, 2023).
31. K. S. Hall, S. Gao, C. L. Emsley, A. O. Ogunniyi, O. Morgan, and H. C. Hendrie, "Community Screening Interview for Dementia (CSI 'D'); Performance in Five Disparate Study Sites," *International Journal of Geriatric Psychiatry* 15, no. 6 (2000): 521–531, [https://doi.org/10.1002/1099-1166\(200006\)15:6<521::aid-gps182>3.0.co;2-f](https://doi.org/10.1002/1099-1166(200006)15:6<521::aid-gps182>3.0.co;2-f).

32. J. C. Morris, A. Heyman, R. C. Mohs, et al. "The Consortium to Establish a Registry for Alzheimer's Disease (CERAD). Part I. Clinical and Neuropsychological Assessment of Alzheimer's Disease," *Neurology* 39, no. 9 (1989): 1159–1165, <https://doi.org/10.1212/wnl.39.9.1159>.
33. M. J. Prince, A. T. F. Beekman, D. J. H. Deeg, et al., "Depression Symptoms in Late Life Assessed Using the EURO-D Scale. Effect of Age, Gender and Marital Status in 14 European Centres," *British Journal of Psychiatry* 174, no. 4 (1999): 339–345, <https://doi.org/10.1192/bjp.174.4.339>.
34. D. Chisholm, M. R. J. Knapp, H. C. Knudsen, F. Amaddeo, L. Gaité, and B. van Wijngaarden, and EPSILON Study Group, "Client Socio-Demographic and Service Receipt Inventory—European Version: Development of an Instrument for International Research: EPSILON Study 5," *British Journal of Psychiatry* 177, no. S39 (2000): s28–s33, <https://doi.org/10.1192/bjp.177.39.s28>.
35. <https://alzheimers.org.nz/explore/dementia-action-plan/>.
36. S. Shiekh, S. L. Cadogan, L. Y. Lin, R. Mathur, L. Smeeth, and C. Warren-Gash, "Ethnic Differences in Dementia Risk: A Systematic Review and Meta-Analysis," *Journal of Alzheimer's Disease* 80, no. 1 (2021): 337–355, <https://doi.org/10.3233/jad-201209>.
37. A. R. Luria, *The Working Brain: An Introduction to Neuropsychology* (Basic Books, 1976).
38. M. Beusenberg and J. H. Orley, and World Health Organization, *A User's Guide to the Self Reporting Questionnaire* (World Health Organization, 1994).
39. A. J. Martin, "Assessing the Multidimensionality of the 12-Item General Health Questionnaire," *Psychological Reports* 84, no. 3 (1999): 927–935, <https://doi.org/10.2466/pr0.84.3.927-935>.
40. C. J. Whitlatch, S. H. Zarit, and A. von Eye, "Efficacy of Interventions With Caregivers: A Reanalysis," *Gerontologist* 31, no. 1 (1991): 9–14, <https://doi.org/10.1093/geront/31.1.9>.
41. S. H. Zarit, K. E. Reever, and J. Bach-Peterson, "Relatives of the Impaired Elderly: Correlates of Feelings of Burden," *Gerontologist* 20, no. 6 (1980): 649–655, <https://doi.org/10.1093/geront/20.6.649>.
42. S. H. Zarit, P. A. Todd, and J. M. Zarit, "Subjective Burden of Husbands and Wives as Caregivers: A Longitudinal Study," *Gerontologist* 26, no. 3 (1986): 260–266, <https://doi.org/10.1093/geront/26.3.260>.
43. M. E. Dewey and J. R. M. Copeland, "Diagnosis of Dementia From the History and Aetiology Schedule," *International Journal of Geriatric Psychiatry* 16, no. 9 (2001): 912–917, <https://doi.org/10.1002/gps.446>.
44. D. I. Kaufer, J. L. Cummings, P. Ketchel, et al. "Validation of the NPI-Q, a Brief Clinical Form of the Neuropsychiatric Inventory," *Journal of Neuropsychiatry and Clinical Neurosciences* 12, no. 2 (2000): 233–239, <https://doi.org/10.1176/jnp.12.2.233>.

### Supporting Information

Additional supporting information can be found online in the Supporting Information section.