# Estimating the incidence of dementia in New Zealand: a cohort study applying capture-recapture modelling to routinely collected linked health datasets

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# Summary

Background Issues of under-diagnosis and under-coding of dementia in routinely collected health data limit their utility for estimating dementia prevalence and incidence in Aotearoa New Zealand (NZ). Capture-recapture techniques can be used to estimate the number of dementia cases missing from health datasets by modelling the relationships and interactions between linked data sources. The aim of this study was to apply this technique to routinely collected and linked health datasets and more accurately estimate the incidence of dementia in NZ.

Methods All incident cases of dementia in the NZ 60+ population were identified in three linked national health data sets—interRAI, Public hospital discharges, and Pharmacy. Capture-recapture analysis fitted eight loglinear models to the data, with the best fitting model used to estimate the number of cases missing from all three datasets, and thereby estimate the 'true' incidence of dementia. Incidence rates were calculated by 5-year age bands, sex and ethnicity.

Findings Modelled estimates indicate 36% of incident cases are not present in any of the datasets. Modelled incidence rates in the 60+ age group were 19.2 (95% CI 17.3–22.0)/1000py, with an incident rate ratio of 1.9 (95% CI 1.9–2.0) per 5-year age band. There was no difference in incidence rates between males and females. Incidence rates in Asian (p < 0.001) but not Māori (p = 0.974) or Pacific peoples (p = 0.110) were significantly lower compared to Europeans, even after inclusion of missing cases.

Interpretation This is the first study to provide estimates of age 60+ dementia incidence in NZ and for the four main ethnic groups and suggests over a third of incident dementia cases are undiagnosed. This highlights the need for better access to dementia assessment and diagnosis so that appropriate supports and interventions can be put in place to improve outcomes for people living with dementia and their families.

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## Introduction

As the Aotearoa New Zealand (NZ) population ages, the prevalence of dementia is projected to more than double to almost 170,000 in 2050.<sup>1</sup> The economic impacts associated with this projected prevalence will place increasing strain on the health system.<sup>1</sup> While dementia

prevalence estimates and projections are essential for the planning and development of healthcare services, so too is an appreciation of dementia incidence. The evidence for the effectiveness of community supports and interventions for people with dementia in the first 12 months post-diagnosis is compelling.<sup>2</sup> Therefore, an





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# **Research in context**

# Evidence before this study

We searched PubMed for inception to March 2024 for studies investigating the incidence of dementia in Aotearoa New Zealand (NZ) with no limits on language or date of publication. To date there has only been one study on the incidence of dementia in NZ. This was a small population cohort study on younger onset dementia (aged 30-64 years). There has never been an epidemiological study on dementia incidence in later life in NZ. Dementia incidence estimates for the NZ population aged >65 years have therefore been extrapolated from international studies that may not reflect the diverse and unique population demographics of NZ. There is increasing evidence that incidence rates are changing over time due to the changing prevalence of risk factors for dementia. The prevalence of these risk factors for dementia vary across the ethnic groups in NZ and there is evidence of a higher age and sex-standardised prevalence in minority ethnic groups compared to the majority European population. This highlights the need for NZ specific incidence data so that accurate forecasts of future need and resourcing requirements can be made.

#### Added value of this study

To the best of our knowledge, this is the first study to estimate the incidence of later onset dementia in NZ. This

understanding of incident cases of dementia is required to inform resourcing requirements. There is little NZ specific research on dementia incidence with the only incidence study to date being a small population based study on young onset dementia,<sup>3</sup> whose needs are very different to the older population. Dementia incidence estimates in NZ for those aged >65 years therefore need to be extrapolated from international studies. Most of these studies are in predominantly white populations from high income countries<sup>4</sup> who do not reflect NZ's diverse and unique population demographics, where 70.2% identify as European, 16.5% as Māori, 15.1% as Asian, and 8.1% as Pacific peoples.<sup>5</sup>

There is increasing evidence that incidence rates are changing over time, likely in response to public health policy measures targeting modifiable risk factors for dementia.<sup>6</sup> The Alzheimer's Cohorts Consortium<sup>4</sup> reviewed trends in dementia incidence between 1988 and 2015 from eight large, long-term population based cohort studies and estimated a 13% reduction in incidence of all cause dementia per decade since 1998 over this 27 year period (HR 0.87, 95% CI 0.81–0.93). In a recent analysis of cohort studies to explore temporal trends, Mukadam et al.<sup>7</sup> described declining dementia incidence in cohorts in the USA and Europe (including Sweden, Netherlands, France and the UK), stable incidence in a Nigerian cohort, and an increase in dementia incidence in a cohort from Japan. While cautioning paper reports incident dementia case ascertainment using routinely collected administrative health data. This data is affected by under-diagnosis and under-coding. Using three linked datasets, we have applied capture-recapture statistical modelling techniques to compensates for these known case ascertainment issues with routinely collected data. This approach models the number of cases not present in any of the datasets and provides a more accurate estimate of dementia incidence. Using this technique we estimate a third of incident dementia cases in NZ go undiagnosed and provide estimates of dementia incidence that include the modelled missing cases for the total NZ population aged 60+, and for the four main ethnic groups.

# Implications of all the available evidence

To our knowledge this is the first study to provide an insight into the incidence of dementia in NZ and for the four main ethnic groups, with our incidence rates using modelled data consistent with international studies. Our estimates that a third of dementia go undiagnosed in NZ highlights the need for better access to dementia assessment and diagnosis so appropriate supports and interventions can be put in place to improve outcomes for people with dementia and their families.

against drawing firm conclusions due to study heterogeneity, they noted the overall trend was for a decline in incidence. More recently there is evidence that the downward trend in dementia incidence may be reversing. Chen et al.<sup>8</sup> analysed UK trends in dementia incidence from 2002 to 2019, demonstrating a 28.8% decline in incidence between 2002 and 2010 (IRR 0.71 95% CI 0.58–0.88) but a 25.2% increase between 2008 and 2016 (IRR 1.25 95% CI 1.03–1.54). They calculated that this trend toward an increase in dementia incidence meant dementia prevalence projections should be 70% higher than forecast. This changing incidence over time highlights the need for NZ specific data to allow surveillance and monitoring of dementia trends over time to allow accurate forecasting of future need.

Chen et al.'s hypothesised explanations for this changing incidence over time include the increasing prevalence of risk factors such as diabetes and obesity over the preceding decades, and the worsening of many risk factors in socially disadvantaged groups.<sup>8</sup> In NZ the population attributable fraction (PAF) for dementia the proportion of dementia cases potentially preventable if a risk factor is completely eliminated–has been demonstrated to be higher in Māori (51.4%) and Pacific peoples (50.4%), but lower in Asians (40.8%), compared to Europeans (47.6%) due to the differential prevalence of modifiable risk factors.<sup>9</sup> With the prevalence of midlife risk factors such as diabetes and obesity in Māori and Pacific peoples being 1.5× to 3× higher than Europeans,<sup>9</sup> we would also expect a higher incidence of dementia in these ethnic groups. It is likely that any changing trends in the prevalence of potentially modifiable risk factors for dementia in NZ will influence dementia incidence over time.

Many of these risk factors cluster around deprivation so a comprehensive community and multiagency approach is required to appropriately address them.

Epidemiological studies are expensive and resource intensive so more recently attention has focussed on the utility of routinely collected health data to estimate disease frequency in a population. In NZ, the Statistics New Zealand Integrated Data Infrastructure (IDI) is a national NZ database holding microdata about people and households from multiple sources including government agencies and Statistics New Zealand national surveys. Each individual in the IDI is allocated a unique, encrypted identifier allowing their data to be linked across different data sources. These datasets have previously been used to calculate dementia prevalence in NZ,<sup>10,11</sup> but these estimates are significantly lower than expected due to low case ascertainment. Using capturerecapture modelling techniques, we have estimated half of prevalent dementia cases were likely to be missing from the datasets.<sup>12</sup> Capture-recapture techniques estimate the number of dementia cases missing from health datasets by modelling the relationships and interactions between linked data sources.13 Adding these missing cases to those already identified in the health datasets produces a more accurate estimate of total cases.

As such, the first aim of this study is to calculate the incidence of dementia in a representative cohort of adults aged 60 year or above in NZ by using routinely collected health data. The second aim is to estimate the incidence of dementia by applying capture-recapture techniques to model the incidence of dementia when missing cases are included.

# Methods

# Ethics

This study received ethical approval from the Auckland Health Research Ethics Committee (REF: AH23608) and from Statistics New Zealand (REF: MAA2022-03).

# Population at risk

The population at risk is defined as all participants in the New Zealand Health Survey (NZHS) from 2011/12 to 2018/19, an annual Ministry of Health (MoH) survey collecting a range of health related information.<sup>14</sup> The NZHS is nationally representative by design and reflects the sociodemographics of the NZ population. The target population of the NZHS is the NZ 'usually resident population' of all ages, with approximately 99% of the population eligible to participate. The NZHS response rate has consistently been 79–80% since the 2011/12 survey.<sup>15</sup> A multi-stage, stratified, probability-proportional-to-size (PPS) sampling method is designed to yield an annual sample size of approximately 14,000 participants aged 15 years and older, approximately 0.4% of the usually resident population. This sampling approach ensures every household in the population has the same probability of being selected. To ensure adequate estimates of Pacific peoples and Asian ethnic groups, the approach has been modified using a targeting factor to give higher probabilities of selection to areas where these groups are more populous. For Māori, it was deemed more statistically efficient to oversample using the electoral roll rather than an area based approach.<sup>16,17</sup>

For practical reasons a small proportion of the target population are excluded, such as those in prisons, hospitals, or dementia care facilities. Health status and lifestyle factors are also representative, with previous research into potentially modifiable risk factors for dementia in NZ demonstrating risk factor prevalence estimates in the NZHS mirrored that of the NZ census or other surveys. Our utilisation of all eight consecutive survey years available mitigates the effect of potential temporal variations in sociodemographic or health characteristics.

All adult participants are required to provide consent, with a legal guardian permitted to consent and complete the survey on their behalf. The NZHS excludes all residents in secure dementia or hospital level care units where the prevalence of dementia is high. There is a possibility that people with an undiagnosed dementia were included at start of follow up given evidence that over half of dementias are undetected.

#### Data linkage

Each person in the IDI is allocated a Unique Person Identifier and the databases are regularly cleaned and updated to avoid any individual having more than one unique identifier. The IDI therefore allows linkage of the NZHS, three health datasets, and sociodemographic details. Data linkage was carried out in Microsoft SQL server using the SQL JOIN function. The NZHS table was used as the base table with sociodemographic details and three health datasets linked to the NZHS using the INNER JOIN and LEFT JOIN functions as appropriate. This linkage therefore allows NZHS participants to be followed up over time, and incident dementia (defined as the occurrence of a coded diagnosis of dementia in any of the 3 datasets) identified (Fig. 1). All participants with a coded diagnosis of dementia dated during or prior to the survey year were excluded to ensure only incident cases were present at start of follow up.

# Case definition & ascertainment

The Statistics New Zealand IDI is a large research database holding de-identified microdata about people



Fig. 1: Flow diagram describing definition of the base population at risk and linkage with the interRAI, Pharmaceutical collection, and Publicly funded hospital discharges.

and households in NZ across a range of disciplines, including health.<sup>18</sup> Identification of dementia diagnoses in each of the datasets have been previously described by Cheung et al.<sup>10</sup> Their approach identified all instances of dementia diagnoses coded in any of the seven Ministry of Health datasets available in the IDI. In this study we used the three health datasets with the largest number of recorded dementia cases identified by Cheung et al.<sup>10</sup> for incident case identification and capture-recapture analysis: *interRAI, Pharmaceutical Collection, and Publicly Funded Hospital Discharges.* If present, a diagnosis of dementia will also have an associated date the diagnosis was made. For participants with multiple instances of coded dementia diagnoses, the earliest date a diagnosis was present was used for censoring.

# Databases

The International Residential Assessment IninterRAI. strument (interRAI) is a comprehensive, evidence based, and standardised assessment that is required to access publicly funded long term community care or aged residential care in NZ.19 Approximately 10% of the 65+ population and 40% of the 80+ population have had an assessment in any given year.20 The interRAI assessment routinely records a diagnosis of "Alzheimer's disease" or "Dementia other than Alzheimer's disease". Trained interRAI assessors determine these diagnoses based on multiple sources of information including referral documentation, health records, discussions with family, carers, or health professionals, and person interview.21 Non-European ethnicities are less likely to receive an interRAI assessment<sup>22</sup> so they are underrepresented in this dataset.

# Publicly funded hospitalisations

The Publicly Funded Hospitalisations collection contains information on all publicly funded hospitalisation events in NZ with all documented diagnoses coded using ICD-9 or ICD-10-AM codes.<sup>23</sup> Dementia case were ascertained based on ICD-9 and ICD-10-AM codes for dementia as described by Cheung et al.<sup>10</sup> Hospitalisation rates increased with age from 275 per 1000 population in those aged 60–64 years, to 935 per 1000 in the 85+ population.<sup>24</sup>

## Pharmaceutical collection

The Pharmaceutical collection contains information on all publicly funded pharmaceuticals dispensed in the community.<sup>23</sup> Two antidementia medications (donepezil tablets and rivastigmine transdermal patches) are funded in NZ and they can only be prescribed for a diagnosis of dementia so are used as proxies for a diagnosis. Only data on funded medications are included in the collection so were unable to identify those prescribed the other two approved antidementia medications in NZ (galantamine tablets and memantine tablets).

# Cohort follow up and censoring

The NZHS is conducted annually from July to June and the IDI currently contains data for eight NZHS survey years (2011/12–2018/19). Start of follow up for each year of the NZHS was defined as January 1st, the mid-point of the survey year. End of follow up was 31 March 2022, the latest date at which all censoring information was available. Censoring occurred at death or the earliest documented date of diagnosis of dementia in any of the three datasets.

## Consent

All participants in the NZHS provide informed consent. Output data for the linked health datasets undergoes confidentiality review prior to release. Access to this data does not require informed consent as per the NZ Health Information Privacy Code<sup>25</sup> which allows for the use of anonymised health data in research without authorisation of the individuals concerned.

# Statistical analysis

STATA 16<sup>26</sup> was used for all statistical analyses.

#### Incidence rates and incidence rate ratios

Incidence rates, rate ratios and significance testing for raw data were calculated with the Mantel-Haenszel type method using the STATA *stmh* command. Incidence rates were presented as cases per 1000 person-years at risk, and by 5-year age band and sex. Incidence rate ratios were calculated to compare incidence rates per 5-year age band We calculated confidence intervals and p-values with a significance level of 0.05 for all estimates. Age 60+, age 65+ and age 80+ figures were presented to allow comparison with international figures.

We also calculated incidence rates and incidence rate ratios for the four main ethnic groups in NZ. Individuals can self-identify with more than one ethnicity in NZ. To ensure fully independent groups for incidence calculations, we used prioritised ethnicity as defined by the Ministry of Health in the prioritised order of Māori, Pacific peoples, Asian, European/other.<sup>16</sup>

The NZHS includes NZDep, an index of socioeconomic deprivation ranging from decile 1 (least deprived) to decile 10 (most deprived).<sup>27</sup> We calculated the incidence rate ratio for the total 60+ population to explore the association between deprivation and dementia.

# Capture-recapture analysis

Capture-recapture analysis was applied to the raw data to estimate missing cases, following the same methods applied by Ma'u et al.<sup>12</sup> to estimate missing prevalent cases using the same datasets. Assumptions for the standard capture-recapture approach are that (1) case ascertainment only identifies true cases, (2) the population is closed, (3) there is independence between sources, and (4) that there is capture homogeneity.

Capture-recapture analysis was carried out using *recap*,<sup>28</sup> a user-written STATA module for performing standard capture-recapture analysis on three sources and calculates 95% confidence intervals based on Regal and Hook's<sup>13</sup> goodness-of-fit model. This approach fits eight loglinear models to the data arranged in a  $2^3$  contingency table (Fig. 1) based on whether a case was present in each source (for example, model *b* is all cases appearing in both the interRAI and public hospital discharges dataset but not the Pharmaceuticals dataset).

The *recap* output presents an estimate of the number of missing cases (with 95% confidence intervals) for each of the loglinear models, and includes the Aikake Information criterion (AIC) and Bayesian information criterion (BIC) as a measure of fit for each of the models. The model with the smallest AIC/BIC is generally considered the best estimate for the number of missing cases and the estimates from this model were used in the results.

To account for the potential impact of the sampling strategy of the NZHS on incidence estimates for the total population, ascertained cases were weighted to reflect the age, gender, and ethnicity distribution of the 2018 NZ population.<sup>5</sup> Separate capture-recapture analysis was performed for each age band, both by sex and for the total population in the age band. For ethnicity, separate capture-recapture analysis was performed for the 60+ population in each ethnic group, both by sex and for the total population.

# Sensitivity analysis

We performed sensitivity analyses for the total 60+ population by conducting capture-recapture modelling using different dataset combinations. This was only possible with the mortality dataset as dementia case ascertainment in the three remaining datasets (private hospitalisations (15 cases), SOCRATES (2 cases) and PRIMHD (1 case) were not sufficient to allow modelling.

# Age-standardisation

For international comparison, incidence in the total 60+ population was age-standardised to the Western Europe population as used in the World Alzheimer's Report 2015<sup>29</sup>

# Results

# **Cohort description**

Table 1 describes the baseline characteristics of the cohort. The cohort comprised 28,912 individuals aged 60+, followed up for a mean (SD) of 5.6 (2.4) years. Mean (SD) age was 71.4 (8.2) years, and females accounted for 57.2% of the cohort, with no statistically significant difference across the four ethnic groups.

The three health datasets identified 1860 incident dementia cases - interRAI (n = 1278), public hospital discharges (n = 1065) and pharmaceuticals (n = 564). Fig. 2 is a Venn diagram showing the association between the three health datasets, with each letter (A-H) denoting the different combinations of the three datasets a diagnosis could be coded in. There were 153 (8.2%) incident cases present in all three health datasets (A). H denotes those not present in any of the three datasets and is the modelled estimate provided by capture-recapture analysis.

The incidence of dementia increased with increasing age, with an incidence rate ratio of 1.9 (95% CI = 1.9-2.0, p < 0.0001) for each one unit increase in age band in the ascertained cases.

Table 2 presents the incidence rates, by age band and sex for the raw data (ascertained dementia cases) and also for the modelled data (includes the missing cases).

	Total N (%) = 28,912 (100%)	Māori N = 3723 (12.8%)	Pacific N = 723 (2.5%)	Asian N = 883 (3.1%)	European N = 23,583 (81.6%)
Ascertained dementia case	25				
n (%)	1860 (100%)	240 (12.9%)	39 (2.1%)	S	1563 (84%)
Age (years)					
Mean (SD)	71.4 (8.2)	69.0 (7.0)	68.4 (6.9)	68.4 (6.7)	71.9 (8.4)
Sex					
Male (%)	12,383 (42.8%)	1483 (39.8%)	300 (41.5%)	412 (46.7%)	10,188 (43.2%)
NZdep					
Median (95% CI)	6 (1-10)	8 (2-10)	9 (3-10)	6 (1-10)	6 (1-10)
NZdep, New Zealand Depriva	tion Index. s, Statistics NZ confident	iality rules applied suppre	essed output due to raw	count of cases being <	:30.
Table 1: Baseline characte	ristics of the cohort at start of	follow up.			

Using modelled estimates, incidence in the NZ 60+ population was 19.2 (95% CI 17.3–22.0) per 1000 person-years, increasing to 63.8 (95% CI 54.6–78.9) per 1000 person-years in those aged 80+. Some modelled estimates (for example the male 60–64 year age band) were multiple times higher with wide confidence intervals, so caution is advised when interpreting these results.

The incidence of dementia increased with increasing deprivation, with an incident rate ratio of 1.1 (95% CI 1.0–1.1) for every one unit increase in deprivation score. Age-standardised incidence in the NZ 60+ population was 14.2 (95% CI 12.6–16.1) per 1000 person-years. for ascertained cases and 22.4 (95% CI 17.8–63.4) per 1000 person-years using modelled estimates.

Table 3 presents the age 60+ incidence rates for dementia by ethnicity and sex. Using both raw and modelled data there was no significant difference in incidence rates in the 60+ age group comparing Māori (p = 0.974) and Pacific peoples (p = 0.110) to Europeans, but incidence rates in Asians remained significantly lower than for European (p < 0.001). As with estimates for the total population, some modelled estimates (for example Māori males) were multiple times higher with wide confidence intervals, so caution is advised when interpreting these results.

# Sensitivity analysis

The mortality dataset ascertained 169 incident dementia cases. A sensitivity analysis was conducted by substituting this dataset for each of the original three datasets and repeating the capture-recapture analysis for the total 60+ population (Table 4). Substituting the pharmaceuticals dataset with the mortality dataset resulted in similar modelled estimates to those of the largest three datasets of 19.5 (95% CI 14.9–29.2) per 1000py. Substituting the mortality dataset for the two datasets with the largest case ascertainment (interRAI



Fig. 2: Venn diagram and associated 2<sup>3</sup> Contingency table demonstrating distribution and overlap of incident dementia cases identified by the three linked health datasets for the total population aged 60+, 2021.

		Ascerta	ned				Missed cases			Ascertained + missed					
	Age band	Cases	PY(000)	Rate	95% CI		N	95% CI		N	95% CI		Rate	95% CI	
				(10^3 PY)	Upper	Lower		Upper	Lower		Upper	Lower	(10 <sup>3</sup> PY)	Upper	Lower
Total	60-64	90	44.2	2	1.6	2.5	377	70	6958	467	160	7048	10.6	3.6	159.5
	65-69	157	40.2	3.9	3.3	4.6	45	22	98	205	179	255	5.1	4.5	6.3
	70-74	298	31.3	9.5	8.5	10.7	73	41	122	371	339	420	11.9	10.8	13.4
	75-79	450	22.6	19.9	18.1	21.8	376	190	816	827	640	1266	36.6	28.3	56.0
	80-84	473	14	33.8	30.8	37	184	95	354	655	568	827	46.8	40.6	59.1
	85-89	311	7.1	43.8	39.1	49	136	74	222	442	385	533	62.3	54.2	75.1
	90+	126	2.4	52.5	43.7	62.5	29	12	51	153	138	177	63.8	57.5	73.8
	60+	1905	162	11.8	11.3	12.3	1212	889	1651	3112	2794	3556	19.2	17.3	22.0
	65+	1815	118	15.4	14.7	16.2	1129	824	1544	2939	2639	3359	25.0	22.4	28.6
	80+	910	23.5	38.7	36.2	41.3	598	374	943	1499	1284	1853	63.8	54.6	78.9
Male	60-64	48	19.3	2.5	1.8	3.3	139	23	2651	187	71	2699	9.7	3.7	139.8
	65-69	76	17.8	4.3	3.4	5.3	40	16	88	116	92	164	6.5	5.2	9.2
	70-74	134	13.7	9.8	8.2	11.6	66	34	120	200	168	254	14.6	12.3	18.5
	75-79	176	8.9	19.8	17	22.9	195	61	863	371	237	1039	41.7	26.6	116.7
	80-84	181	5.4	33.5	28.8	38.8	77	40	139	258	221	320	47.8	40.9	59.3
	85-89	114	2.5	45.6	37.6	54.8	63	28	131	177	142	245	70.8	56.8	98.0
	90+	35	0.8	43.8	30.5	60.8	8	1	24	43	36	59	53.8	45.0	73.8
	60+	764	68.5	11.2	10.4	12.0	588	373	952	1352	1137	1716	19.7	16.6	25.1
	65+	716	49.2	14.6	13.5	15.7	497	310	817	1213	1026	1533	24.7	20.9	31.2
	80+	330	8.7	37.9	33.9	42.3	160	99	250	490	429	580	56.3	49.3	66.7
Female	60-64	42	24.8	1.7	1.2	2.3	9	4	22	51	46	88	2.1	1.9	3.5
	65-69	81	22.4	3.6	2.9	4.5	31	13	65	112	94	146	5.0	4.2	6.5
	70-74	164	17.6	9.3	7.9	10.9	22	10	41	186	174	205	10.6	9.9	11.6
	75-79	274	13.7	20	17.7	22.5	190	81	493	464	355	767	33.9	25.9	56.0
	80-84	292	8.6	34	30.2	38.1	88	38	203	380	330	495	44.2	38.4	57.6
	85-89	197	4.6	42.8	37.1	49.2	176	59	637	373	256	834	81.1	55.7	181.3
	90+	91	1.6	56.9	45.8	69.8	21	9	42	112	100	133	70.0	62.5	83.1
	60+	1141	93.3	12.2	11.5	13	665	449	1002	1806	1590	2143	19.4	17.0	23.0
	65+	1099	68.4	16.1	15.1	17	590	395	893	1689	1494	1992	24.7	21.8	29.1
	80+	580	14.8	39.2	36.1	42.5	265	144	499	845	724	1079	57.1	48.9	72.9

Table 2: Incidence rates in the 60+ cohort, by age-band and sex, for ascertained dementia cases and including the modelled estimate of missing cases.

and publicly funded hospitalisations) modelled much higher missing cases but with very wide confidence intervals indicating significant uncertainty in the estimates.

# Discussion

To our knowledge this is the first study to estimate the incidence of later-onset dementia in NZ using a representative cohort of the four main ethnic groups. Our capture-recapture analysis suggests a third of incident dementia cases are not present in any of the three health datasets, which is consistent with UK estimates that only 62.2% of dementia cases are coded in primary care.<sup>30</sup> Combining the identified cases with those missed cases increased the incidence rate in the 60+ age group to 19.2 (17.3–22.0/1000py, bringing the estimates in line with international research such as those reported in a meta-analysis by Prince et al.<sup>29</sup> who reported

dementia incidence rates of 17.3/1000py globally, 18.4/ 1000py in high income countries and 14.1/1000py in low and middle income countries. Age-standardising to the same population used in their meta-analysis demonstrate an even higher incidence of 22.4 (17.8-63.4)/1000py in the modelled estimates but this should be interpreted with caution due to the wide confidence intervals. Dementia incidence increased with age, with an incident rate ratio (IRR) of 1.9 (95% CI = 1.9-2.0/1000py per 5-year age-band. Consistent with a previous meta-analyses,<sup>31</sup> there was no statistically significant difference in the modelled incidence estimates between males and females. Increasing deprivation was associated with dementia incidence, with an IRR of 1.1 (95% CI 1.0-1.1) per one unit increase in score, a 1.6× increase in risk in the most deprived compared to the least deprived decile.

We found even after modelling the number of missing cases that dementia incidence rates in Asians

	Ascertained cases				Missed cases Asc			Ascerta	rtained + missed					
	cases	PY(000)	Rate	Lower	Upper	N	95% CI		N	95% CI		Rate	Lower	Upper
							lower	Upper		lower	Upper			
Total														
Maori	240	20.1	11.9	10.6	13.6	53	34	83	293	274	323	14.6	13.6	16.1
Pacific	39	4.1	9.5	6.7	12.7	13	5	34	52	44	73	12.7	10.7	17.8
Asian	s	s	4.7	3.1	7.0	s	s	s	s	s	s	5.8	5.0	9.0
Euro	1563	132.4	11.8	11.4	12.6	866	553	1357	2429	2116	2920	18.3	16.0	22.1
Male														
Maori	78	8.0	9.8	7.8	12.2	360	1	216,547	438	79	216,625	54.8	9.8	27,122
Pacific	s	s	10.7	6.8	17.0	s	s	s	S	s	s	14.6	11.8	24.6
Asian	s	s	5.1	2.6	8.4	s	s	s	s	s	s	8.5	5.6	28.4
Euro	630	56.5	11.2	10.5	12.2	250	166	376	880	796	1006	15.6	14.1	17.8
Female														
Maori	162	12.1	13.3	11.5	15.7	33	21	53	195	183	215	16.1	15.0	17.7
Pacific	s	s	8.6	5.3	12.7	s	s	s	s	s	s	12.0	9.5	21.0
Asian	s	s	4.4	2.7	8.1	s	s	s	s	s	s	4.9	4.5	6.7
Euro	933	76.0	12.3	11.7	13.3	492	272	890	1425	1205	1823	18.8	15.9	24.0

remained significantly lower compared to the other ethnic groups. This finding could be partly explained by the lower prevalence of apolipoprotein E4 in people of Asian ethnicity.<sup>32</sup> However, our incidence rate estimates in all non-European ethnic groups are likely to be an underestimate because of their younger age structure compared to Europeans<sup>5</sup> and a generally lower engagement with health services which could result in undercoding. For example, Cullum et al.33 has demonstrated that Māori and Pacific peoples are significantly less likely to enter aged residential care and Ma'u et al.<sup>22</sup> has shown a lower uptake of home based support services in the same cohort. Both aged residential care and home based support services require an interRAI assessment, so Māori and Pacific peoples will therefore be less likely have interacted with, and therefore have a diagnosis of dementia coded in this dataset compared to Europeans. Similarly, Chan et al.<sup>34</sup> have demonstrated that both Māori and Pacific peoples with a diagnosis of dementia are less likely to be dispensed anti-dementia medications so will therefore be under-represented in the pharmaceuticals database. The reasons for the lower engagement of non-European ethnic groups in NZ with health services are multifactorial. Health literacy, including conceptualisations of health, cognition and ageing, as well as stigma,<sup>35–37</sup> impact rates of assessment and diagnosis, with recent modelling suggesting more than half of dementias go undiagnosed in NZ.<sup>12</sup> Financial barriers affect access to a general practitioner and filling a prescription.<sup>38</sup> Experiences of colonisation and both structural and systemic racism by non-European ethnic groups have also been demonstrated to influence healthcare access.<sup>39</sup> Even in those who receive a diagnosis of dementia, uptake of postdiagnostic support services is low due to the perceived cultural inappropriateness of available services.<sup>35,36,40</sup>

Lower engagement with health services likely impacted dementia case ascertainment and therefore lower incidence estimates in Māori and Pacific peoples compared to Europeans, even after modelling missing cases. This also meant our study was not powered to allow modelling by ethnicity and age band so age-standardisation to account

	Cases	N	95% CI		Rate (10^3 PY)	95% CI	
			lower	Upper		Lower	Upper
A^B^D	1694	3160	2414	4728	19.5	14.9	29.2
A^C^D	1629	5107	3120	10,794	31.6	19.3	66.7
B^C^D	1524	5983	3477	12,745	37.0	21.5	78.8
A, interRAI; B, P	1524 Jblic Hospital discharges; (	5983 2, Pharmaceutical col	34// llection; D, Mortalit	12,/45 y.	37.0	21.5	

for the significantly younger age structure of these population groups compared to Europeans<sup>5</sup> was not possible.

Cheung et al.<sup>10</sup> have previously demonstrated a higher age- and sex-standardised dementia prevalence in the 60+ population in Māori (34% higher) and Pacific peoples (58% higher) compared to Europeans. This higher age- and sex-standardised dementia prevalence has also been demonstrated by Ryan et al. in young onset dementia.11 Both these findings are likely explained by the differential prevalence of risk factors for dementia in these ethnic groups9 and it is possible our study would show similar findings with sufficient power. This possibility is further strengthened by our finding of an association between increasing deprivation and dementia incidence. Increasing social disadvantage is associated with a higher prevalence of many risk factors for dementia so the significantly higher median deprivation score of Māori (8) and Pacific peoples (9) compared to Europeans (6) means these groups are at an increased risk of dementia.

## Strengths and limitations

This study has a number of strengths. Unique identifiers in IDI allowed accurate linkage of individuals across all datasets. The robust sampling strategy used by Statistics New Zealand to identify NZHS participants means the incidence cohort followed in this study is representative of the usually resident NZ population. The representative nature of the study population also means those with a greater risk of developing dementia are included. For example, in the NZHS 2018/19 cohort aged 75+, 18.2% had a history of ischaemic heart disease, 8.5% had a history of stroke, and 52.8% were currently prescribed medication for hypertension.<sup>41</sup> The exclusion of all participants with a dementia diagnosis in any of the linked datasets predating the start of follow up means only coded incident cases were identified. The median duration of follow up of 5.6 years is reasonable and in line with a median of 5 years follow up in international studies.42 However, this duration of follow up may not be sufficient for incident cases of dementia to develop so longer follow-up studies are indicated.

The sampling strategy of the NZHS is acknowledged as a potential limitation. The NZHS is designed to increase the number of Māori, Pacific peoples and Asian participants and potentially therefore less representative of the NZ population. In our cohort, this has resulted in a higher proportion of Māori (12.8%) than is in the total 60+ population (8.2%) but lower for Asian (3.1% vs 8.6%). The proportion of Europeans (81.6%) and Pacific peoples (2.5%) in the NZHS cohort was similar to that of the total 60+ population (82.2% European and 3.5% Pacific peoples). This has been addressed by weighting the number of ascertained cases to reflect the age and gender distribution of each ethnic group.

Limitations of case ascertainment with routinely collected data pertain to issues of under-diagnosis and under-coding, and the need to have interacted with one of the included datasets in order to be identified. Underdiagnosis of dementia is a recognised issue worldwide, with an estimated 60% of dementias going undiagnosed in high income countries and an even greater proportion in lower and middle income countries.43 The lack of capture of dementia cases diagnosed in primary care likely contributes to an under-count of incident cases. The results of this capture-recapture analysis suggests only two thirds of incident cases in our cohort were identified and coded in the datasets. While our capturerecapture analysis was limited to utilising three of the seven available datasets at any time to identify cases of dementia, the remaining four datasets only identified an additional 33 cases not already present in the three datasets used in this analysis. This means our analysis included almost all (98%) coded dementia cases. A sensitivity analysis substituting the fourth largest dataset (mortality) for each of the three largest (interRAI, Publicly funded hospitalisations and Pharmaceuticals collection) only identified 80.5%-89.5% of all coded dementia cases. Modelled incidence estimates using the mortality dataset were higher but with large confidence intervals indicating uncertainty in the results. Case ascertainment using routinely collected data also means the diagnosis is not standardised. While the diagnosis of dementia in NZ is almost invariably made by a medical practitioner, variations in dementia assessment and diagnostic practices across the country and we acknowledge this limitation. The risk of overreporting dementia diagnoses is low, and evidence indicates dementia is underdiagnosed, with recent modelling in NZ suggesting over 50% of dementia is undiagnosed12 and that a third of patients at a NZ memory service were first diagnosed at a moderate-severe stage of dementia.44 There is also evidence from primary care that general pracititioners underdiagnose dementia.45 The end of our follow-up period included the first two years of the COVID-19 pandemic and it is possible this impacted engagement with health datasets. There is evidence that the volume of interRAI assessments reduced during initial months of the pandemic but picked up with the relaxation of public health measures.<sup>46</sup> While it is less likely that the COVID-19 pandemic affected public hospitalisations or pharmaceutical dispensing, we acknowledge this as a limitation in case ascertainment.

There are limitations associated with use of capturerecapture techniques and potential violation of some of the underlying assumptions. A biased estimate of missing cases is more likely if some sources capture very few cases. Each source we have used for case ascertainment identified sufficient cases, both in absolute terms and as a proportion of cases in the combined dataset. While the population was closed and no new participants were able to enter the study, we were unable to account for possible migration out of NZ. However, migration statistics indicate migration in the 60+

population is generally low. For example, in 2019, the 60+ population accounted for 22% of the total population but only 5.5% of long term migration out of NZ.47 It is possible some participants left the country and were lost to follow up. The assumption of independence in capture-recapture analysis means the likelihood of a case being coded in one dataset does not depend on being identified in another, but this is not always the case, particularly in health. The *recap* analysis outputs log-linear models for all eight one-way interactions (including the model with all possible one-way interactions). This allows an assessment and comparison of the dependence and interactions between sources, and subsequent selection of the best fitting model. In conjunction with the use of AIC and BIC to choose the best fitting model, it is also recommended that the best approach is to use the model with all possible interactions.13 In our study, the best fitting model was generally the one with all possible one way interactions and therefore somewhat accounts for interaction between the three datasets.

# Implications for policy

This study uses national health data to provides an insight into the incidence of dementia in NZ. Applying the incidence rates from this study to 2024 population estimates for NZ,<sup>48</sup> we estimate there are approximately 22,000 new cases of dementia per year. Based on an ageing population alone, and assuming no change in incidence, NZ can expect 29,500 incident dementia cases per year by 2040. With increasing evidence for the benefits of early diagnosis and intervention,<sup>2</sup> these estimates have significant implications for future health budget considerations for dementia service design and delivery.

The implications of a third of dementia going undiagnosed are also significant given that access to postdiagnostic community supports and interventions invariably require a diagnosis of dementia. Furthermore, even in those who have a coded diagnosis of dementia, only 70% received the mandated interRAI assessment required for funded social supports. This proportion will be even lower if we include individuals who were diagnosed with dementia in primary care in the denominator. Māori and Pacific peoples already receive a diagnosis at a more severe stage of dementia,44 are less likely to utilise aged residential care,33 and this lower aged residential care uptake is not compensated for by an increase in home based support service utilisation.22 Improving access to dementia assessment and diagnosis for these communities is imperative to improve outcomes by facilitating access to postdiagnostic supports and reduce the burden of care currently borne by their families. Policies reducing the practical barriers to healthcare access are clearly important but are only part of the solution and reducing inequities requires consideration of the entire dementia journey. Culturally tailored community awareness campaigns can improve health literacy, help seeking behaviour for cognitive symptoms, and navigation of the health system. Upskilling the health workforce in the assessment and diagnosis of dementia for minority ethnic groups is essential to improve rates of diagnosis.

# Conclusions

This study provides an insight into the incidence of dementia in NZ, with our incidence rates using modelled data consistent with international studies. While our study demonstrates the utility of using routinely collected health data in understanding the epidemiology of dementia, minority population groups are likely underrepresented using this approach. To address this, true community based, representative, longitudinal studies are required to better estimate dementia incidence and track potential changes over time. Our estimate that a third of dementia remains undiagnosed in NZ highlights the need for better access to dementia assessment and diagnosis. This requires a whole of system approach that not only addresses practical access barriers to assessment but also the wider influences of health literacy and help seeking behaviour so that appropriate supports and interventions can be put in place to improve outcomes for people with dementia and their families.

## Contributors

All authors conceptualised and designed the study. EM conducted the literature search, the calculations and wrote the first draft of the manuscript. EM, GC, SC, and CR had access to, and verified, the raw data. All authors commented on and edited the manuscript. EM had final responsibility to submit for publication.

#### Data sharing statement

These results are not official statistics. They have been created for research purposes from the Integrated Data Infrastructure (IDI) which is carefully managed by Stats NZ. For more information about the IDI, including access to the raw data, please visit https://www.stats.govt.nz/integrated-data/.

#### Declaration of interests

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