



Dementia Economic Impact Report 2020

Prepared for Alzheimers New Zealand
September 2021



FOREWORD

The Dementia/Mate Wareware Plan is needed urgently

Welcome to the 2020 Dementia Economic Impact Report (DEIR).

This latest DEIR strongly reinforces the fact that dementia constitutes a major – and still rapidly growing – problem for Aotearoa New Zealand, with a multiplicity of impacts and costs across human, societal, health system and fiscal boundaries.

It indicates nearly three per cent of all Aotearoa New Zealanders will have dementia by 2050, including over 10 per cent of our 65+ population. This is a 240 per cent increase in dementia numbers in the next 30 years.

The Report also confirms the likelihood of significant equity issues affecting the dementia community due to the rapid growth of the condition among Māori and Pasifika communities.

It is well known that existing dementia support services are woefully inadequate to deal with current case loads.

They are provided inconsistently around the country, they are underfunded and are of variable quality, and they are nowhere near what will be required to cope with the rapidly growing number of Aotearoa New Zealanders who will develop dementia as they age.

This Report makes the point clearly that, left unchanged, the current model of care provision will place unsustainable strain on health and social care, people living with dementia and their care partners.

The DEIR 2020 provides further proof, if any was needed, that Aotearoa New Zealand needs a plan to address the dementia challenge facing us as a nation.

We need to act, and act quickly, to fund and implement a coherent and consistent plan that actively and effectively addresses the issues facing the dementia community now and in the future.

Thankfully, such a plan exists. The Dementia/Mate Wareware Action Plan has been developed to drive the changes needed to address this challenge and improve the health, independence and quality of life of people living with dementia/mate wareware in a sustainable way.

The Plan sets out the most urgent steps, based on best practice, for the next five years.

The Labour Government gave the dementia community in Aotearoa New Zealand an election manifesto commitment to work with us on the Plan. But the time for talk is now past; now is very much the time for delivery.

The many thousands of New Zealanders living with dementia now, and the many, many thousands more who will be diagnosed with the condition must be able to get the help they need without overburdening the health system.

It's time to deliver for dementia. The findings in the DEIR 2020 make that an imperative.

Clare Hynd

Chair

Alzheimers NZ

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ABBREVIATIONS

Acronym	Full name
AIHW	Australian Institute of Health and Welfare
ARC	Aged residential care
AWE	Average weekly earnings
CSC	Community services card
DALY	Disability-adjusted life years
DEIR	Dementia Economic Impact Report
DHB	District health boards
DWCD	Dementia Worldwide Cost Database
GP	General practitioner
HC	Home care
HIV	Human immunodeficiency virus
ICD	International Classification of Diseases
IDI	Integrated data infrastructure
LTCF	Long-term care facility
MoH	Ministry of Health
NZ	New Zealand
PRIMHD	PRIMHD mental health data
SLP	Supported living payment
TAS	Technical Advisory Service
TLA	Territorial local authority
VSLY	Value of a statistical life year
WHO	World Health Organization
YLD	Years lived with disability
YLL	Years of life lost

EXECUTIVE SUMMARY

This report acknowledges the status of Māori as tangata whenua (people of the land) of Aotearoa New Zealand and the obligations and responsibilities that arise from te Tiriti o Waitangi (the Treaty of Waitangi).

In 2012, with the worldwide prevalence of dementia predicted to triple in the next three decades, the World Health Organization (WHO) declared dementia a global public health priority, and in 2017 called on member states to develop national dementia strategies by 2025. The NZ Government is contemplating a dementia plan for Aotearoa New Zealand and requires robust data regarding the extent and impact of dementia, for both the present, and future years. In the absence of epidemiological studies to determine the true extent of dementia in Aotearoa NZ, previous Dementia Economic Impact Reports for 2008, 2012, and 2016, have extrapolated dementia prevalence from international data. It is now 13 years since the publication of the first report and there has still been no epidemiological study on dementia prevalence in Aotearoa NZ, so this report has also had to rely on international data. This is an unavoidable limitation and highlights the urgent need for accurate NZ prevalence data.

This Dementia Economic Impact Reports (DEIR) updates earlier estimates from the DEIRs in 2008, 2012 and 2016. Where possible, we have made estimations of the costs associated with dementia using data from national NZ health, disability and social support services datasets (the methods and sources used are detailed in the appendix). On the whole, we have used the same methods as used in previous reports and the results are therefore directly comparable. All costs and cost projections throughout this report are presented in 2020 New Zealand dollars (NZD). Total economic costs are projected using both 2020 NZD as well as with different inflation assumptions to explicitly show the effect of cost inflation on total costs.

We have introduced two new aspects in our DEIR for 2020: how we value unpaid care and differences in cost of care and financial impact on families across ethnic groups in Aotearoa NZ. We have presented unpaid care (provided by families) in two different ways – firstly by calculating the cost of replacing all unpaid care with paid care (replacement cost) and secondly using the opportunity cost approach which only includes the cost of providing unpaid care if the carer would have been in employment were they were not providing care. This is a departure from previous reports which only presented the opportunity costs of unpaid care. When valued as a replacement cost, the cost of unpaid care is ten-fold higher than when valued as an opportunity cost, but we felt it was important to recognise the huge contribution that families make towards dementia care. When comparing with previous reports we have used opportunity costs in order to make a fair comparison. We have also presented findings for each ethnic group, categorised at level 1 ethnicity groupings by Statistics NZ, as risk factors for dementia and preferred models of care for people living with dementia differ across the major Aotearoa NZ ethnic groups.

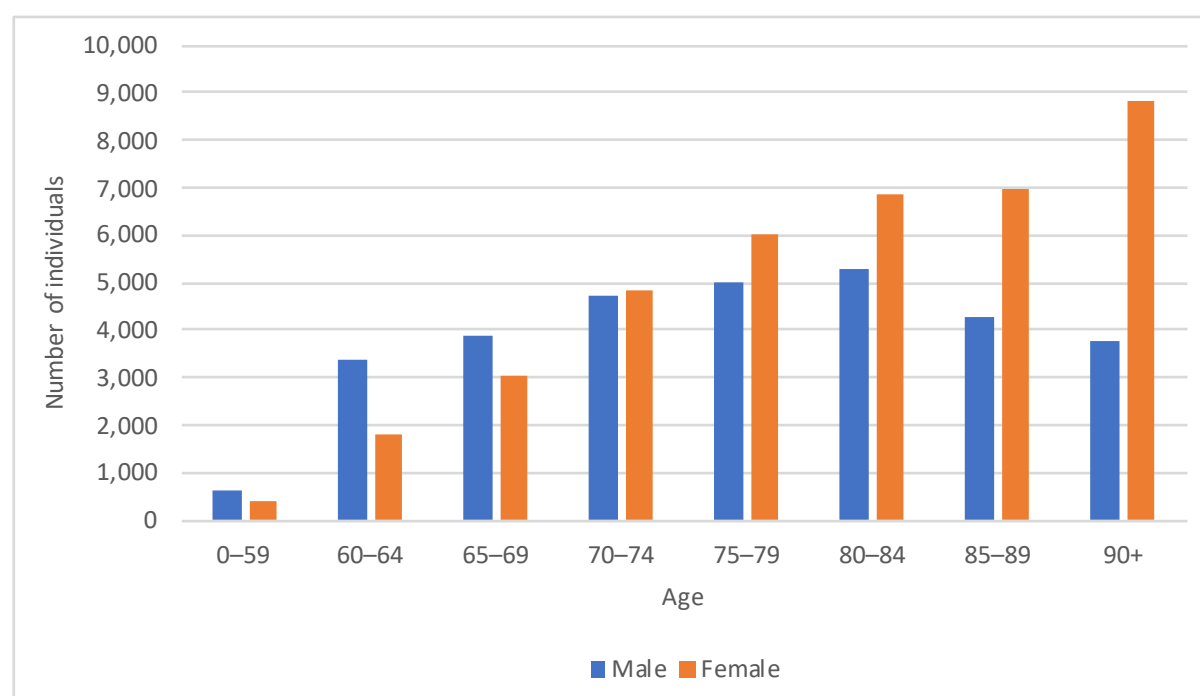
This 2020 report demonstrates the impact that dementia has on costs for the NZ Government, communities, families and individuals, and on loss of productivity for the economy, providing an estimate of the prevalence of dementia and associated costs in Aotearoa NZ in 2020, and expected prevalence and costs based on population projections. The report presents the financial cost for whānau and families, who provide most of the care for people living with dementia. Our findings also show considerable ethnic differences in use of long-term care services for people living with dementia, and the financial impact on those families. This particularly impacts Māori whānau who choose not to use aged residential care (ARC) but do not receive compensatory increase in culturally appropriate community support services, so whānau members bear the economic burden of providing care. This constitutes an inequity in allocation of resources which is not in line with Treaty obligations. These findings will help inform future dementia policy and service development for people living with dementia in Aotearoa New Zealand.

Prevalence, mortality and the burden of disease associated with dementia

Prevalence of dementia

The estimated number of people living with dementia in Aotearoa NZ in 2020 is **69,713** which is 1.4% of the total population. The majority are aged 65+ comprising 63,525 people or 8.0% of the 65+ population. The prevalence of dementia increases with age and there are more females than males in older age groups (Figure 1).

Figure 1. Dementia prevalence by age and sex, 2020.

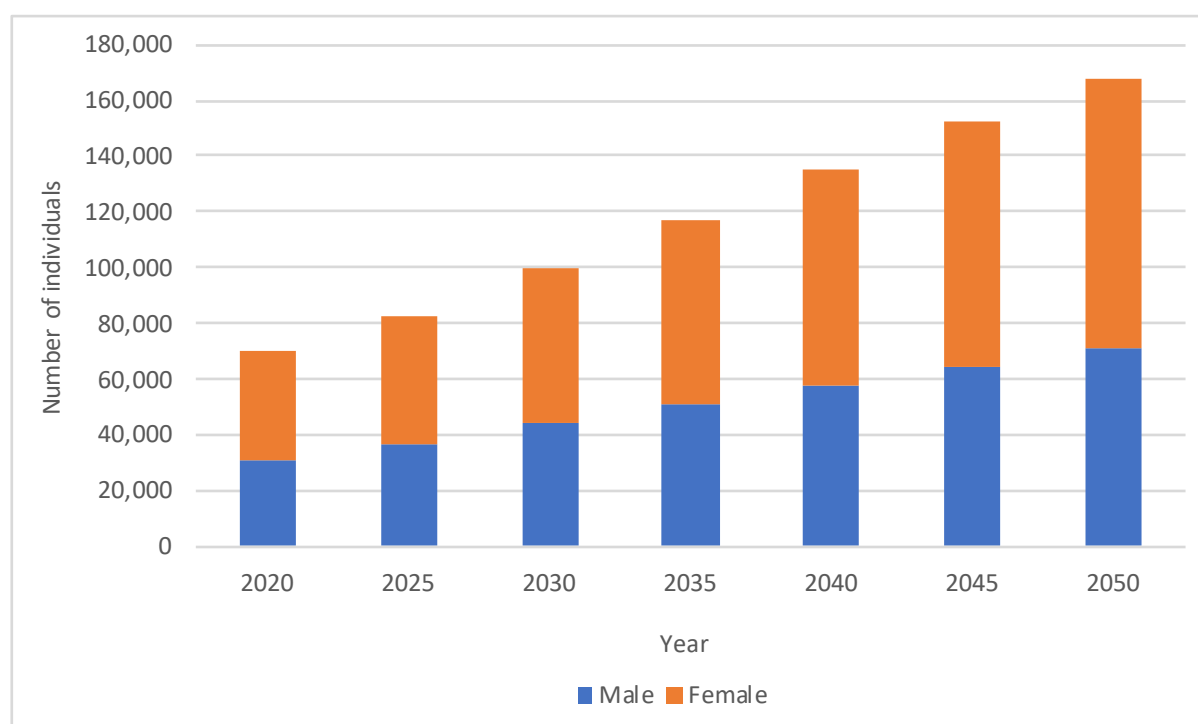


Source: Deloitte Access Economics (2016) and Statistics NZ population estimates (2020).

The number of people living with dementia is projected to more than double to **167,483** in the year 2050, comprising 2.7% of the total population and 10.8% of the population aged 65+ (Figure 2).

Unsurprisingly, the estimates for prevalence and projected dementia prevalence in this report are similar to those in the 2016 Deloitte Economic Impact Report (DEIR 2016), due to the same methods for calculation being used in both reports, the only difference being that we used the latest census data.

Figure 2. Projected prevalence of dementia by age and sex, 2020–2050.



Source: Deloitte Access Economics (2016) and Statistics NZ population projections (2020).

There is a greater proportion of young onset dementia (dementia starting before age 65) in Māori (19.0%), Pacific (18.0%), and Asian (16.8%) populations compared to Europeans (8.0%), resulting in a greater impact on financial income for families in these communities. This may be due to differences in the current age structure of these populations, with a much greater proportion being in the younger age groups compared to the European population, but may also be due to ethnic differences in prevalence of dementia risk factors.

Population ageing for Māori, Pacific and Asian populations will increase rapidly over the coming years. This will result in a more rapid increase in the number and proportion of people aged 65+ in these groups compared to the European population. The number of Europeans living with dementia in Aotearoa NZ is projected to almost double from 60,500 to 106,500, but dementia amongst Māori (4,300), Pacific (1,930) and Asian (4,800) populations will almost triple to 12,030, 5,450 and 17,990 respectively in 2050.

Mortality

Dementia is associated with increased mortality. We used new NZ data to calculate mortality so our estimates are not comparable with DEIR 2016.

In 2020, over one quarter of people (27.8%) who died in Aotearoa NZ had a diagnosis of dementia at the time of death, with one third of these (9.4% of total deaths) having dementia reported as the primary cause of death.

Burden of disease

The burden of disease is calculated using disability-adjusted life years (DALYs); a measure of the morbidity and mortality associated with dementia. Applying the value of a statistical life year (VSLY) for the Aotearoa NZ population to the number of DALYs associated with dementia estimates the burden of disease in 2020 at **\$6.2 billion**. This is an increase of 24% since DEIR 2016, due to the increase in dementia prevalence and in the unit cost of a VSLY.

Economic costs associated with dementia in 2020

The WHO defined the economic costs of dementia as the costs incurred from the provision of health and social care, and the hidden cost of unpaid care that is mostly provided by families. Social care for dementia in Aotearoa NZ is mostly funded through the health budget but we have presented it as a separate social care cost as it is important to distinguish this form of care from that received in hospital and primary healthcare settings. These costs are mostly comparable with DEIR 2016 as we used the same methods for calculations but using 2020 cost data. This report also includes productivity losses associated with reduced employment in people of employment age, and deadweight losses (an economic term for market inefficiencies, calculated as a percentage of costs borne by the government) as these were included in previous reports.

Health care costs

Health care costs in 2020 are estimated to be **\$274 million** or \$3,930 per person with dementia. The biggest contributor to this is the cost of inpatient hospital admissions (\$237.1 million), accounting for 86% of all health care costs. This is an increase of 45% since DEIR 2016. Part of this increase is due to our higher estimation of the number of people with dementia who are receiving health care services, the rest is due to increase in service costs.

Social care costs

In this report we have used the WHO definition of social care for dementia, which includes community support services, aged residential care (ARC), respite care and carer support. In Aotearoa NZ much of this is funded by NZ Government with some out-of-pocket payment for ARC and support services for those above a means tested threshold.

Social care costs in 2020 are estimated to be **\$1.39 billion** or \$19,970 per person with dementia. This is an increase of 47% since DEIR 2016, wholly accounted for by increased dementia prevalence and increased service costs. The greatest driver of social care cost is the cost of ARC (**\$1.21 billion**) which has increased by 42% since 2016 and accounts for 87% of all social care costs.

Compared to Europeans living in Aotearoa (\$20,530), the social care cost per person with dementia is lower for Māori (\$15,870), Pacific (\$16,020) and Asian (\$10,090) populations. This is predominantly due to the lower utilisation of ARC by these ethnic groups.

Unpaid care costs

In 2020 over 1 million hours of unpaid care is provided (mostly by family members) to people living with dementia every week – **52.7 million hours per year**, which would cost **\$1.19 billion** if it were provided by paid carers (valued as replacement cost).

The opportunity cost (cost to government) incurred by unpaid carers who would otherwise have been in employment were they not providing care, is estimated at **\$110.7 million** or \$1,590 per person with dementia.

This is an increase of 61% since DEIR 2016, due to an increase in the average wage of paid carers following a pay equity settlement in Aotearoa NZ.

Regardless of how the cost is valued, the burden of unpaid care is higher in Māori (11% higher than Europeans), Pacific (12% higher) and Asian carers (21% higher), mostly due to these populations' lower rates of utilisation of ARC.

Productivity and income support costs

The productivity costs associated with dementia in people of employment age due to reduced employment, absenteeism and premature mortality are estimated at \$232 million, and the cost of income support is \$82 million. The total cost associated with productivity costs and income support is **\$314 million** or \$4,510 per person with dementia. This is an increase of 9% since DEIR 2016.

The annual cost of productivity losses and income support per person living with dementia is \$9,200 for Māori, \$8,940 for Pacific and \$8,050 for Asian peoples, which is more than twice that of Europeans (\$3,380). This is due to a higher proportion of dementia occurring in people of employment age in these groups.

Deadweight losses

This report includes deadweight losses (an economic term for market inefficiencies, calculated as a percentage of costs borne by the government) as these were included in previous reports. Deadweight losses were estimated to be \$373.5 million dollars in 2020.

Costs of dementia across ethnic groups

Māori, Pacific and Asian people living with dementia and their carers are disadvantaged across multiple domains. They are disproportionately impacted by the lost productivity due to the higher prevalence of dementia in working age populations. They also utilise less social care resources which results in a higher cost of unpaid care being placed on families and whānau. Therefore, while the total economic cost per person for Europeans (\$35,250), Māori (\$35,680) and Pacific peoples (\$35,570) may appear similar (and that of Asian populations (\$27,650) significantly lower), they actually bear a greater economic disadvantage.

Total economic costs of dementia in 2020

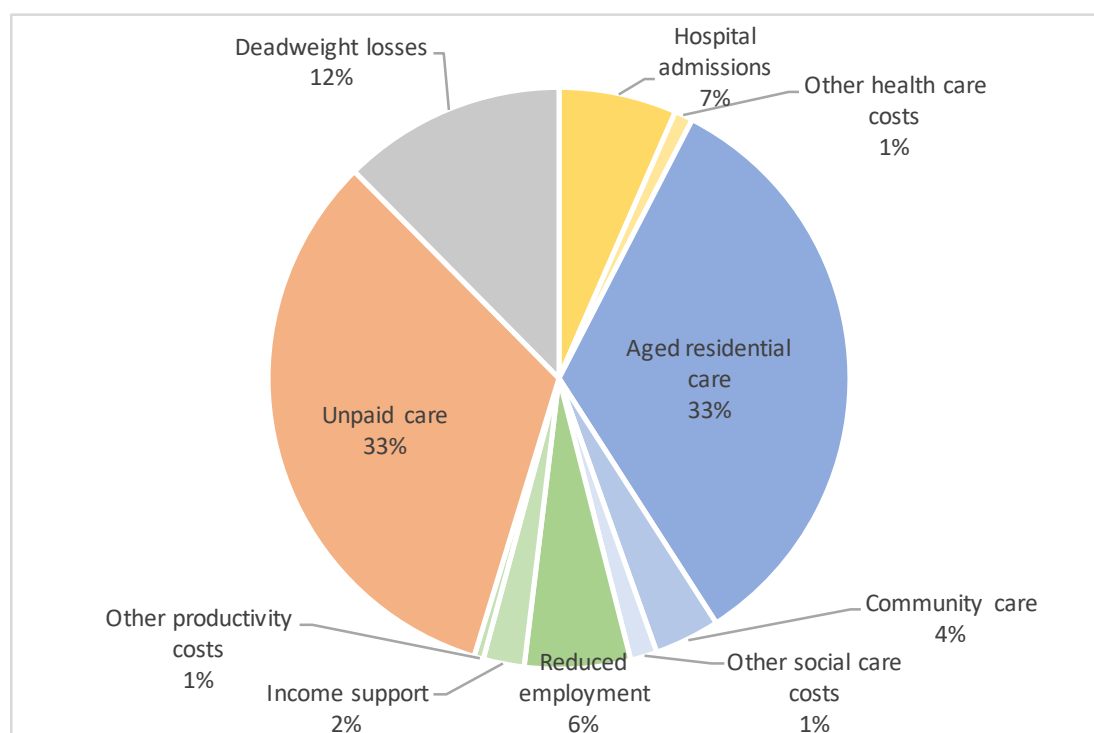
If unpaid care is valued as a replacement cost, and all unpaid care is valued as if it were provided by paid carers, the total economic cost of dementia in 2020 would be **\$3.62 billion** or \$51,930 per person with dementia. Two thirds of this estimated cost is associated with the provision of ARC (33%) and unpaid care (33%) (Figure 3). The cost of unpaid care to families is therefore over \$1 billion dollars.

If unpaid care is valued as an opportunity cost (the cost incurred by unpaid carers who otherwise would have been in employment were they not providing care), the total economic cost of dementia in 2020 would be **\$2.46 billion** or \$35,360 per person with dementia (Figure 3).

Using the second estimate, over half (56%) of the estimated total economic cost of dementia to the NZ Government in 2020 is accounted for by social care costs – the majority of which is due to ARC; 12% due to health care costs; 9% due to productivity losses and 4% due to unpaid care (Figure 4). The remaining costs are due to deadweight losses.

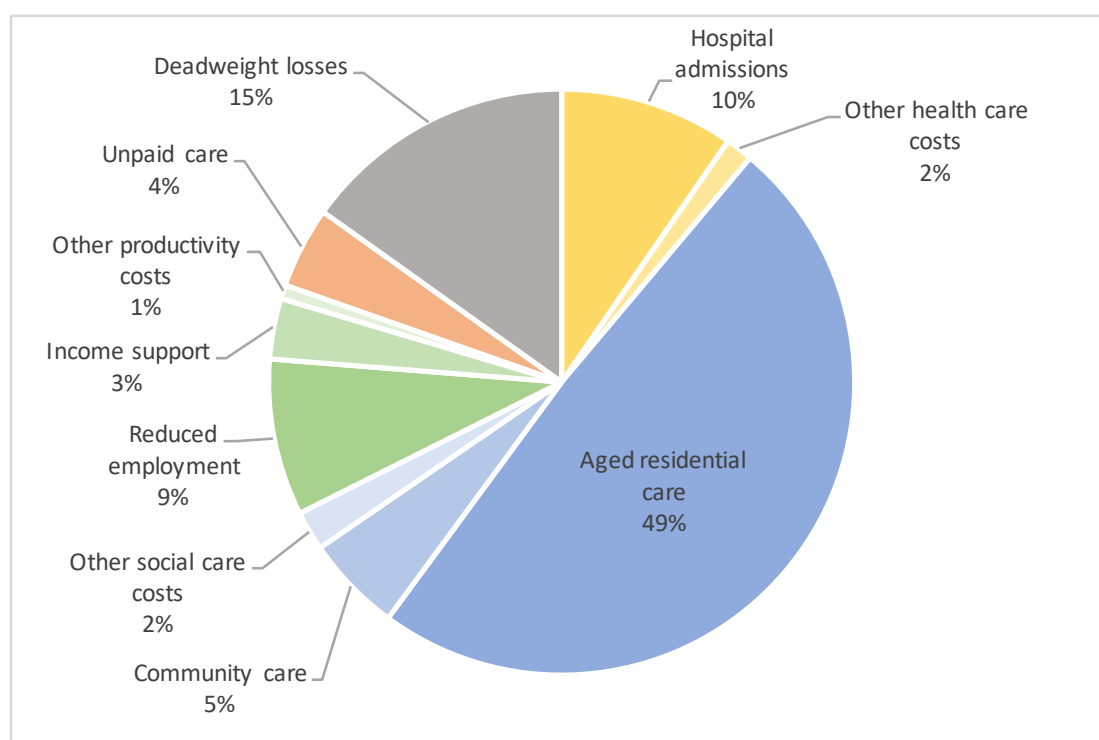
The total economic cost of dementia in 2020 has increased by 43% since DEIR 2016. Beyond the increase in dementia prevalence, most of the cost increase is due to higher service costs, and very little is due to methodological differences between the reports. Therefore these are real cost increases.

Figure 3. Total economic cost of dementia to Aotearoa NZ, 2020 (using replacement cost for unpaid care).



Source: University of Auckland calculations.

Figure 4. Total economic cost of dementia to Aotearoa NZ, 2020 (using opportunity cost for unpaid care).



Source: University of Auckland calculations.

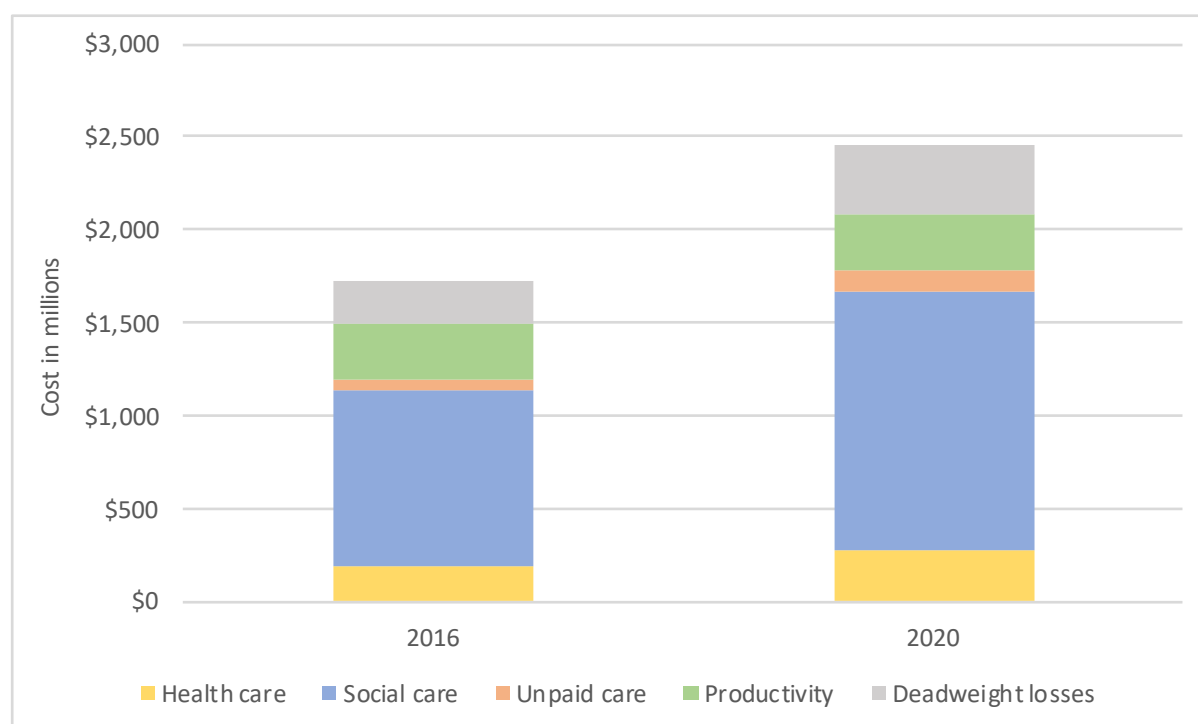
Economic cost comparison with the previous report

It should be noted that DEIR 2016 projected an increase in costs of dementia of 14% by 2020, but there is in fact a 43% difference between the 2016 projected costs and the costs that we have estimated. This is mostly due to an increase in the cost of ARC and community care.

Figure 5 compares the costs between DEIR 2016 and DEIR 2020 and shows the biggest driver of cost increase is social care, which increased by \$447 million and accounts for 60% of the increase in costs. This was calculated the same way as DEIR 2016 so is a real increase, it is not attributable to methodological differences.

Cost calculations in this report used the same method as those employed in DEIR 2016, with the exception of the health care costs due to inpatient care for people with dementia (which utilised a more accurate approach compared to DEIR 2016). It is important to note that, had we used the DEIR 2016 method to calculate the cost of inpatient care, there would still have been a 40% increase in the cost of inpatient care and an increase in the total economic cost of 42%. This means that the increase in the total economic cost is not attributable to methodological differences, but to the increased cost of health and social care services.

Figure 5. Total economic cost comparison between DEIR 2016 and DEIR 2020.

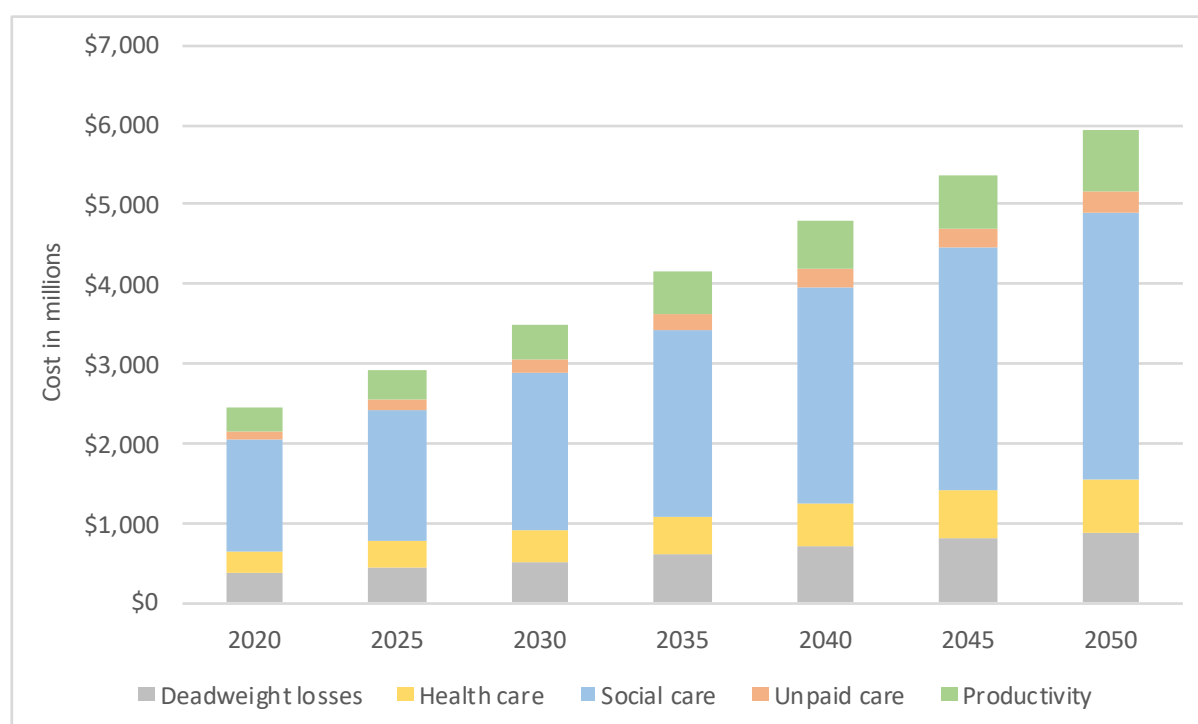


Source: University of Auckland calculations.

Projected economic costs due to dementia to 2050

The economic cost of dementia is projected to more than double by 2050 to **\$5.9 billion** (Figure 6). By 2050, health care costs are estimated to be \$658 million, social care costs \$3.2 billion, and productivity costs and income support to be \$755 million. If annual inflation at 2% is included, current costs will quadruple by 2050 to **\$10.7 billion**.

Figure 6. Projected economic cost of dementia using the opportunity cost of unpaid care (cost borne by the NZ Government).

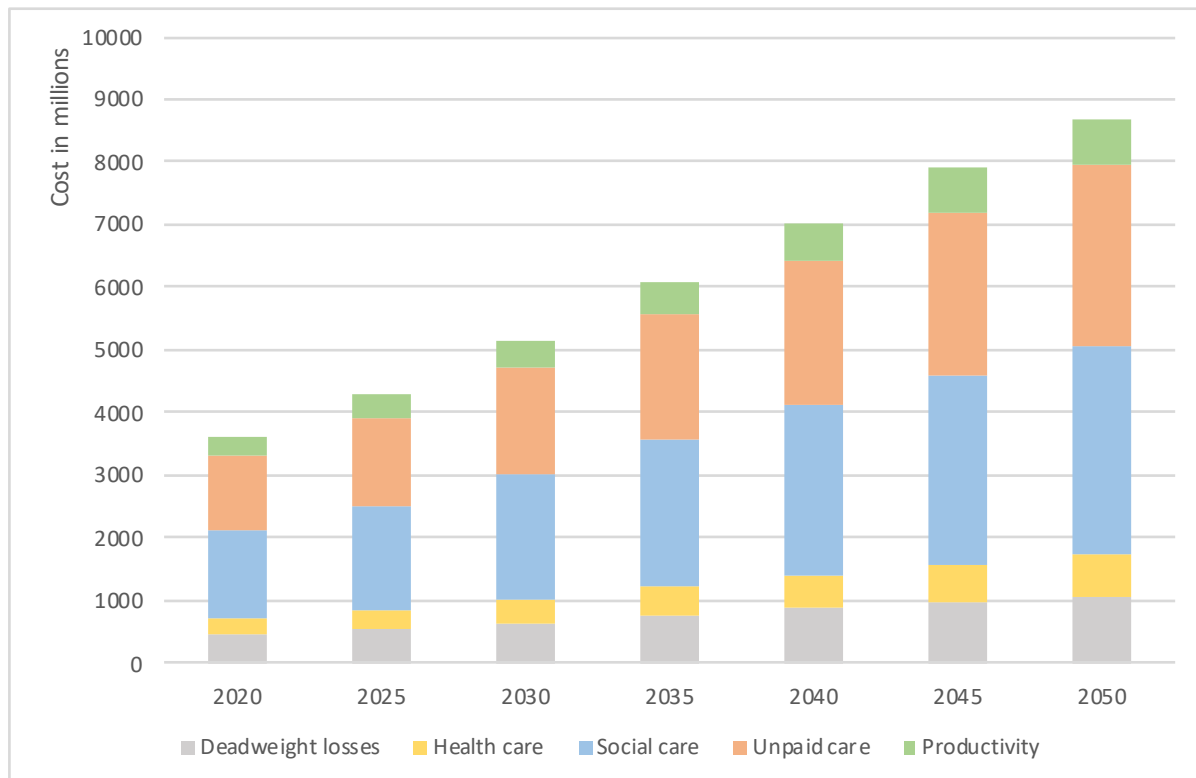


Source: University of Auckland calculations.

The opportunity cost of unpaid care is projected to more than double to \$266 million per year by 2050. However, if all unpaid family care were replaced by paid care (replacement cost), then unpaid care is estimated to be \$2.8 billion by 2050 (Figure 7) and the total economic costs to NZ Government and families in 2050 would be \$8.7 billion dollars, or over \$15 billion dollars if 2% inflation is included.

It should be noted that our estimates of costs are derived from real data and will therefore not include people whose dementia has not yet been identified. If identification of dementia improves, then costs are likely to increase further.

Figure 7. Projected economic cost of dementia using the replacement cost of unpaid care (cost borne by the NZ Government and by families).



Source: University of Auckland calculations.

Cost benefit of delaying aged residential care

Most people living with dementia wish to remain at home for as long as possible, and there are significant benefits for both people living with dementia and their families to remain living in the community. Entry into ARC generally occurs when an individual's care needs exceed available resources (subsidised, privately funded and unpaid) to adequately support them in the community. Currently, community support services for dementia in Aotearoa NZ are usually capped, limiting the choice to continue caring for a relative with dementia at home because support services are not available.

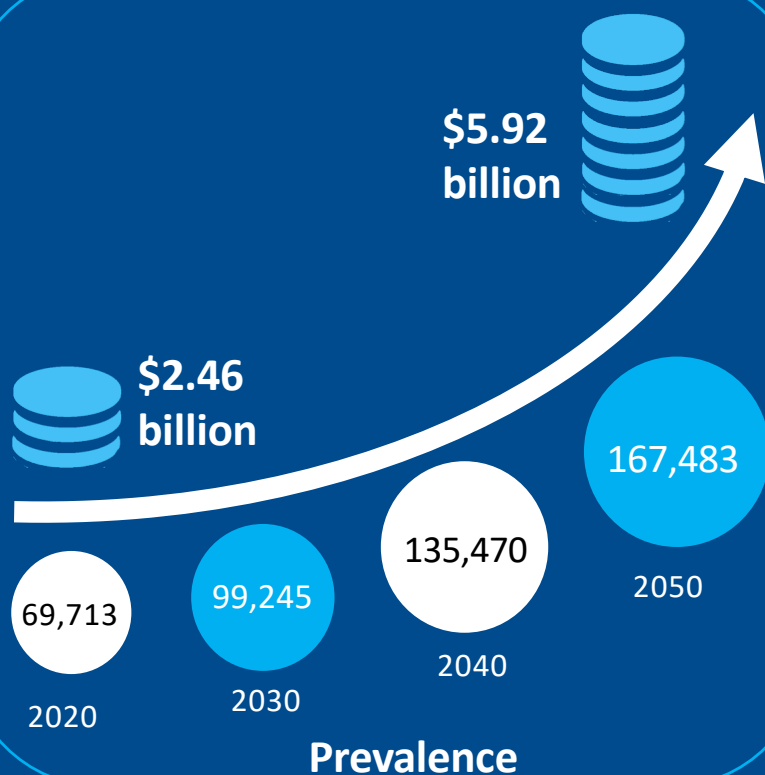
In 2020 aged residential care (ARC) currently represents half of the current total economic cost of dementia borne by the NZ Government (**\$1.21 billion**). We estimated the economic impact of delaying entry into ARC for people living with dementia, by comparing the savings from reduced ARC use against the additional costs associated with being cared for in the community. We made a simplified estimation that the savings associated with delaying entry into ARC would pay for an additional **7 hours of community support services per day**. These additional community support services would particularly help people who choose to care for their loved one with dementia at home and facilitate the development and delivery of culturally appropriate dementia care.

Conclusions

The prevalence of dementia in Aotearoa NZ will more than double in the next few decades, and the already high economic costs associated with dementia will increase. Developing community support services that facilitate independent living for people living with dementia may help to contain costs and reduce strain on health and social care. A national dementia strategy and corresponding action plan, as well as a co-ordinated national research agenda on dementia has the potential to deliver and promote evidence-based and culturally safe interventions at the individual, whānau/family, community, organisational and national level.

Dementia: a rapidly growing problem for Aotearoa NZ

September 2021

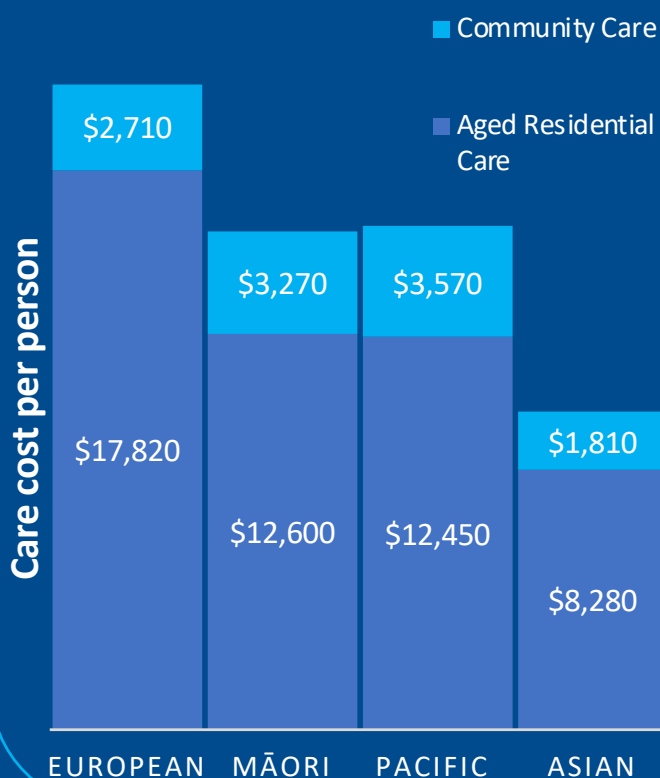


Carers provide
52.7 million hours
of unpaid care



Valued at
\$1.19 billion
per year

There is **inequity**
in dementia care across
Aotearoa NZ ethnic groups



One in four people
will die with
dementia



Dementia is increasing **faster**
in Māori, Pacific, and Asian peoples

Priority Areas

- Research on the true rates of dementia in Aotearoa NZ
- Culturally appropriate care that maximises quality of life
- A National Dementia Plan for Aotearoa NZ

1. INTRODUCTION

Dementia is a syndrome characterised by progressive loss of cognitive function with associated impairment in activities of daily living. As dementia progresses over the years, cognitive and functional impairment becomes more apparent until the person requires assistance with all aspects of life. Dementia is a considerable cause of disability and dependence, with significant impacts on individuals and their whānau/ family, communities and society. The underlying pathology of dementia is usually degenerative and the most common types of dementia are Alzheimer's disease dementia, vascular dementia, dementia with Lewy bodies and frontotemporal dementia.(1)

1.1 Dementia as a public health priority

Dementia is recognised as a global public health priority.(2) Age is the greatest risk factor for dementia, and as the world's population ages, the global prevalence of dementia is projected to increase from 50 million in 2015 to 130 million in 2050.(3) The current global cost of dementia is estimated at over \$US1 trillion dollars. Similarly, the *2016 Dementia Economic Impact Report* (DEIR 2016) estimated there were 62,287 people living with dementia in Aotearoa NZ in 2016 with a forecasted increase to 170,212 by 2050.(4) The cost of dementia care in Aotearoa NZ was estimated at \$1.67 billion in DEIR 2016 and was projected to treble by 2050.

It should be noted that the DEIR 2016 estimates for prevalence of dementia were extrapolated from other countries' prevalence data as an Aotearoa NZ dementia prevalence study has never been conducted, so these estimates may not reflect the unique ethnic diversity of Aotearoa NZ. Recent research has highlighted that Māori and Pacific people have higher prevalence of risk factors for dementia compared to Europeans in Aotearoa NZ, and therefore may be at higher risk.(5) Dementia is an area of great concern to Māori(6) and to other communities,(7) so it is important that we address the impact of dementia on different ethnic groups, despite a lack of relevant epidemiological research data.

In 2017, in response to the predicted global tripling of dementia prevalence, the WHO called on all 194 member states to produce a national dementia plan or strategy by 2025.(8) As part of the WHO *Global Action Plan*, it was envisaged that governments would make dementia a national priority and develop, implement and monitor a national research agenda on prevention, diagnosis, treatment and care of people living with dementia in collaboration with academic and research institutions, and also support families living with dementia. The NZ Government has yet to implement a plan for Aotearoa NZ.(9)

1.2 Economic impact of dementia in Aotearoa NZ in 2020

This report aims to estimate the economic impact of dementia in Aotearoa NZ. In this report we have attempted to use Aotearoa NZ data available in the public domain to estimate the prevalence, mortality, burden and costs of dementia, using similar statistical modelling techniques to previous DEIRs. In some areas, we have used alternative assumptions to estimate costs. For these reasons, our findings are not always directly comparable with previous reports, and we highlight this where appropriate. Where possible, we have disaggregated our findings by ethnicity, as there is now considerable evidence that different ethnic groups access different services for dementia and will therefore incur different costs. We have also included a summary of which of these costs are borne by the NZ Government to help inform the development of policy for dementia care.

We believe that, by using NZ-specific data where available, we have produced the most accurate estimates of the economic impact of dementia in Aotearoa NZ to date. We estimate the cost of dementia from a societal perspective including health care costs, social care costs, productivity costs and the costs of unpaid care, and applied these costs to the estimated numbers of people living with dementia at each stage of care.

1.3 Dementia services and clinical pathways

There is currently no cure for dementia. Interventions are mainly aimed at providing accurate diagnosis, addressing medical comorbidities, maximising function, providing appropriate support and care at different stages of dementia, and supporting family and care partners who provide most of the care. Pharmacological interventions are limited and mostly comprise of interventions to optimise physical health which will in turn optimise cognitive function (e.g. medications for diabetes and hypertension), in addition to cholinesterase inhibitors, drugs specifically developed to slow the rate of cognitive decline but do not reverse the progressive nature of the disease.

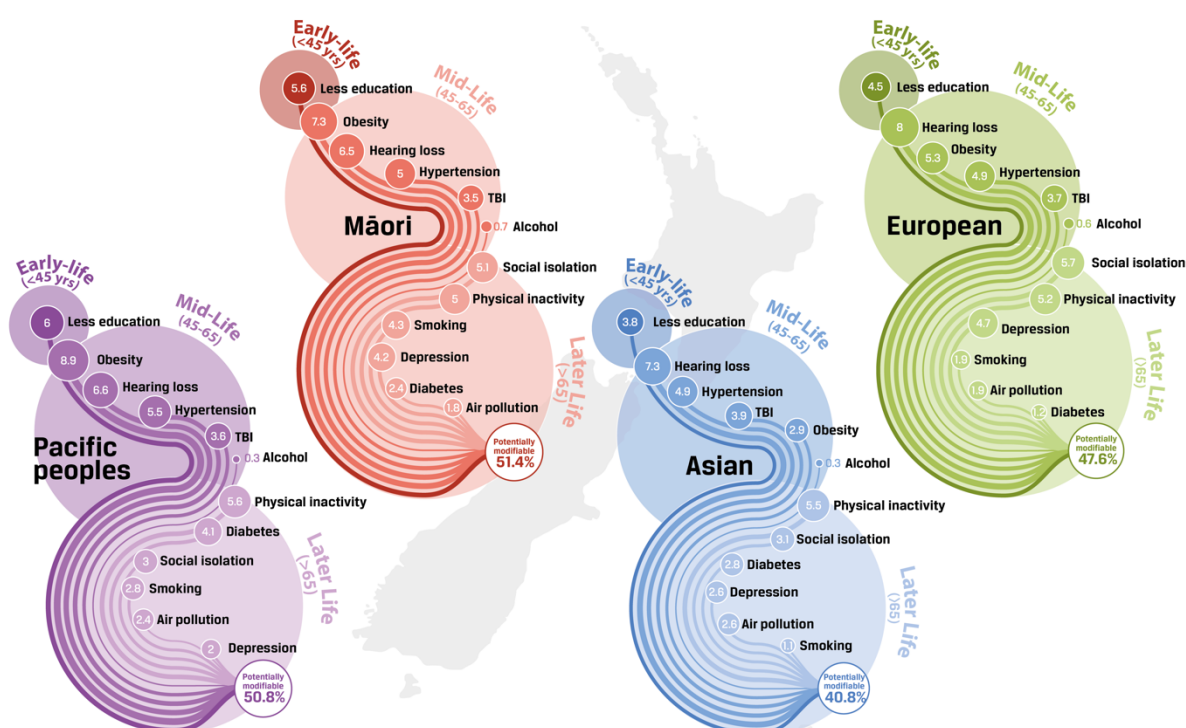
Dementia services in Aotearoa NZ are mostly provided by private and public sector and non-governmental organisations (e.g. Alzheimers New Zealand, Dementia New Zealand). Long-term residential care is mostly privately provided but publicly funded via District Health Boards (DHBs).

The New Zealand Framework for Dementia Care(10) provides guidance for the development of cognitive impairment pathways, which includes online tools and resources to assist mainly primary care clinicians in the diagnosis and management of dementia in each of the DHBs. The framework has three guiding principles: 1) following a person-centred and people-directed approach; 2) providing accessible, proactive and integrated services that are flexible to meet a variety of needs; and 3) developing the highest possible standard of care. The framework also highlights five key elements for effective dementia care: 1) awareness and risk reduction; 2) assessment, diagnosis, early intervention and ongoing support; 3) living well; 4) meeting challenges to maximise wellbeing; and 5) end of life care.

1.4 Dementia prevention

Evidence is emerging that up to 40% of dementia is preventable by reducing physical and psychosocial risk factors such as deafness, obesity, diabetes, hypertension, alcohol intake, social isolation and depression.(11, 12) Recent research evidence in Aotearoa NZ(5) suggests that this is particularly true for Māori and Pacific peoples with higher prevalence of these risk factors compared to Europeans (Figure 8). As such, developing interventions aimed at reducing the risk of dementia are of increasing relevance, but are in very early stages of development.

Figure 8. Relative population attributable fraction contributions of each risk factor across four ethnic groups in Aotearoa NZ.



Note: From "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," by E. Ma'u, S. Cullum, G. Cheung, G. Livingston, & N. Mukadam (2021). *The Lancet Regional Health – Western Pacific*, 13. <https://doi.org/10.1016/j.lanwpc.2021.100191>. © 2021 The Authors. Published by Elsevier Ltd.

1.5 Structure of the report

Section 2 presents estimates of dementia prevalence, mortality attributable to dementia and the burden of disease attributable to dementia.

Section 3 presents the health care costs associated with dementia.

Section 4 presents the social care costs associated with dementia.

Section 5 presents the real costs of unpaid care for dementia which is usually provided by families.

Section 6 presents the productivity losses due to dementia.

Section 7 presents the total costs of dementia, the projected costs of dementia care and the costs specifically borne by the NZ Government.

Section 8 summarises the issues presented in this report and considers policy implications.

The Appendix provides technical details for the modelling of the prevalence and costs of dementia.

2. PREVALENCE, MORTALITY AND BURDEN OF DISEASE

KEY FINDINGS

1. There were an estimated **69,713** people living with dementia in Aotearoa NZ in 2020, equivalent to 1.4% of the total population, of which 63,525 were aged 65+ (8.0% of the 65+ population). This represents an increase of 11.9% since DEIR 2016.
2. The number of people living with dementia is projected to more than double to **167,483** in 2050 – 2.7% of the total population, and 10.8% of the population aged 65+. Māori, Pacific and Asian populations will comprise a greater proportion of all individuals living with dementia in future years.
3. The younger age structure of our largest ethnic populations means there is a greater proportion of young onset dementia (dementia starting before age 65) in Māori (19.0%), Pacific (18.0%) and Asian (16.8%) populations compared to Europeans (8.0%). This means these populations will carry a higher burden of disease – estimated at **\$6.2 billion** in 2020 due to the increased years of life lost (YLL) and years lived with disability (YLD).
4. Dementia is associated with increased mortality. In 2020, over one quarter of people (27.8%) who died in Aotearoa NZ had a diagnosis of dementia at the time of death, although in only one third of these (9.4% of the total) was dementia reported as the primary cause of death.

2.1 Introduction

2.1.1 Prevalence

Prevalence is defined as the proportion of a population identified as having a disease at a specific point in time. Published prevalence estimates of dementia vary across the world(3) due to differences in age structures between population groups, methodological approaches in study design, and differences in prevalence of risk factors across countries and cultures.

Dementia prevalence in previous DEIRs(4, 13, 14) was estimated using data from other countries, as epidemiological data from Aotearoa NZ were not available. More recently, potential dementia prevalence in Aotearoa NZ has been estimated using routinely collected data from linked Aotearoa NZ administrative datasets.(15, 16) However, the latter approach only identifies individuals living with dementia who interact with health services; therefore, as up to 60% of people living with dementia remain unidentified,(17) this approach may underestimate the true prevalence of dementia. Large scale, community-based epidemiological studies are considered the gold standard for determining prevalence, but to date, such a study on dementia prevalence in Aotearoa NZ has not been conducted. In this report we have therefore used the same methods as used in DEIR 2016 to estimate dementia prevalence, applying prevalence data derived from international epidemiological studies to the Aotearoa NZ population. We recognise this method has shortcomings (which will also impact on cost calculations that are dependent on correct prevalence data) but it is the best available evidence to date.

2.1.2 Mortality

Deaths attributable to dementia as the primary underlying cause are reported by the MoH;(18) however, there is evidence that dementia is under-recorded as a cause of death.(19) Many individuals will die *with* dementia rather than as a result of their dementia, but these deaths may not be recorded. International evidence indicates a diagnosis of dementia is present in one third of all deaths.(20) In this report we have presented officially recorded figures for dementia diagnoses recorded at time of death, and included recent research that uses statistical modelling techniques to estimate the true number of individuals that died with a dementia diagnosis.(21)

2.1.3 Burden of disease

A standard method of assigning a value to life and health utilises disability-adjusted life years (DALYs), an approach that assigns a disability weighting to a disease between 0 (no health impact) and 1 (death). DALYs are a measure of the combined impact of years lived with disability (YLD) due to a disease and years of lives lost (YLL) due to premature mortality. This method is used by the Global Burden of Disease Study(22) and is the preferred method used by the MoH to assess the burden of disease. In this report we utilised this approach to calculate the burden of disease attributable to dementia.

2.2 Data sources and methods (see Appendix, p. 100)

2.3 Overall prevalence and prevalence by age and sex

Table 1 presents dementia prevalence estimates by age and sex for the Aotearoa NZ population in 2020 and prevalence projections to 2050 in five-year intervals. There were an estimated 69,713 people living with dementia in 2020, or 1.4% of the total population. The majority of these individuals were aged 65+, comprising 63,525 people or 8.0% of the 65+ population.

The number of people living with dementia is projected to more than double by 2050 to **167,400**, affecting 2.7% of the total population, and 10.8% of the population aged 65+.

Table 1. Projected prevalence by age and sex, 2020–2050.

	2020	2025	2030	2035	2040	2045	2050
Male							
0–59 years	605	614	627	640	657	670	675
60–64 years	3,386	3,742	3,739	3,768	3,564	3,965	4,574
65–69 years	3,856	4,378	4,864	4,880	4,934	4,685	5,219
70–74 years	4,752	5,189	5,939	6,633	6,693	6,799	6,486
75–79 years	4,997	6,574	7,265	8,395	9,461	9,626	9,842
80–84 years	5,264	6,679	8,942	10,031	11,761	13,419	13,830
85–89 years	4,297	5,282	6,826	9,356	10,714	12,815	14,861
90+ years	3,797	4,469	5,611	7,358	10,248	12,499	15,322
Male total	30,953	36,926	43,813	51,062	58,032	64,478	70,810
Male (% of total)	44.40	44.52	44.15	43.51	42.84	42.42	42.28
Female							
0–59 years	399	402	408	415	424	431	434
60–64 years	1,798	2,002	1,985	2,006	1,842	2,029	2,322
65–69 years	3,058	3,523	3,946	3,924	3,972	3,660	4,034
70–74 years	4,814	5,368	6,226	6,992	6,983	7,093	6,560
75–79 years	6,022	7,886	8,861	10,343	11,684	11,731	11,973
80–84 years	6,876	8,566	11,352	12,900	15,196	17,299	17,531
85–89 years	6,966	8,471	10,707	14,448	16,641	19,888	22,876
90+ years	8,829	9,801	11,948	15,269	20,696	25,394	30,942
Female total	38,760	46,018	55,432	66,296	77,438	87,525	96,673
Female (% of total)	55.60	55.48	55.85	56.49	57.16	57.58	57.72
Total	69,713	82,945	99,245	117,358	135,470	152,003	167,483
% total population	1.37	1.56	1.79	2.04	2.28	2.48	2.67

Source: Deloitte Access Economics (2016) and Statistics NZ population projections (2020).

The prevalence and proportion of people living with dementia in 2020 in the 0–64 year age group was 0.14% and 8.0% in the 65+ age group (Table 2). Over 90% of all dementia occurs in people aged 65+ years.

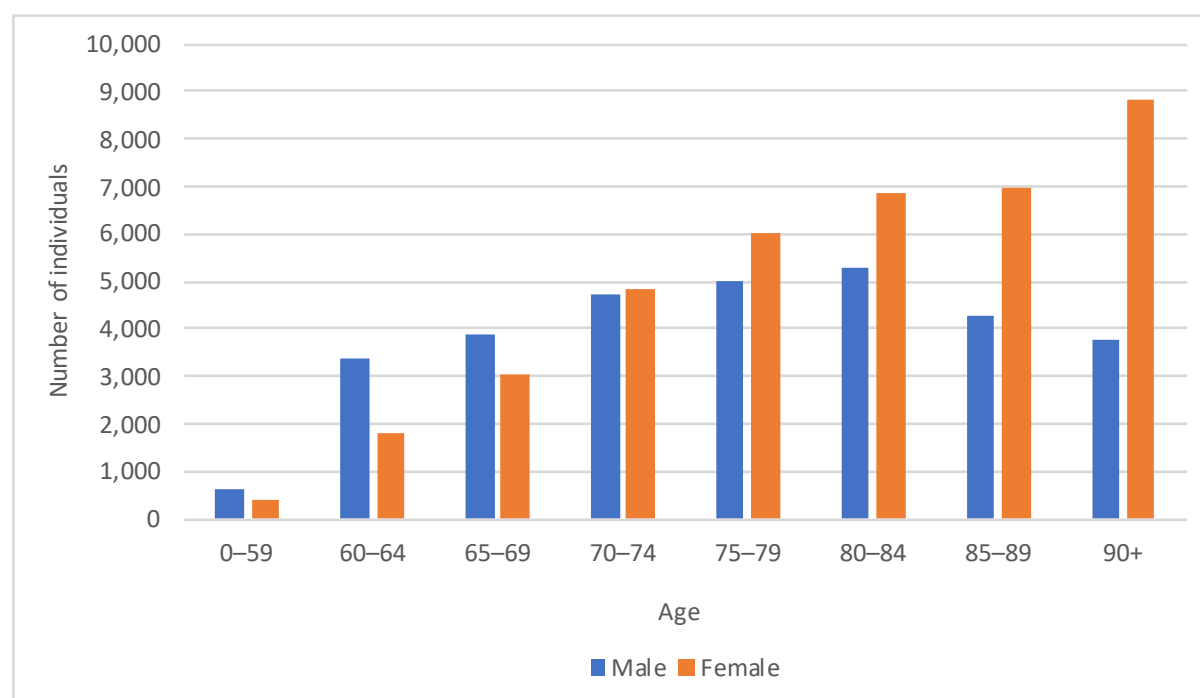
Table 2. Prevalence of dementia at 0–64 and 65+ years, 2020.

	Age band (years)	
	0–64	65+
Prevalence	6,188	63,525
% of total population	0.15	8.01
% of dementia prevalence	8.9	91.1

Source: Deloitte Access Economics (2016) and Statistics NZ population estimates (2020).

Figure 9 presents the number of people living with dementia by age and sex, and shows the relative sex differences in dementia prevalence, with males having a higher prevalence in the 60–70 year age group and females a higher prevalence from the age of 75 years. The predominance of women in older age groups is likely due to their greater life expectancy(23) as age is the greatest risk factor for dementia.

Figure 9. Prevalence of dementia by age and sex, 2020.



Source: Deloitte Access Economics (2016) and Statistics NZ population estimates (2020).

2.4 Prevalence by stage of dementia

The prevalence estimates by stage of dementia show Aotearoa NZ has an estimated 38,343 people with mild dementia (55.0%), 20,914 with moderate dementia (30.0%), and over 10,456 with severe dementia (15.0%).

2.5 Prevalence by ethnicity

Table 3 presents estimates of prevalence of dementia by age, sex and ethnicity in 2020. Almost 87% of those with dementia were of European ethnicity, followed by Asian (6.9%), Māori (6.2%) and Pacific peoples (2.8%).

As a result of the younger age structure of Māori, Pacific and Asian populations, the proportion of dementia prevalence in the younger age bands is higher compared to European, with only 8.0% of dementia in the 0–64 year age group for Europeans, compared to Māori (19.0%), Pacific (18.0%) and Asian (16.8%).

Table 3. Estimated prevalence of dementia by age, sex and ethnicity, 2020.

	European	Māori	Pacific	Asian
Male				
0–59 years	396	115	60	116
60–64 years	1,978	279	112	252
65–69 years	2,682	308	134	322
70–74 years	3,915	324	140	351
75–79 years	4,515	315	135	323
80–84 years	4,750	275	125	375
85–89 years	4,222	183	81	264
90+ years	4,022	115	38	192
Male total	26,481	1,914	825	2,194
Female				
0–59 years	395	114	58	116
60–64 years	2,047	310	119	326
65–69 years	2,803	342	137	389
70–74 years	4,140	369	153	383
75–79 years	4,988	368	173	383
80–84 years	5,838	375	175	425
85–89 years	5,948	284	142	325
90+ years	7,890	230	153	268
Female total	34,048	2,391	1,110	2,614
Total	60,529	4,305	1,935	4,808

Note: Individuals can self-identify with more than one ethnicity so the sum of dementia prevalence by ethnicity will be greater than 100% of total prevalence.

Source: Deloitte Access Economics (2016) and Statistics NZ population estimates (2020).

Table 4 and Figure 10 present dementia prevalence estimates by ethnicity in 2020 and projected forward in five-year intervals. Māori, Pacific and Asian populations are ageing more rapidly than Europeans (who already have a large proportion of the population aged 65+), and, as age is the greatest risk factor for dementia, will therefore account for a larger proportion of dementia cases in the future. Those of Asian ethnicity will see the largest increase, almost doubling to 13.3% of all cases by 2040. An increase of over 40% will be seen in the proportion of cases for both Māori (8.9%) and Pacific (4.0%) populations, and a corresponding reduction in the proportion of Europeans with dementia from 86.8%–78.7%.

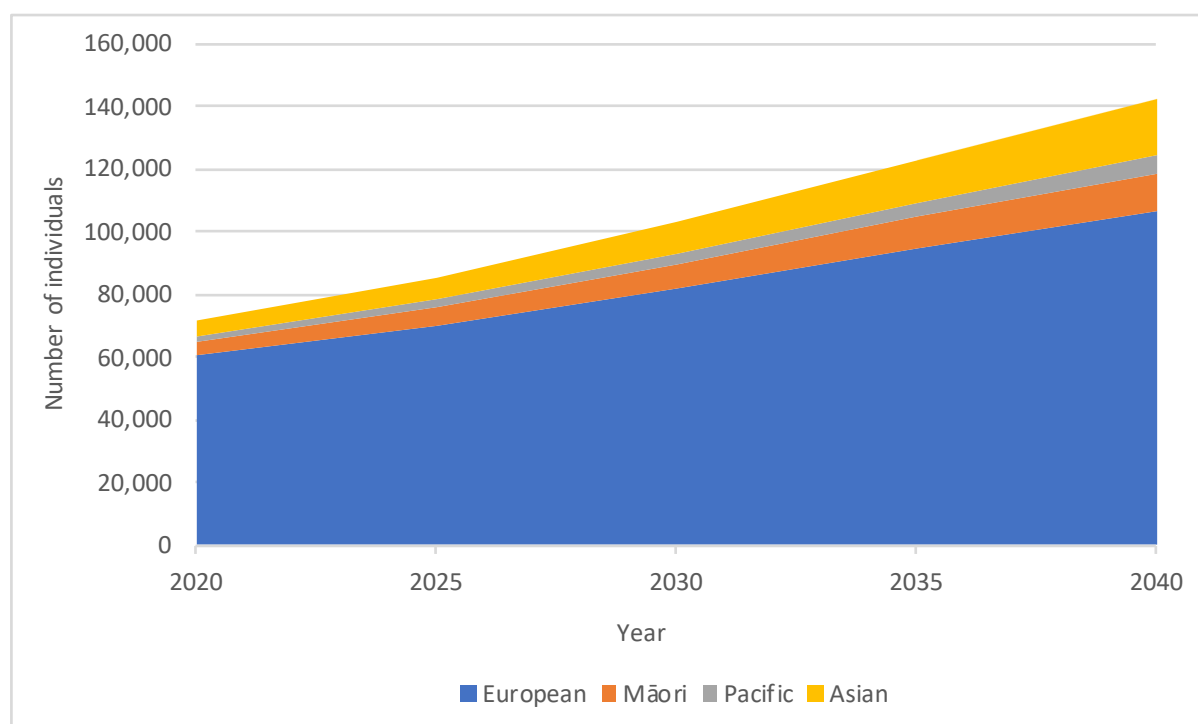
Table 4. Prevalence projections by ethnicity and as a proportion of total dementia prevalence, 2020–2040.

Ethnicity and prevalence	2020	2025	2030	2035	2040
European					
Dementia prevalence	60,529	70,297	82,148	94,891	106,566
% total prevalence	86.8	84.8	82.8	80.9	78.7
Māori					
Dementia prevalence	4,305	5,698	7,413	9,572	12,029
% total prevalence	6.2	6.9	7.5	8.2	8.9
Pacific					
Dementia prevalence	1,935	2,544	3,289	4,292	5,456
% total prevalence	2.8	3.1	3.3	3.7	4.0
Asian					
Dementia prevalence	4,808	7,103	10,042	13,567	17,991
% total prevalence	6.9	8.6	10.1	11.6	13.3

Note: Individuals can self-identify with more than one ethnicity, so the sum of dementia prevalence by ethnicity will be greater than 100% of total prevalence.

Source: Deloitte Access Economics (2016) and Statistics NZ population projections (2021).

Figure 10. Dementia prevalence projections by age and ethnicity, 2020–2040.



Source: Deloitte Access Economics (2016) and Statistics NZ population projections (2021).

2.6 Mortality associated with dementia

Due to concerns about the impact of COVID-19 on the accuracy of Aotearoa NZ mortality estimates for 2020,(24) our mortality estimates for dementia in 2021 are calculated using modelled data from McLeod et al.(21) This means that our estimates for mortality associated with dementia are not directly comparable with mortality estimates in DEIR 2016.

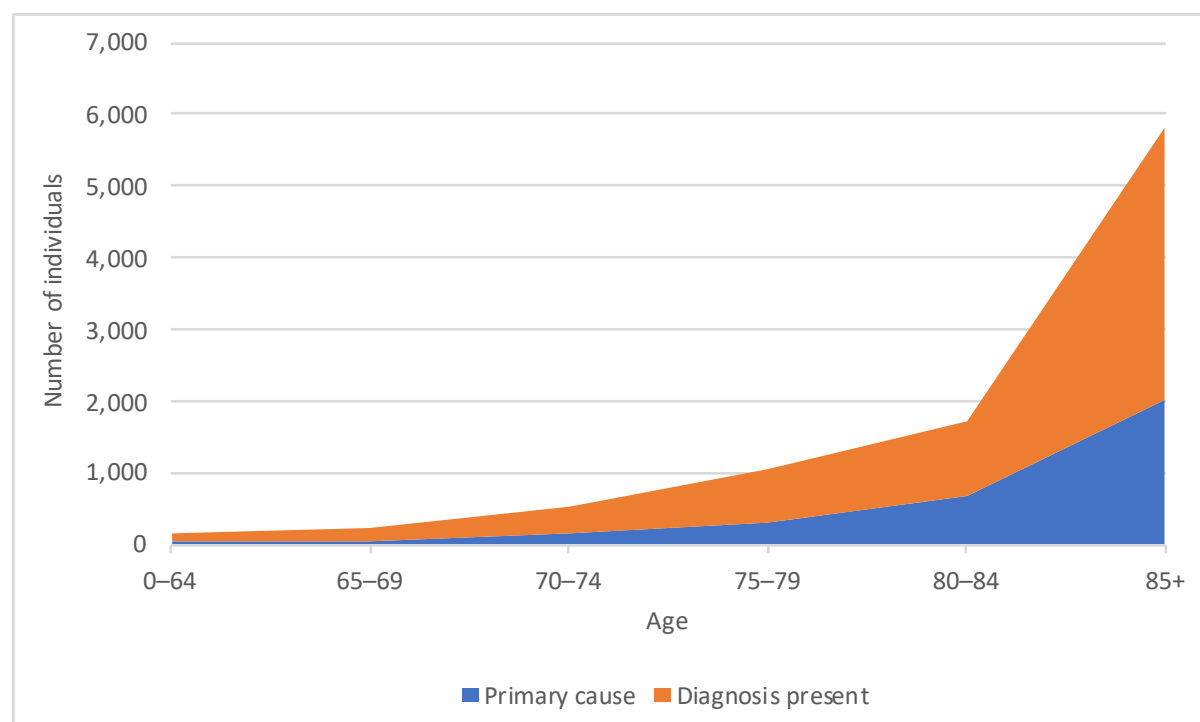
Table 5 presents our mortality projections for 2021. Both dementia diagnosis being present at death and dementia identified as the primary cause of death are presented. Out of an estimated total of 34,201 deaths in 2021, dementia is estimated to be present in 9,499 deaths (27.8% of all-cause mortality), with 3,205 of those deaths directly attributed to dementia (9.4% of all-cause mortality). Table 5 shows the proportion of individuals by age band, estimated to have a diagnosis of dementia at death and/or dementia reported as the primary cause of death.

Table 5. Dementia diagnosis present at death and/or dementia as the primary cause of death, 2021 mortality projections.

Years	All-cause mortality	Dementia diagnosis present at death (%)	Dementia as primary cause of death (%)
0–64	6,192	172 (2.8%)	31 (0.5%)
65–69	2,461	215 (8.7%)	41 (1.7%)
70–74	3,421	516 (15.1%)	144 (4.2%)
75–79	4,461	1,046 (23.4%)	311 (7.0%)
80–84	5,192	1,732 (33.4%)	663 (12.8%)
85+	12,474	5,818 (46.6%)	2,015 (16.2%)
Total	34,201	9,499 (27.8%)	3,205 (9.4%)

Source: Ministry of Health (2020) and McLeod (2019).

Figure 11. Estimated mortality due to dementia versus diagnosis of dementia present, 2021.



Source: Ministry of Health (2020) and McLeod (2019).

2.7 Burden of disease

Table 6 presents the burden of disease associated with dementia. Using the disability weights for dementia severity from the *Global Burden of Disease 2017 study*(22, 25) a weighted total of 15,181 years lived with disability (YLD) was calculated. Years of life lost (YLL) are calculated using the life expectancy at each age band from Statistics NZ Life Tables.(26) DALY are calculated as the sum of YLD and YLL. The burden of disease estimate is calculated as the product of the total number of DALYs and the VSLY, valued at \$181,000.(27) The estimate for the burden of disease due to dementia in Aotearoa NZ is **\$6.2 billion**.

Table 6. Years lived with disability, years of life lost, disability-adjusted life years and economic cost by age and sex, 2020.

Sex/Age band	Years lived with disability	Years of lives lost	Disability-adjusted life years	Cost (\$ millions)
Male				
0–59 years	132	52	184	33.3
60–64 years	555	236	791	143.2
65–69 years	737	406	1,143	206.9
70–74 years	1,015	857	1,873	339.0
75–79 years	1,137	1,501	2,638	477.5
80–84 years	1,188	2,018	3,206	580.3
85+ years	1,953	2,242	4,195	759.3
Female				
0–59 years	87	262	349	63.2
60–64 years	393	211	603	109.1
65–69 years	668	336	1,004	181.7
70–74 years	1,051	1,254	2,305	417.2
75–79 years	1,315	1,954	3,269	591.7
80–84 years	1,502	3,198	4,699	850.5
85+ years	3,450	4,723	8,173	1,479.3
Total	15,181	19,251	34,432	\$6.23 billion

Source: University of Auckland calculations.

3. HEALTH CARE COSTS ASSOCIATED WITH DEMENTIA

KEY FINDINGS

1. The total health care costs attributable to dementia in 2020 are estimated at **\$274 million** or \$3,930 per person living with dementia.
2. Costs associated with inpatient hospital admissions (\$237 million) account for 86% of all health care costs.
3. Health care costs (excluding aged care and community care costs) in DEIR 2016 were \$189 million. Health care costs have therefore increased by 45% since 2016. This increase is partly due to methodological differences.
4. Health care costs are projected to more than double to **\$658 million** by 2050.

3.1 Introduction

Dementia is associated with increased morbidity and incurs significant health care costs compared to people without dementia.(28) The main driver of health care costs attributable to dementia are due to inpatient hospital admissions, because individuals with a diagnosis of dementia have longer durations of stay in hospital regardless of whether dementia is the primary reason for admission.(29) Dementia is associated with increased health care costs due to the co-occurrence of frailty and other comorbidities(30) but this cost is difficult to quantify. To account for this, a weighting for 'Dementia and other chronic disturbances of cerebral function' is applied to the average cost of a hospital admission (see Appendix, p. 105 for a detailed explanation of this).

A diagnosis of dementia is not always identified or recorded during a hospital admission.(31) Hospital discharge statistics may therefore underestimate the true number of hospital admissions with a diagnosis of dementia present. We have addressed this by using modelled data (see Appendix, p. 104 for details) that provides a more accurate estimate of the numbers of individuals admitted to hospital with a diagnosis of dementia.(16)

Other health care costs include costs associated with pathology and imaging investigations, outpatient care, general practitioner (GP) visits, allied health services and pharmaceuticals.

People living with dementia and their family carers are also offered non-pharmacological interventions. For example, Cognitive Stimulation Therapy (CST) is an evidence based psychosocial group treatment aimed to improve cognition and quality of life of people with dementia. Rongoa Māori is traditional Māori healing which encompasses non-pharmacological practices and spiritual healing and can be useful for the prevention, management and treatment of *mate wareware*. These interventions are offered in the community by several members of Alzheimers New Zealand and affiliates of Dementia New Zealand, as well as some other residential and day programme providers. For this reason they are difficult to cost on a national level, and we have not included them in this report.

3.2 Data sources and methods (see Appendix, p. 104)

3.3 Cost of hospital admissions

Hospital admissions are the main driver of health care costs associated with dementia. The cost of hospital admissions in 2020 is estimated at **\$237.1 million** if all people living with dementia are included, including those who do not have their diagnoses coded at hospital discharge.

3.4 Other health care costs associated with dementia

3.4.1 Outpatient care

The cost of outpatient care in 2020 is estimated at **\$22.5 million**.

3.4.2 General practitioner visits

It is known that not all consultations for people living with dementia are for their dementia. Applying the assumption that 0.5% of all GP consultations are for dementia, there are an estimated 14.5 million GP consultations of which 73,850 are for dementia with an associated cost of **\$4.3 million**.

3.4.3 Pharmaceuticals

The cost associated with the dispensing of cognitive enhancers donepezil and rivastigmine are estimated at **\$660,000**. Both these medications are now off patent and available in generic form so, despite the increase in dementia prevalence, the cost associated with pharmaceuticals for dementia has decreased from \$800,000 in DEIR 2016.

3.4.4 Allied health

Allied health services available to people living with dementia include psychological, physical and occupational therapy. The cost associated with allied health services is estimated at **\$9.5 million**.

3.4.5 Pathology and imaging

There were 14,337 tests in 2008 attributable to dementia. Inflating for prevalence growth, this equates to 21,723 tests in 2020 at a cost of **\$0.2 million**.

3.5 Summary of health care costs due to dementia

Table 7 summarises annual health care costs associated with dementia, estimated at **\$274.2 million** or **\$3,930** per person.

Table 7. Summary of health care costs due to dementia, 2020.

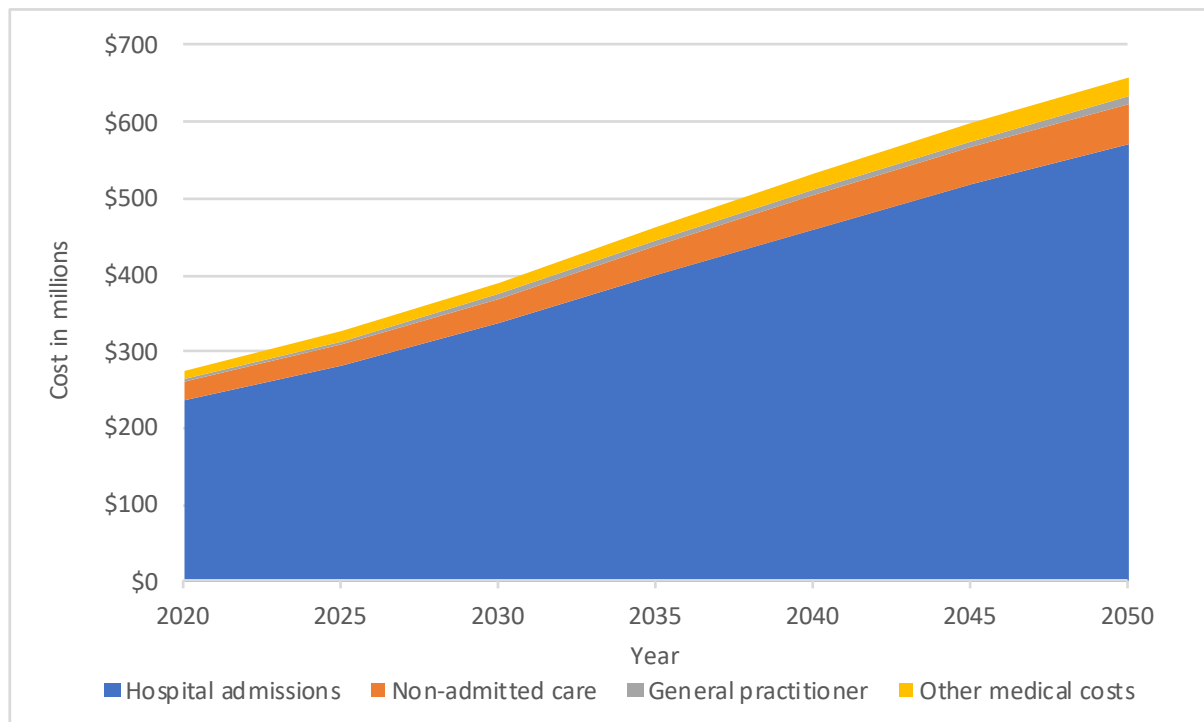
Type of cost	Cost (\$ millions)	Cost per person (\$)
Hospital admissions	237.1	3,400
Other health care costs	37.1	530
Non-admitted care	22.5	
General practitioner	4.3	
Pharmaceuticals	0.6	
Allied health	9.5	
Pathology and imaging	0.2	
Total	274.2	3,930

Source: University of Auckland calculations.

3.6 Projected health care costs

Figure 12 shows the projected medical costs due to dementia increasing in 2050 to **\$658 million** in today's dollars.

Figure 12. Projected health care costs due to dementia, 2020–2050.



Source: University of Auckland calculations.

4. SOCIAL CARE COSTS ASSOCIATED WITH DEMENTIA

KEY FINDINGS

1. Social care is defined by the WHO as care provided for people living with dementia in their own home and in ARC. For the sake of transparency, we have presented social care costs separately from other health care costs.
2. The total social care costs due to dementia in 2020 are estimated at **\$1.39 billion** or \$19,970 per person living with dementia.
3. Costs associated with ARC (\$1.21 billion) account for 87% of all social care costs and are projected to increase to \$2.9 billion by 2050.
4. The estimated social care cost per person living with dementia is lower for Māori (\$15,870), Pacific (\$16,020) and Asians (\$10,090) compared to Europeans (\$20,530). This is predominantly due to these groups' lower utilisation of ARC.
5. Social care costs in DEIR 2016 were estimated at \$945 million. Estimates of social care costs have therefore increased by 47% since 2016. This increase is not due to methodological differences.
6. Social care costs are projected to increase to **\$3.34 billion** in today's dollars by 2050.

4.1 Introduction

The WHO defines social care costs associated with dementia as care provided for people living with dementia in their own home (including community care, respite care, carer support and travel costs) and for care provided in ARC. For the sake of transparency in assessing the allocation of resources for dementia care, we have chosen to present social care costs separately from health care costs in this report.

Community care (home-based support services) and ARC may be funded privately, but much is funded by the NZ Government and co-ordinated locally by Needs Assessment and Services Co-ordination services.(32) Care can include assistance with personal care (e.g. showering), and/or home management (e.g. housework). The amount of funded support available is limited and is not available overnight, so any additional care requirements have to be met by the individual or their families (see Section 5). When an individual's care needs exceed the support available (from both funded, privately sourced and/or unpaid care), admission into an ARC facility is often recommended.

Carer support and respite services are funded by NZ Government to assist the unpaid full-time carer of a disabled person to take a break from caring for that person. Options include paying for family or friends to provide care, for access to an activity or day programme, employing a support worker to spend time with the person or facility-based respite.(33) Not all carers utilise the support or respite services they are eligible for, with an Australian study(34) estimating that only 39% of carers for people living with dementia access these services.

Research conducted in Aotearoa NZ has reported that entry into ARC varies between ethnic groups, with Māori and Pacific people living with dementia three times less likely to be in ARC compared to Europeans. (35) The reasons for this include cultural and familial preferences as well as concerns about the appropriateness of the services on offer.(6, 36) The differential utilisation of ARC highlights the need to disaggregate social care costs by ethnicity so that equity of resource allocation and utilisation can be evaluated.

4.2 Data sources and methods (see Appendix, p. 110)

4.3 Cost of aged residential care attributable to dementia

The total cost associated with ARC for people living with dementia is **\$1.21 billion** in 2020 (Table 8) or \$17,310 per person living with dementia.

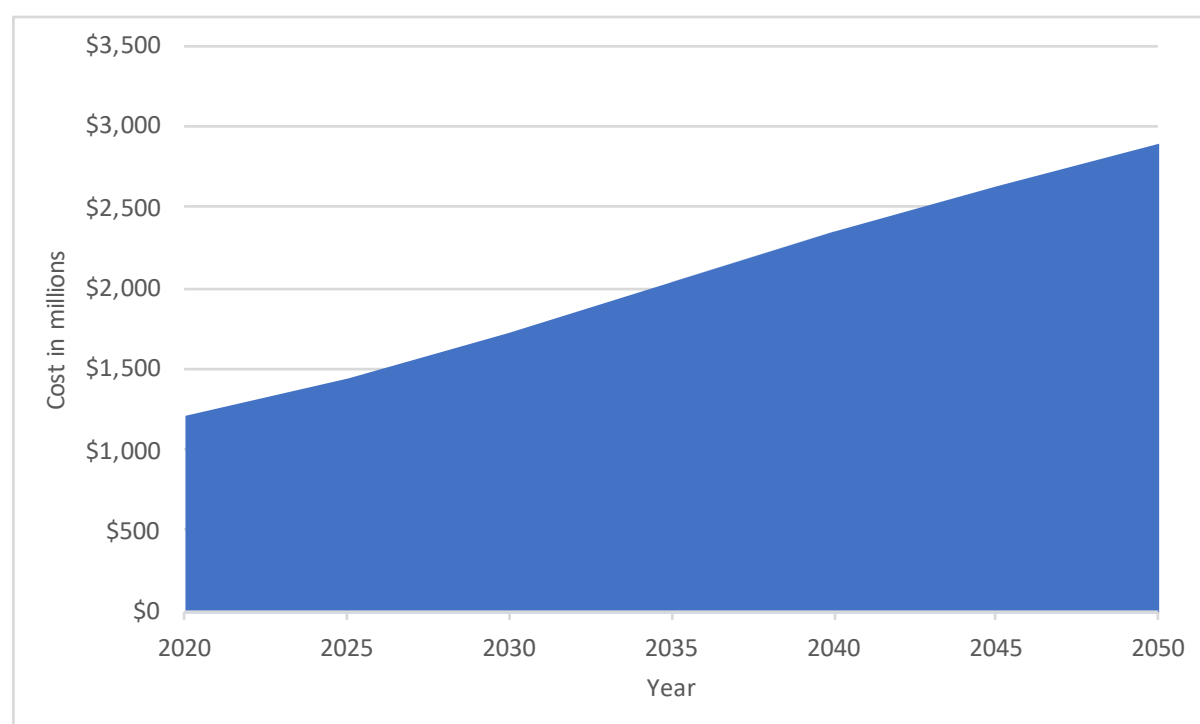
Table 8. Aged residential care occupied bed days and cost by level of care with dementia as the primary reason for care, 2020.

Level of care	Number of aged residential care bed days due to dementia (\$ millions)	Cost (\$ millions)
Rest home	2.2	356.9
Hospital	1.9	483.7
Dementia	1.5	331.1
Psychogeriatric	0.1	35.1
Total	5.7	1,206.8
Cost per person		17,310

Source: TAS (2021) and NZACA (2020).

Figure 13 shows the projected costs for ARC increasing to \$2.91 billion in today's dollars in 2050.

Figure 13. Projected aged residential care costs, 2020–2050.



Source: University of Auckland calculations.

4.4 Cost of aged residential care attributable to dementia by ethnicity

Table 9 presents the cost of ARC care attributable to dementia by level of care and ethnicity in 2020. Compared to Europeans (\$17,820 per person), the average spend on ARC per person living with dementia in 2020 is estimated to be approximately \$5,000 lower for Māori and Pacific, and \$9,000 lower for Asian peoples. This is consistent with previous research showing reduced ARC utilisation by non-European ethnic groups(35) as a result of both cultural preferences and perceptions of currently available services.

Table 9. Aged residential care cost in 2020 with dementia as the primary reason for care, by ethnic group.

Cost	European	Māori	Pacific	Asian
Total (\$ millions)	1,079.3	54.2	24.1	39.8
Per person (\$)	17,820	12,600	12,450	8,280

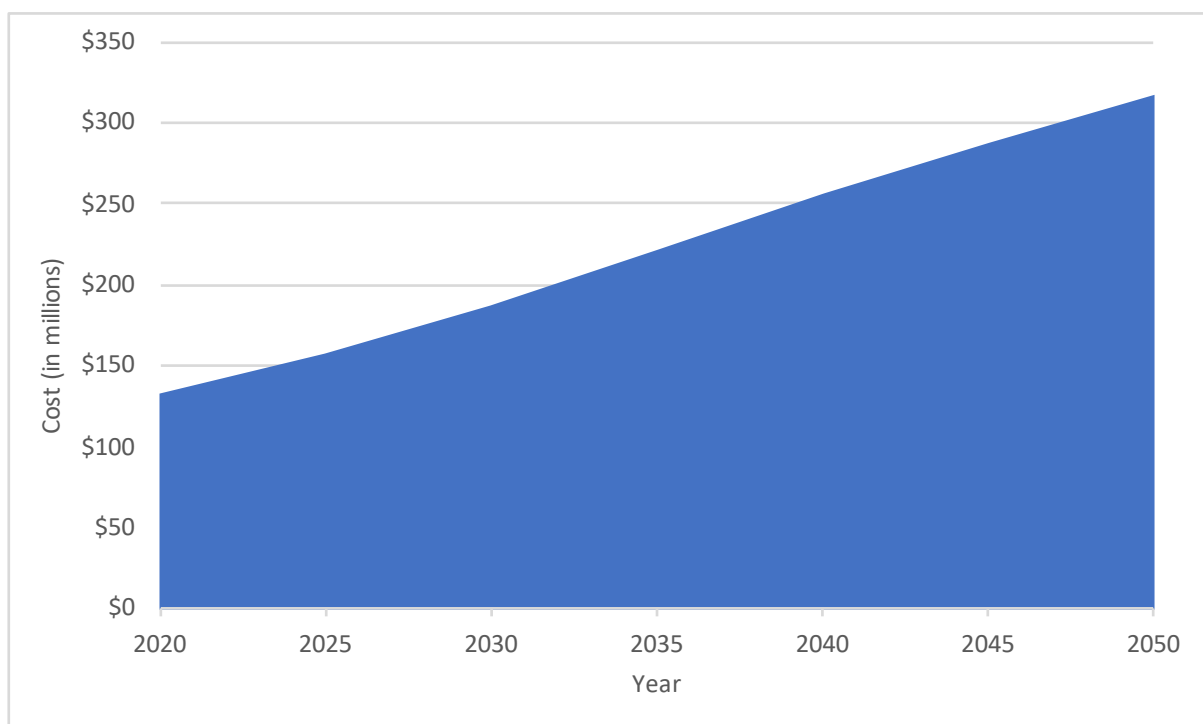
Source: TAS (2021) and NZACA (2020).

4.5 Costs of community care attributable to dementia

The costs associated with community care attributable to dementia in 2020 is estimated at **\$131.7 million** in 2020 or \$1,890 per person living with dementia.

Figure 14 shows the projected costs for community care increasing to \$316 million in today's dollars in 2050 (\$664 million if adjusted for inflation).

Figure 14. Projected community care costs, 2020–2050.



Source: University of Auckland calculations.

4.6 Cost of community care attributable to dementia by ethnicity

Table 10 presents the cost of community care attributable to dementia in 2020 by ethnicity. Compared to Europeans (\$1,890 per person), the average spend on community care per person living with dementia is almost \$500 higher for Māori and Pacific people (which is likely to be due to lower use of ARC in these groups, thus requiring more support at home) but over \$1,000 lower for Asian peoples (the reason for this is unknown but is likely to be due to the lack of culturally and linguistically appropriate services).

Table 10. Cost of community care attributable to dementia in 2020 by ethnicity.

Cost	All	European	Māori	Pacific	Asian
Total (\$ millions)	131.7	116.6	10.4	5.2	4.1
Per person (\$)	1,890	1,920	2,410	2,680	850

Note: Individuals can self-identify with more than one ethnicity so the sum of costs by ethnicity will be greater than 100% of total costs.

Source: TAS (2021) and interRAI (2020).

4.7 Cost of respite and carer support attributable to dementia

The cost of respite and carer support attributable to dementia in 2020 is **\$38.8 million** in 2020 or \$555 per person living with dementia.

4.8 Cost of respite and carer support attributable to dementia by ethnicity

Table 11 presents the cost of respite and carer support attributable to dementia in 2020 by ethnicity. It is important to note that the assumptions used in the estimation of respite and carer support (see Appendix, p. 113) are not based on real (i.e. interRAI-HC) data and are therefore likely to overestimate the amount of respite utilised in non-European groups.

Table 11. Cost of respite and carer support attributable to dementia in 2020 by ethnicity.

Cost	All	European	Māori	Pacific	Asian
Total (\$ millions)	38.8	33.2	2.6	1.2	3.2
Per person (\$)	555	550	600	620	670

Note: Individuals can self-identify with more than one ethnicity so the sum of costs by ethnicity will be greater than 100% of total costs.

Source: University of Auckland calculations.

4.9 Travel costs

Travel costs for people with disabilities or long-term health conditions are funded or subsidised by both central and local government. Based on the assumption of two trips per month, the travel costs related to dementia are estimated at **\$14.8 million in 2020** or \$212 per person living with dementia per year.

4.10 Summary of social care costs attributable to dementia

Table 12 presents the total costs associated with social care which is estimated to be **\$1.39 billion** or \$19,970 per person living with dementia. Social care costs in DEIR 2016 were estimated at \$945 million. Estimates of social care costs have therefore increased by 47% since 2016. This increase is due to increased cost of services and not due to methodological differences.

Higher social care costs for Europeans are due to their higher utilisation of ARC. Compared to Europeans, the social care costs for Māori and Pacific populations are approximately \$4,000 lower per person living with dementia and \$10,000 lower for those of Asian ethnicity. This is consistent with research findings and interRAI data that indicate Māori and Pacific people living with dementia are three times less likely to enter ARC.(35, 37).

Table 12. Summary of social care costs in 2020 by cost type and ethnicity.

Cost	All	European	Māori	Pacific	Asian
Aged care	1,206.8	1,079	54.2	24.1	39.8
Community care	131.7	116.6	10.4	5.2	4.1
Respite and carer support	38.8	33.2	2.6	1.2	3.2
Travel costs	14.8	14.1	1.1	0.5	1.4
Total (\$ millions)	1,392.1	1,242.9	68.3	31.0	48.5
Cost per person (\$)	19,970	20,530	15,870	16,020	10,090

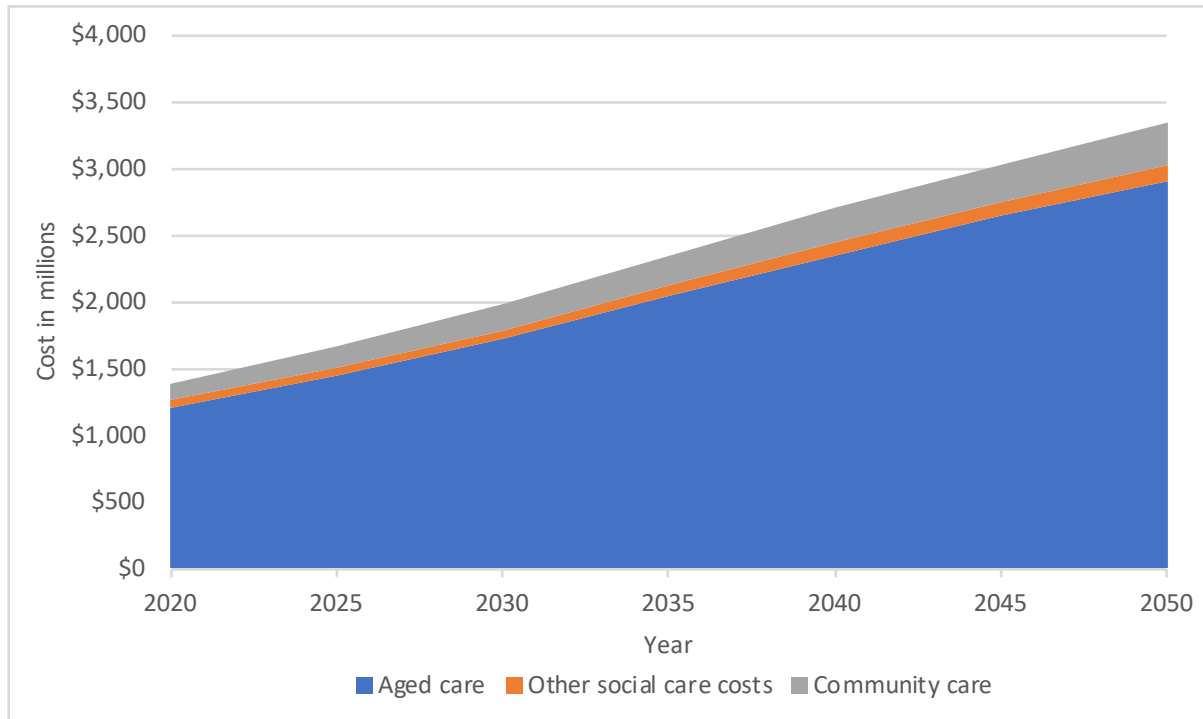
Note: Individuals can self-identify with more than one ethnicity so the sum of costs by ethnicity will be greater than 100% of total costs.

Source: University of Auckland calculations.

4.11 Projected social care costs

Figure 15 shows that the projected social care costs in 2050 will more than double to **\$3.34 billion** in today's dollars.

Figure 15. Projected total social care costs, 2020–2050.



Source: University of Auckland calculations.

5. UNPAID CARE COSTS FOR PEOPLE LIVING WITH DEMENTIA

KEY FINDINGS

1. Over 1 million hours of unpaid care was provided to people living with dementia in Aotearoa NZ every week or 52.7 million hours in 2020. If this care were provided by paid carers (replacement cost) the cost is estimated at **\$1.19 billion** or \$17,070 per person living with dementia. Alternatively, if only the cost incurred by unpaid carers who would otherwise have been in employment (opportunity cost) is counted, then the cost is estimated at **\$111 million** or \$1,590 per person living with dementia.
2. The opportunity cost of unpaid care in DEIR 2016 was estimated at \$68.6 million. Estimates of unpaid care costs (if valued as an opportunity cost) have therefore increased by 61% since 2016.
3. The cost of unpaid care differentially affects Māori (11% higher than Europeans), Pacific (12% higher), and Asian carers (21% higher) due to their lower utilisation of social care as shown in Section 4.
4. Projected costs for unpaid care will double by 2050 whether valued as an opportunity cost or as a replacement cost. By 2050, opportunity costs are projected to increase to \$266 million and replacement costs are projected to increase to \$2.8 billion.

5.1 Introduction

Unpaid care is defined as the provision of unpaid care to a dependent or disabled person with whom they have a social relationship.(38) This encompasses any care and support provided to an individual living with dementia for their basic activities of daily living such as eating, toileting and dressing and instrumental activities of daily living such as shopping, managing finances and transportation, or supervision and oversight.

Section 4 presented the social care costs and highlighted lower ARC utilisation by non-European ethnic groups, but without an equitable increase in formal community care to compensate. This means non-European ethnic groups incur extra unpaid care costs as a result of a greater proportion of individuals living with dementia residing in the community. The differential cost of unpaid care costs highlights the need to break down costs by ethnicity so that equity of resource allocation and utilisation can be evaluated.

While it is clear that unpaid care costs incur a significant economic burden, putting a monetary value on the provided care is not straightforward, with different assumptions yielding different outcomes. Carers have also been shown to have poorer health outcomes and likely incur additional health care costs, but these are difficult to quantify.(39)

In this report we have chosen to present the costs associated with unpaid care using two approaches. The replacement cost approach measures the cost of buying the same amount of care from the paid care sector if unpaid care was unavailable and is therefore an estimate of the cost of care carried by families. The opportunity cost approach looks at the probability that the person providing unpaid care would otherwise have been in employment and calculates the financial loss incurred.

5.2 Data sources and methods (see Appendix, p. 115)

5.3 Costs of unpaid care

The **opportunity cost** of unpaid care is **\$111 million** or \$1,590 per person living with dementia. However, the total **replacement cost** of providing the 52.7 million hours of unpaid care using the replacement method is estimated as ten-fold higher at **\$1.19 billion** or \$17,070 per person living with dementia.

5.4 Cost of unpaid care by ethnicity

Table 13 presents the cost of unpaid care by ethnicity. Māori, Pacific and Asian ethnic groups bear a higher financial cost of unpaid care as people living with dementia from these groups are less likely to be in ARC and are therefore counted as requiring unpaid care provided by their families at home.

Table 13. Hours of unpaid care and associated total cost and cost per person living with dementia by ethnicity, 2020.

Ethnicity	Hours per year (millions)	Replacement cost		Opportunity cost	
		Total (\$ millions)	Cost per person (\$)	Total cost (\$ millions)	Cost per person (\$)
Māori	3.6	80.9	18,790	7.5	1,750
Pacific	1.6	36.6	18,910	3.4	1,760
Asian	4.3	98.1	20,400	9.1	1,900
European	45.2	1,019.9	16,850	94.9	1,570
All	52.7	1,190.0	17,070	110.7	1,590

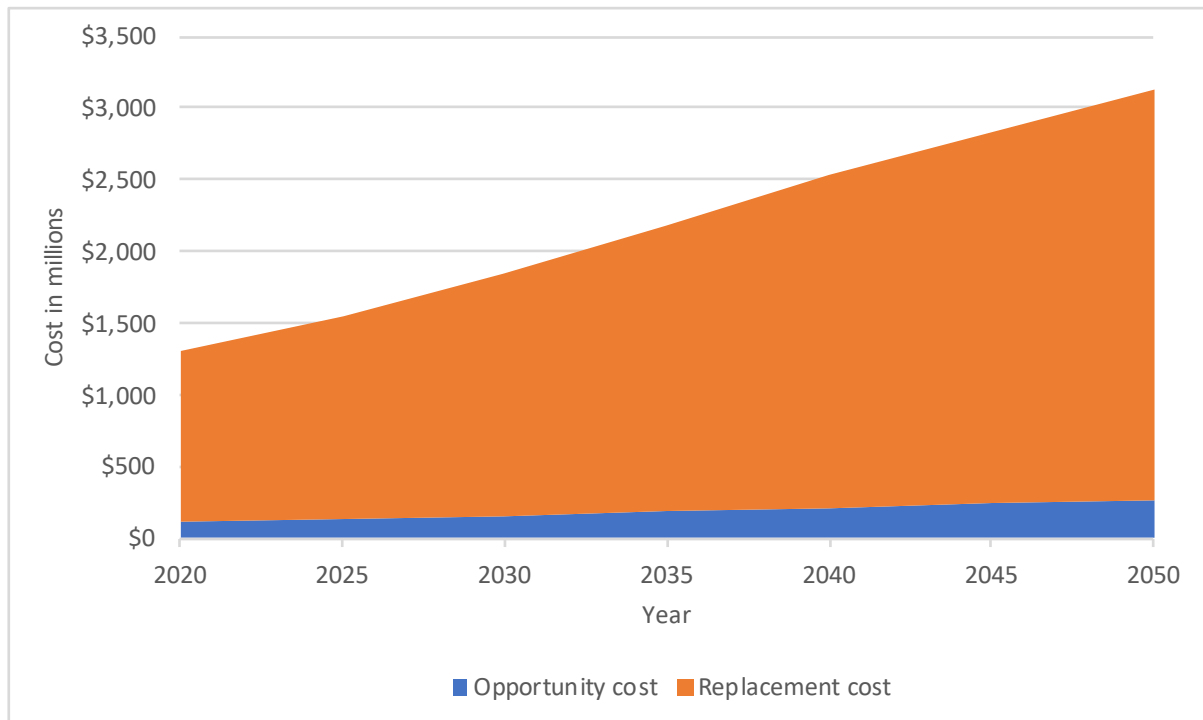
Note: Individuals can self-identify with more than one ethnicity so the sum of costs by ethnicity will be greater than 100% of total costs.

Source: University of Auckland calculations.

5.5 Projected unpaid care costs (replacement and opportunity)

Figure 16 shows that the projected replacement value of unpaid costs in 2050 will reach **\$2.80 billion** and the projected opportunity cost of unpaid care costs will reach **\$266.3 million** in 2050.

Figure 16. Projected cost of unpaid care, 2020–2050.



Source: University of Auckland calculations.

6. PRODUCTIVITY LOSSES AND INCOME SUPPORT COSTS ASSOCIATED WITH DEMENTIA

KEY FINDINGS

1. Productivity costs associated with dementia (due to reduced employment, absenteeism and premature mortality) in 2020 are estimated at **\$232 million** or \$3,330 per person living with dementia.
2. The cost of income support in 2020 for people living with dementia is estimated at **\$82 million** or \$1,180 per person.
3. The annual total cost associated with productivity costs and income support is estimated at \$314 million or \$4,510 per individual living with dementia.
4. Productivity costs in DEIR 2016 were estimated at \$241 million and income support at \$50.7 million. Productivity costs and income support costs have therefore increased by 9% overall since 2016.
5. The burden of productivity costs differentially affects Māori, Pacific and Asian people living with dementia due to a higher proportion of dementia occurring in those of employment age. The annual productivity and income support costs per person living with dementia for these populations ranges from \$8,050 to \$9,200, more than double that for Europeans (\$3,880).
6. Productivity and income support costs are projected to more than double by the year 2050 to \$755 million.

6.1 Introduction

Dementia is associated with productivity losses. People living with dementia are employed at lower rates compared to those without dementia and leave the workforce early due to the progression of their cognitive difficulties.⁽⁴⁰⁾ Further, people living with dementia who do remain in employment are more frequently absent from work compared to those without dementia. However, quantifying the magnitude of the reduction in employment is difficult, and some reports use the assumption that no one with dementia is employed.⁽⁴¹⁾ Other costs incurred include those associated with premature mortality due to the lost income individuals living with dementia would otherwise have earned if they had remained alive, did not have dementia, and remained in the workforce. This means families of people living with dementia in the younger age groups suffer a greater financial burden due to the double impact of lost income and the associated costs of providing unpaid care (detailed in Section 5).

People living with dementia who are below the retirement age of 65 years and not in employment are not eligible for superannuation, so will require alternate avenues of income support from the NZ Government. While not usually considered a productivity loss, we have chosen to include the cost associated with income support for people living with dementia in this section as this cost would not otherwise have been incurred if they had been in employment.

As described in Section 2, Māori, Pacific and Asian populations have higher proportions of people living with dementia in the younger age groups, which means they will be disproportionately affected by reduced productivity. The differential burden of productivity costs highlights the need to break down costs by ethnicity. In this report we have chosen to present the costs associated with reduced employment based on two assumptions: 1) no one with dementia is in employment; and 2) those with dementia are employed at a reduced rate.

6.2 Data sources and methods (see Appendix, p. 117)

6.3 Cost of reduced employment attributable to dementia

Under the first scenario where all people living with dementia are out of the workforce, the economic cost of reduced employment is **\$293 million**. Under the second scenario where some people living with dementia are still employed, the economic cost of reduced employment is estimated at **\$213 million**.

6.4 Cost of reduced employment attributable to dementia by ethnicity

Table 14 presents the costs associated with reduced employment by ethnicity and highlights the burden of reduced employment carried by Māori, Pacific and Asian individuals living with dementia due to their disproportionate prevalence in those of employment age. This is reflected in a cost per person that is more than double that of Europeans.

Table 14. Cost of reduced employment by ethnicity, 2020.

Cost	All	European	Māori	Pacific	Asian
Total (\$ millions)	213.3	155.9	27.3	11.8	26.8
Per person (\$)	3,060	2,580	6,341	6,100	5,570

Note: Individuals can self-identify with more than one ethnicity so the sum of costs by ethnicity will be greater than 100% of total costs.

Source: University of Auckland calculations.

6.5 Absenteeism

Applying the DEIR 2016 assumption of those with dementia being absent from work for 12 additional days compared to individuals without dementia, there are 14,450 additional sick days at a cost of **\$3.7 million**.

6.6 Costs due to income support for people living with dementia

Under the first scenario where all people living with dementia are out of the workforce, the cost associated with income support is \$102.3 million. In the second scenario, of the 6,188 with dementia, only 1,204 are estimated to be in employment with the remaining 4,984 receiving income support. This produces an estimate for the cost of income support of **\$82.4 million**.

6.7 Costs due to income support for people living with dementia by ethnicity

Table 15 shows the breakdown of income support costs by ethnicity. Māori, Asian and Pacific peoples comprise a greater proportion of dementia cases under the age of 65 (see Section 2), so carry a greater burden of unemployment and therefore require more income support.

Table 15. Income support costs due to dementia by ethnicity, 2020.

Cost	All	European	Māori	Pacific	Asian
Total (\$ millions)	82.4	64.4	10.9	4.6	10.8
Per person (\$)	1,180	1,060	2,530	2,380	2,250

Note: Individuals can self-identify with more than one ethnicity so the sum of costs by ethnicity will be greater than 100% of total costs.

Source: University of Auckland calculations.

6.8 Economic cost of dementia attributable to premature mortality

The economic costs associated with premature mortality is estimated at **\$15.1 million**.

6.9 Summary of productivity costs attributable to dementia

Table 16 presents the productivity costs associated with dementia, estimated at **\$314.5 million** or \$4,510 per person living with dementia. This cost disproportionately affects Māori, Pacific and Asian people as they comprise a higher proportion of younger people living with dementia who are affected by reduced employment, and who therefore also require more income support. Compared to Europeans, the costs associated with reduced productivity are more than twice as for Māori, Pacific and Asian individuals living with dementia.

Table 16. Summary of productivity costs associated with dementia by ethnicity, 2020.

Cost	All (\$ millions)	European (\$ millions)	Māori (\$ millions)	Pacific (\$ millions)	Asian (\$ millions)
Reduced employment	213.3	155.9	27.3	11.8	26.8
Premature mortality	15.1	12.1	0.9	0.7	0.6
Absenteeism	3.7	2.7	0.5	0.2	0.5
Income support	82.4	64.4	10.9	4.6	10.8
Total	314.5	235.1	39.6	17.3	38.7
Cost per person (\$)	4,510	3,880	9,200	8,940	8,050

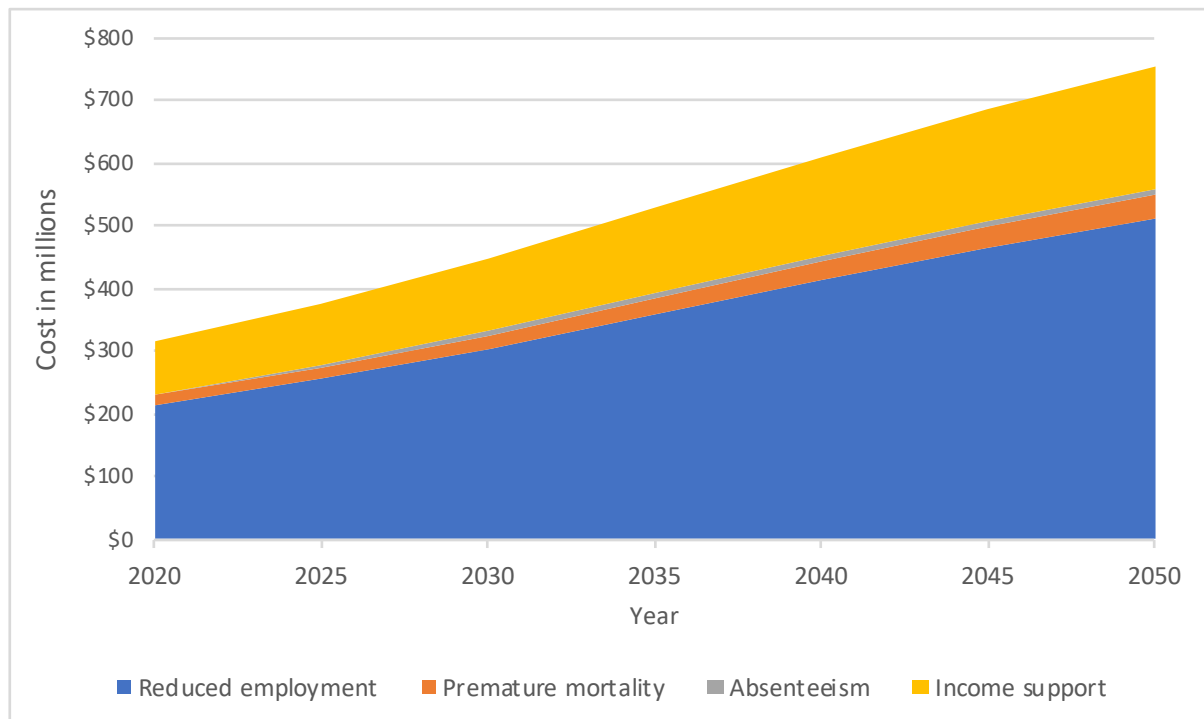
Note: Individuals may self-identify with more than one ethnicity so the sum of costs by ethnicity will be greater than 100% of total costs.

Source: University of Auckland calculations.

6.10 Projected costs associated with reduced productivity

Figure 17 shows productivity losses are projected to more than double by 2050 to **\$755.2** million.

Figure 17. Projected costs associated with reduced productivity, 2020–2050.



Source: University of Auckland calculations.

7. ECONOMIC IMPACT OF DEMENTIA

KEY FINDINGS

1. If unpaid care is valued as a replacement cost (i.e. all unpaid care is valued as if it were provided by paid carers), the total economic cost of dementia in 2020 is estimated at **\$3.62 billion** or \$51,930 per person living with dementia. This is the cost borne by both NZ Government and NZ families.
2. If unpaid care is valued as an opportunity cost, the total economic cost of dementia in 2020 is estimated at **\$2.46 billion** or \$35,360 per year per person living with dementia. This is the cost borne by the NZ Government. Estimates of the total cost of dementia have therefore increased by 43% since DEIR 2016.
3. Two thirds of the estimated total cost is associated with the provision of ARC (33%) and unpaid care (33%) (Figure 18). The cost of unpaid care to families is therefore over \$1 billion dollars.
4. Despite having significantly lower social care costs, the total economic costs of dementia in Māori, Pacific and Asian populations are similar to those of Europeans. This is because these groups are disproportionately impacted by productivity losses and carry a higher cost of unpaid care for families. A quarter of the total economic costs for Māori, Pacific and Asian populations are due to productivity losses, compared with 11% for Europeans.
5. The total economic cost of dementia is projected to more than double to **\$5.9 billion** by 2050 in today's dollars.

7.1 Introduction

This section presents the collated costs associated with health care, social care, unpaid care and productivity losses associated with dementia outlined in the preceding sections, to estimate the total economic costs due to dementia.

The total economic cost of dementia changes depending on where the burden of cost sits. A narrow view of the economic impact of dementia focuses solely on the costs incurred by the government from health system spending on health and social care, as well as lost taxation from reduced productivity and the opportunity cost of unpaid care. A broad assessment of the economic impact of dementia considers the replacement costs associated with the provision of unpaid care and the income loss due to premature mortality, in addition to the costs incurred by government. The latter approach takes into account the greater financial burden borne by families (often non-European) who do not wish to use ARC, and therefore provide care themselves. We have therefore chosen to present both the narrow and the broad approaches.

7.2 Data sources and methods (see Appendix, p. 121)

7.3 Total economic cost of dementia

If all unpaid care were replaced with paid care, the total economic cost of dementia is **\$3.62 billion** or \$51,930 per person living with dementia (Table 17). Two thirds of the cost estimated is associated with the provision of ARC (33%) and unpaid care (33%) (Figure 17). The cost of unpaid care to families is therefore over \$1 billion dollars

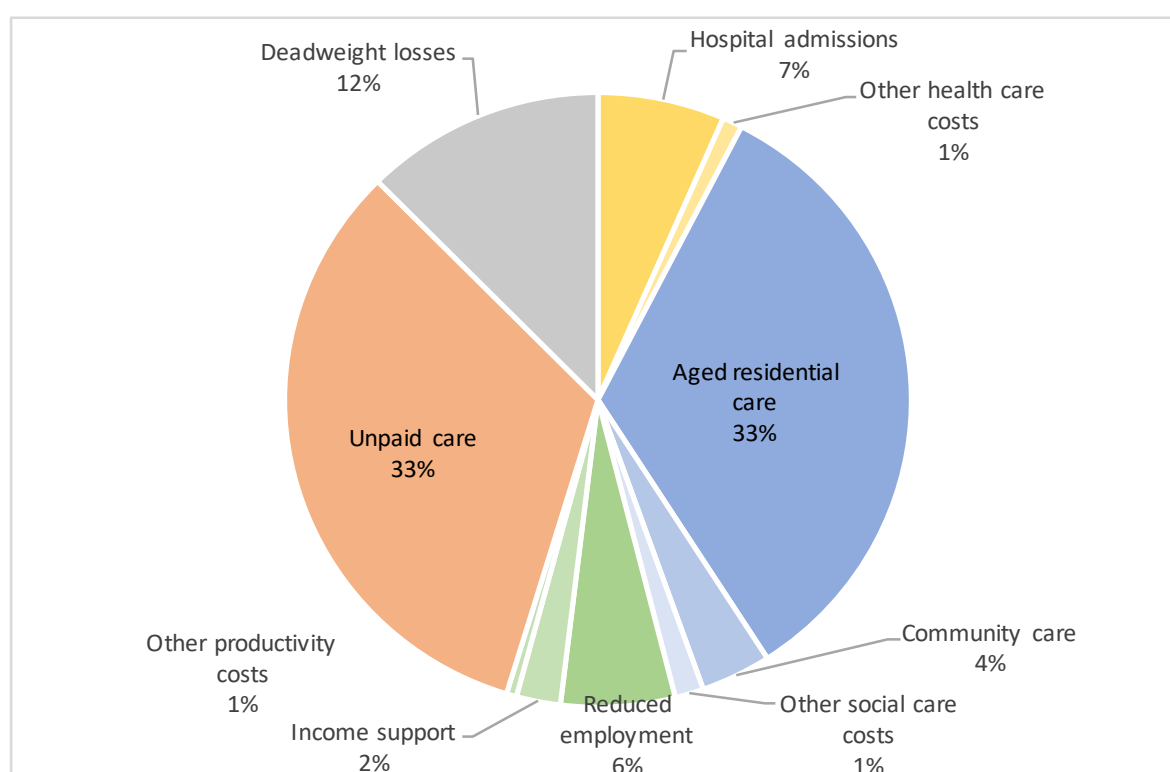
If unpaid care is valued as an opportunity cost, incurred by unpaid carers who otherwise would have been in employment were they not providing care, the total economic cost of dementia in 2020 is **\$2.46 billion** or \$35,360 per person living with dementia (Table 18). Over half (56%) of the total economic cost of dementia estimated is accounted for by social care costs; 12% due to health care costs, 13% due to productivity losses and income support and 4% due to unpaid care (Figure 18).

Table 17. Summary of the total economic costs and average cost per person due to dementia, 2020 (unpaid care valued as replacement cost).

Type of cost	Cost (\$ millions)	Cost per person (\$)
Health care costs	274.2	3,930
Hospital admissions	237.1	
Other health care costs	37.1	
Social care costs	1,392.1	19,970
Aged residential care	1,206.8	
Community care	131.7	
Other social care costs	53.6	
Unpaid care (valued as replacement cost)	1,190	17,070
Reduced productivity	314.5	4,510
Reduced employment	213.3	
Income support	82.4	
Other productivity costs	18.9	
Deadweight losses	449.4	6,450
Total economic cost	3,620.2	51,930

Source: University of Auckland calculations.

Figure 18. Total economic cost of dementia in Aotearoa NZ, 2020 (using replacement cost for unpaid care).



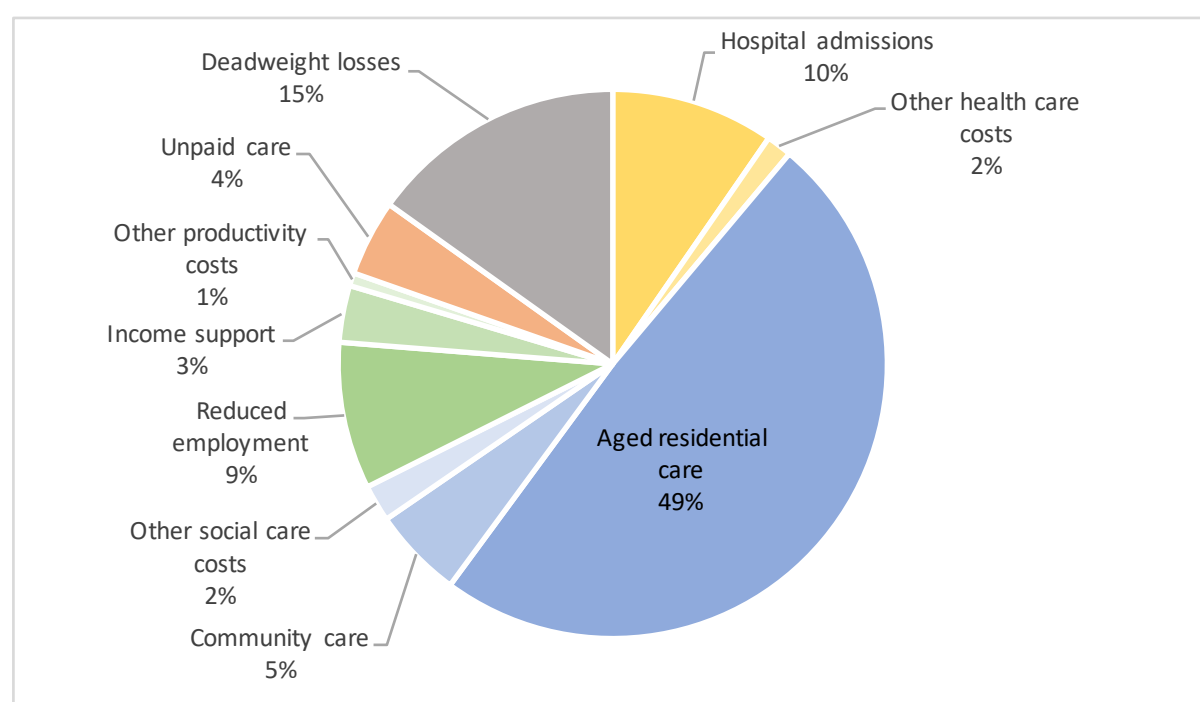
Source: University of Auckland calculations.

Table 18. Summary of the total economic costs and average cost per person due to dementia, 2020 (unpaid care valued as opportunity cost).

Type of cost	Cost (\$ millions)	Cost per person (\$)
Health care costs	274.2	3,930
Hospital admissions	237.1	
Other health care costs	37.1	
Social care costs	1,392.1	19,970
Aged residential care	1,206.8	
Community care	131.7	
Other social care costs	53.6	
Unpaid care (valued as opportunity cost)	110.7	1,590
Reduced productivity	314.5	4,510
Reduced employment	213.3	
Income support	82.4	
Other productivity costs	18.9	
Deadweight losses	373.5	5,360
Total economic cost	2,465.0	35,360

Source: University of Auckland calculations.

Figure 19. Total economic cost of dementia in Aotearoa NZ, 2020 (using opportunity cost for unpaid care).



Source: University of Auckland calculations.

7.4 Total economic costs by ethnicity

Tables 19 and 20 present the total economic costs by ethnicity, valuing unpaid care as a replacement cost and an opportunity cost respectively. While the total cost per person for Europeans, Māori and Pacific peoples are similar, the main drivers of cost are different (total cost for Asian peoples are lower than all other groups). Social care costs account for two thirds of the economic cost for Europeans, but only half the total economic cost for Māori and Pacific peoples, and 42% for Asian populations. Conversely, the costs incurred from lost productivity and income support only account for 13% of total economic costs for Europeans, but 29% of the costs for Māori and Pacific peoples and 33% of the cost for Asian populations.

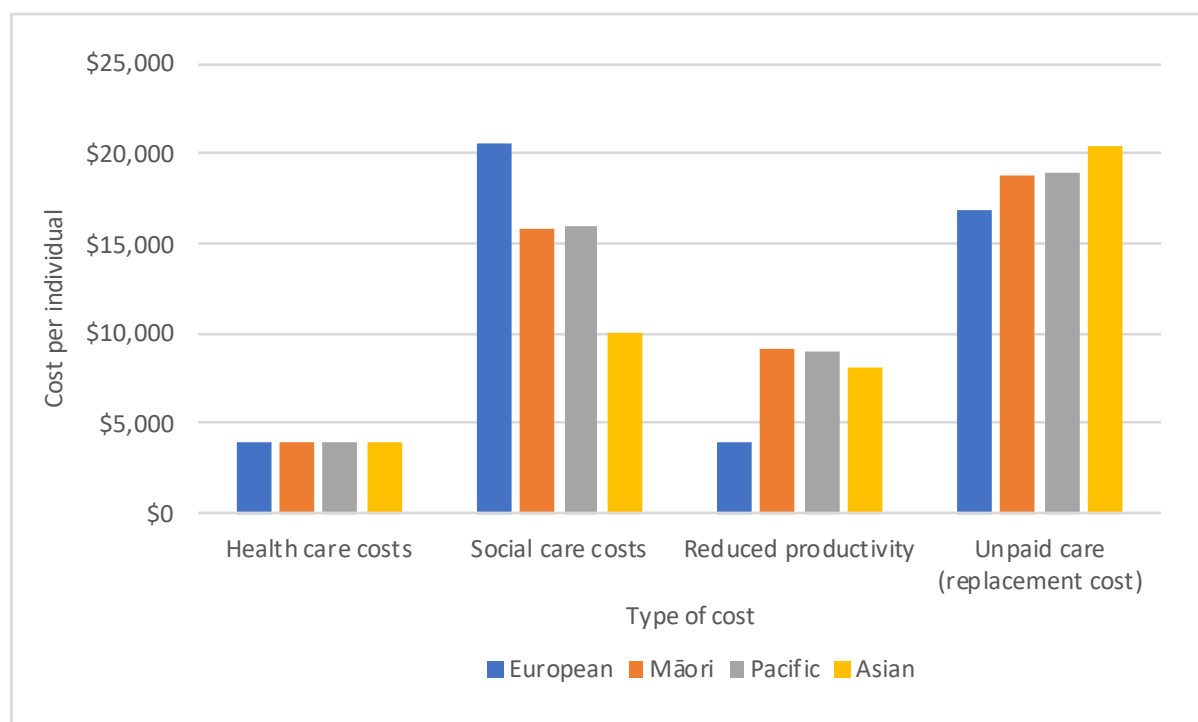
Figures 20 and 21 demonstrate that, compared to Europeans, Māori, Pacific and Asian people living with dementia and their carers are disadvantaged across multiple domains. They are disproportionately impacted by the lost productivity due to the higher prevalence of dementia in working age populations and use less social care which results in a higher cost of unpaid care being placed on carers and whānau. It should be noted that healthcare costs appear to be the same across ethnic groups in Figures 19 and 20, because ethnicity data for service utilisation were not available from the MoH. We know, due to evidence of inequity in healthcare access for some ethnic groups, that this is unlikely to be a reflection of the true picture.

Table 19. Summary of the average cost per person due to dementia in 2020 by ethnicity (unpaid care valued as replacement cost).

Type of cost	European	Māori	Pacific	Asian
Health care costs	\$3,930	\$3,930	\$3,930	\$3,930
Social care costs	\$20,530	\$15,870	\$16,020	\$10,090
Aged residential care	\$17,820	\$12,600	\$12,450	\$8,280
Community care	\$1,930	\$2,410	\$2,690	\$850
Other social care costs	\$780	\$860	\$880	\$960
Unpaid care (valued as replacement cost)	\$16,880	\$18,820	\$18,920	\$20,430
Reduced productivity	\$3,880	\$9,200	\$8,940	\$8,050
Reduced employment	\$2,580	\$6,340	\$6,100	\$5,570
Income support	\$1,060	\$2,530	\$2,380	\$2,250
Other productivity costs	\$240	\$330	\$460	\$230
Deadweight losses	\$6,420	\$6,140	\$6,130	\$4,990
Total cost per person	\$51,640	\$53,960	\$53,940	\$47,490

Source: University of Auckland calculations.

Figure 20. Average cost per person due to dementia in 2020 by ethnicity (unpaid care valued as replacement cost).



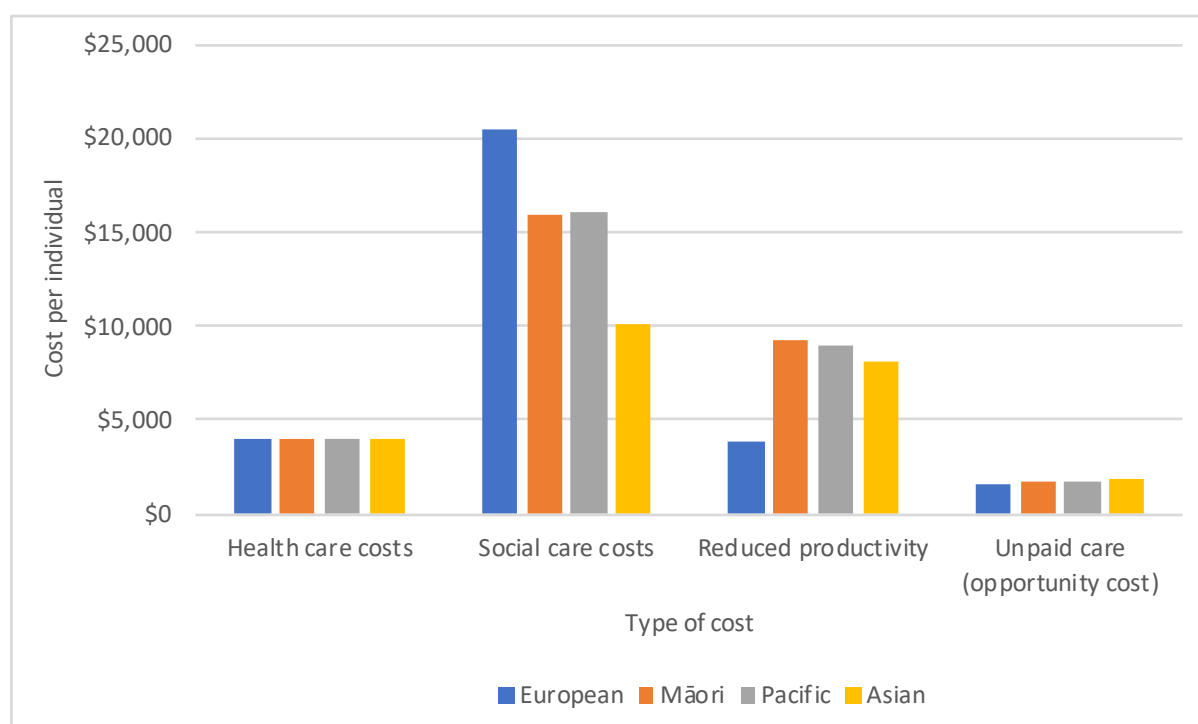
Source: University of Auckland calculations.

Table 20. Summary of the average cost per person due to dementia in 2020 by ethnicity (unpaid care valued as opportunity cost).

Type of cost	European	Māori	Pacific	Asian
Health care costs	\$3,930	\$3,930	\$3,930	\$3,930
Social care costs	\$20,530	\$15,870	\$16,020	\$10,090
Aged residential care	\$17,820	\$1,2600	\$12,450	\$8,280
Community care	\$1,930	\$2,410	\$2,690	\$850
Other social care costs	\$780	\$860	\$880	\$960
Unpaid care (valued as opportunity cost)	\$1,570	\$1,750	\$1,760	\$1,900
Reduced productivity	\$3,880	\$9,200	\$8,940	\$8,050
Reduced employment	\$2,580	\$6,340	\$6,100	\$5,570
Income support	\$1,060	\$2,530	\$2,380	\$2,250
Other productivity costs	\$240	\$330	\$460	\$230
Deadweight losses	\$5,340	4,930	4,920	3,680
Total cost per person	\$35,250	\$35,680	\$35,570	\$27,650

Source: University of Auckland calculations.

Figure 21. Average cost per person due to dementia in 2020 by ethnicity (unpaid care valued as opportunity cost).



Source: University of Auckland calculations.

7.5 Projected costs of dementia

We have noted that DEIR 2016 projected an increase in costs of dementia of 14% by 2020, but there was in fact a 43% difference between the 2016 projected costs and the 2020 costs that we have estimated. This was mostly due to a greater than expected increase in the costs of services, especially the cost of ARC. We have provided costs for 2030/2050 with the caveat that these too are likely to be an underestimate.

The total economic cost associated with dementia is projected to more than double by 2050 to \$8.7 billion (with unpaid care valued as replacement cost) or \$5.9 billion (with unpaid care valued as opportunity cost) due to the increase in dementia prevalence (Table 21 and Table 22).

Figure 22 shows the total cost of dementia in 2050 under different inflation assumptions (with unpaid care valued as replacement cost) exceeding \$11.7 billion at 1% inflation or \$15.7 billion at 2% inflation.

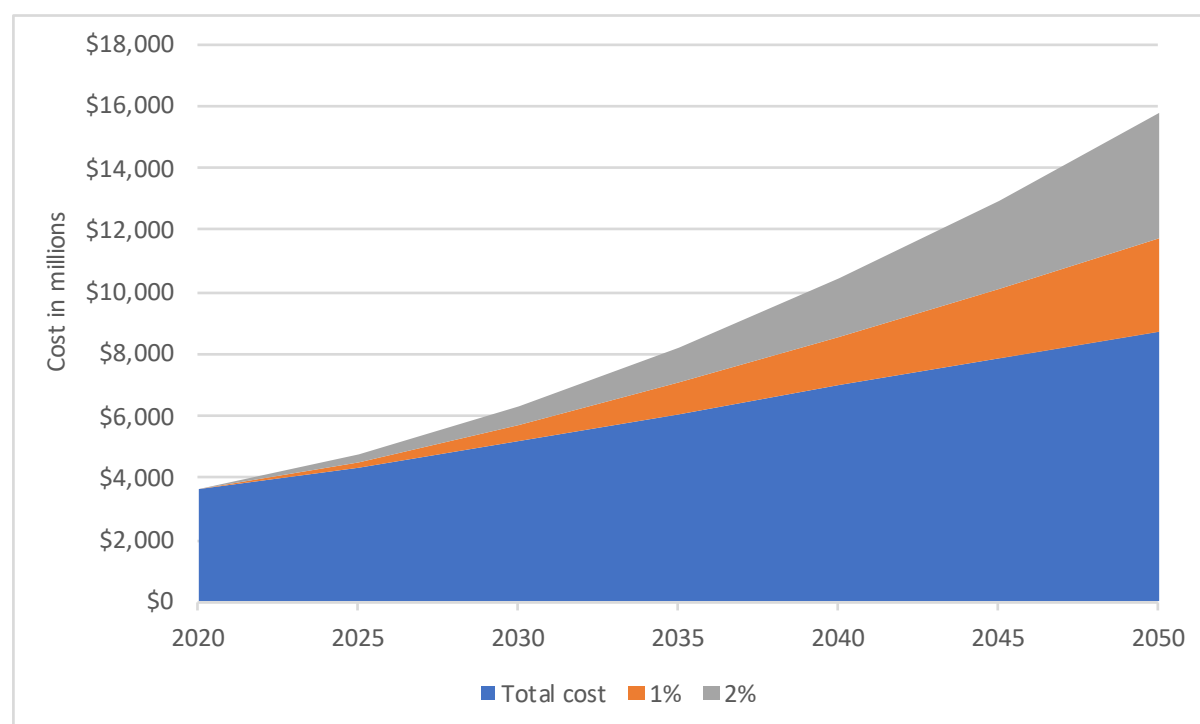
Figure 23 shows that the total cost of dementia in 2050 under the same inflation assumptions (but with unpaid care valued as opportunity cost) will exceed \$7.9 billion at 1% inflation or \$10.7 billion at 2% inflation. This is the cost to the NZ Government.

Table 21. Projected total economic cost in (\$ millions) of dementia and by type of cost (unpaid care valued as replacement cost) 2020–2050.

Cost	2020	2025	2030	2035	2040	2045	2050
Health care	274.0	326.0	390.0	461.2	532.4	597.4	658.2
Social care	1,392.2	1,656.4	1,981.9	2,343.6	2,705.3	3,035.5	3,344.6
Unpaid care	1,190.0	1,415.9	1,694.1	2,003.3	2,312.5	2,594.7	2,858.9
Productivity	314.4	374.1	447.6	529.3	611.0	685.5	755.3
Deadweight losses	449.6	535.0	640.1	757.0	873.8	980.4	1,080.3
Total	3,620.2	4,307.3	5,153.8	6,094.4	7,035.0	7,893.5	8,697.4

Source: University of Auckland calculations.

Figure 22. Projected total economic cost of dementia (unpaid care valued as replacement cost), 2020–2050.



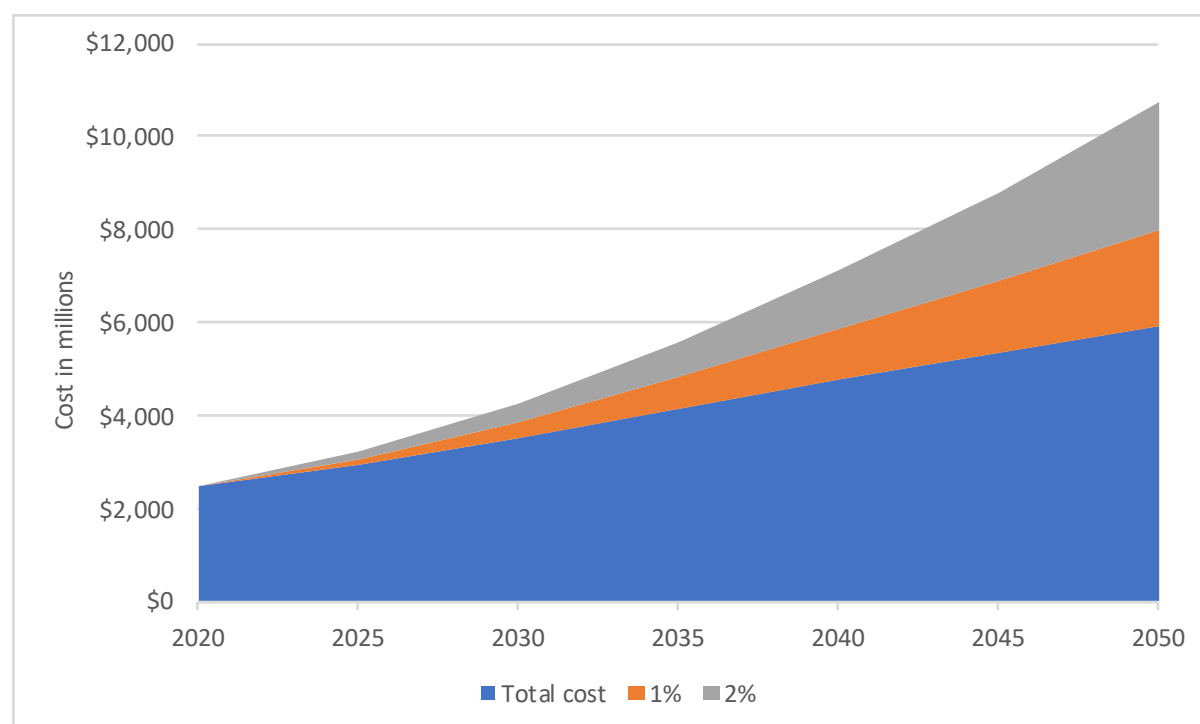
Source: University of Auckland calculations.

Table 22. Projected total economic cost in (\$ millions) of dementia and by type of cost (unpaid care valued as opportunity cost), 2020–2050.

Type of cost	2020	2025	2030	2035	2040	2045	2050
Health care	274.2	326	390	461.2	532.4	597.4	658.2
Social care	1,392.1	1,656.4	1,981.9	2,343.6	2,705.3	3,035.5	3,344.6
Unpaid care	110.7	131.7	157.6	186.3	215.1	241.3	265.9
Productivity	314.5	374.1	447.6	529.3	611	685.5	755.3
Deadweight losses	373.5	444.6	532.0	629.0	726.1	814.7	897.7
Total	2,465.00	2,932.8	3,509.1	4,149.4	4,789.9	5,374.4	5,921.7

Source: University of Auckland calculations.

Figure 23. Projected total economic cost of dementia (unpaid care valued as opportunity cost), 2020–2050.



Source: University of Auckland calculations.

7.6 Cost borne by the NZ Government

The current cost borne by the NZ Government are a combination of the costs incurred from providing health and social care, lost income from taxation revenue forgone due to lost productivity, income support for those not in employment and the opportunity cost of reduced employment for unpaid carers.

7.6.1 Economic costs due to lost tax revenue

The revenue forgone by the NZ Government due to lost taxes includes the taxable income lost from reduced productivity (due to reduced employment and the opportunity cost of unpaid care), employer losses due to absenteeism and the reduced indirect tax take. The taxation revenue forgone was estimated at **\$119.1 million** or \$1,710 per individual living with dementia.

Table 23 shows the total economic costs borne by the NZ Government as a result of taxation revenue forgone and the costs incurred from expenditure on health care, social and community care, and income support. This was calculated as \$2.24 billion or \$32,150 per person living with dementia. This is a more accurate figure than the full \$2.46 billion quoted elsewhere in this report, due to the fact that the NZ government does not bear the full cost of unpaid care and reduced employment, only the associated tax and GST.

Table 23. Total economic impact due to dementia as a result of lost revenue and health system costs.

Cost	Total cost (\$ millions)	Cost per person (\$)
Direct health care costs	274.2	3,930
Aged residential care	1,206.8	17,310
Community care	131.7	1,890
Income support	82.4	1,180
Other social care costs	53.6	770
Taxation revenue forgone	119.1	1,710
Total transfers	1,867.8	26,790
Deadweight losses	373.5	5,360

Source: University of Auckland calculations.

7.7 Cost–benefit analysis of delaying entry to aged residential care

Most individuals living with dementia wish to remain at home for as long as possible, and there are significant benefits for both individuals living with dementia and their families for those individuals to remain living in the community. These benefits include the security and peace of mind associated with being in a familiar environment, as well as the ability to remain in close proximity to their social network of whānau/family, friends and neighbours. Entry into ARC generally occurs when an individual's care needs exceed the available resources (subsidised, privately funded and unpaid) to adequately support them in the community.

The cost–benefit analysis of delaying institutional care weighs the cost savings associated with delaying entry into ARC against the costs of remaining in the community. The analysis assumes that if an individual remains in the community, they receive both community support and unpaid care. We acknowledge this is a simplified approach that does not account for other important factors such as impact on survival, so we present the calculations as a 'proof of concept' to highlight the cost-effectiveness of supporting individuals and their whānau/family and carers to remain living in the community.

Table 24 presents the net benefit and benefit–cost ratio associated with delaying entry into ARC based on different assumptions of the duration an individual will be in care. While the absolute net benefit varies depending on the assumptions used and duration of delay, the benefit–cost ratio is 4 (i.e. it is four times more cost-effective for an individual living with dementia to be cared for in the community compared to being in ARC). This is lower than the benefit-cost ratio of 6.6 calculated in the previous report and is due to the cost of carer support increasing more rapidly than that of ARC. This indicates the development and implementation of interventions to support individuals living with dementia and their carers to live at home as long as possible could result in significant savings. Furthermore, the cost savings from each day of delayed entry into ARC could provide an estimated seven additional hours of paid carer time per day (almost 50 hours per week of delayed institutionalisation) without incurring additional costs over and above the cost of otherwise being in ARC.

Table 24. Benefit–cost ratio based on different durations in aged residential care and at 3 months, 6 months and 12 months delay in institutionalisation.

Duration in care (years)	Delay (months)	Benefit (\$ millions)	Cost (\$ millions)	Net benefit (\$ millions)	Benefit–cost ratio
2.5	3	120.7	28.8	91.9	4.2
	6	241.4	57.6	183.8	4.2
	12	482.8	115.2	367.6	4.2
3.3	3	91.9	22.2	69.7	4.1
	6	183.8	44.4	139.4	4.1
	12	367.7	88.8	278.8	4.1
6.6	3	45.9	11.1	34.8	4.1
	6	91.8	22.2	69.7	4.1
	12	183.8	44.4	139.4	4.1

Source: University of Auckland calculations.

7.8 Cost comparison between DEIR 2016 and DEIR 2020

Table 25 presents a summary of the economic costs calculated in 2016 and compares them with the current cost estimates. The total economic cost of dementia in 2016 was projected to increase by 14% by 2020 but has actually increased by 43%. While changes in the method of calculating costs may explain some of the increases (e.g. the cost of inpatient care), the main additional expense is the increase in the unit costs of dementia care. Figure 24 shows the main driver of cost increases has been the cost of social care which have been calculated the same way as the previous report. The cost of social care alone has increased by \$447 million and accounts for more than 60% of the overall cost increase.

The cost comparison also highlights the need for regular cost updates as the cost projections made in DEIR 2016 for 2030 and beyond are 25% lower than those made in this report, despite using similar prevalence estimates. This means, for example, that the 2016 cost projections underestimate the economic cost of dementia in 2030 by \$680 million and by \$1.20 billion in the year 2050.

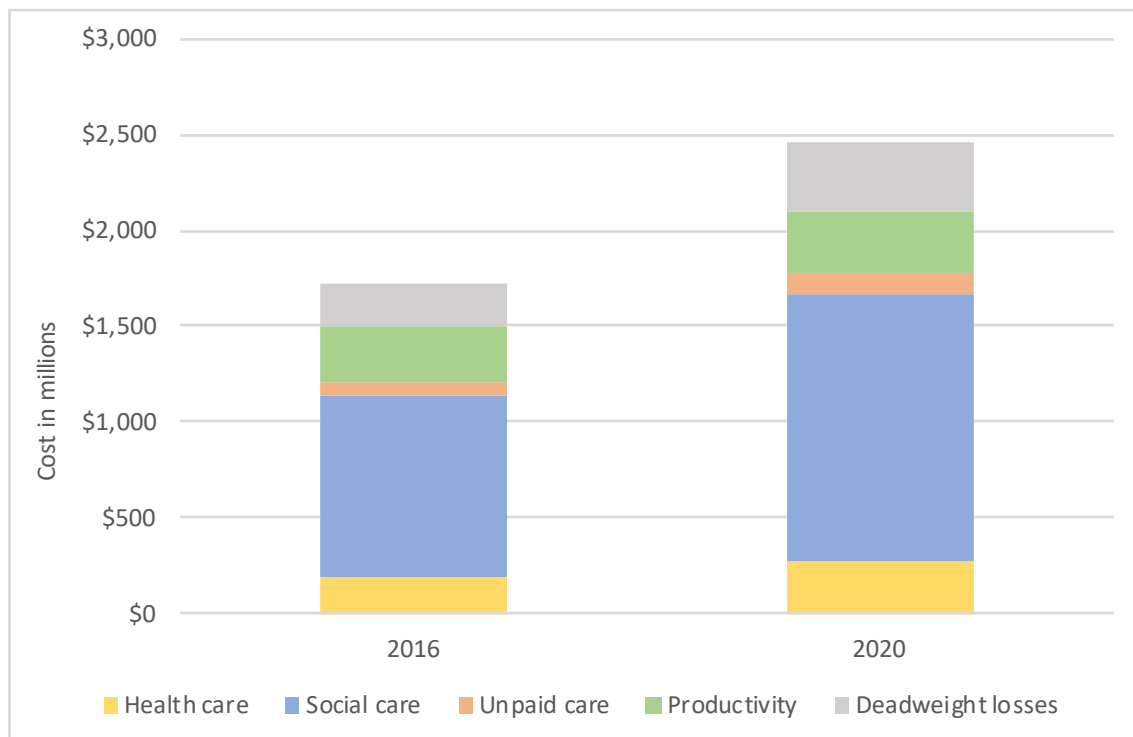
Table 25. Cost comparison, percentage change in costs, DEIR 2016–DEIR 2020.

Cost	Cost (\$ millions)		% change
	DEIR 2016	DEIR 2020	
Health system costs			
Inpatient	159.9	237.1	48.3%
Outpatient	13.8	22.5	63.0%
General practitioner	3.4	4.3	26.5%
Pharmaceuticals	0.8	0.6	-25.0%
Pathology and imaging	0.4	0.2	-50.0%
Research	4.8	*	
Allied health	5.6	9.5	69.6%
Aged residential care	849.2	1,206.8	42.1%
Community care	67.3	131.7	95.7%
Total health costs	1,105.2	1,612.7	45.9%
Other costs			
Reduced employment	207.4	213.3	2.8%
Absenteeism	17.4	3.7	-78.7%
Premature mortality'	16.2	15.1	-6.8%
Unpaid care	68.6	110.7	61.4%
Respite and carer support	21.9	38.8	77.2%
Mobility aids and modifications	5.5	*	
Travel costs	6.5	14.8	127.7%
Income support	50.7	82.4	62.5%
Deadweight losses	226.9	373.5	64.4%
Total other costs	621.1	851.8	37.1%
Total economic cost	1,726.3	2,465.0	42.8%
Cost projections			
2030	2,827.3	3,509.1	24.1%
2050	4,717.4	5,921.7	25.5%

Note: * = missing data points.

Source: University of Auckland calculations.

Figure 24. Total economic cost comparison between DEIR 2016 and DEIR 2020.



Source: University of Auckland calculations.

8. POLICY IMPLICATIONS

KEY FINDINGS

1. An estimated **69,713** people were living with dementia in Aotearoa NZ in 2020. This number has increased by 11.9% since DEIR 2016 and is projected to be 167,400 by 2050.
2. Between 2020 and 2040, the increase in the number of Māori, Pacific and Asian people living with dementia will be double the increase in Europeans.
3. The total economic cost of dementia in 2020 was **\$2.46 billion**, an increase of 43% since DEIR 2016.
4. Social care costs in 2020 are estimated to be **\$1.39 billion**.
5. Compared to Europeans, the average spend on ARC per person living with dementia is \$5,000 lower for Māori, Pacific and Asian populations, because they choose not to use these facilities. Māori, Pacific and Asian populations receive an extra \$500 per person in community support services. This represents an inequitable allocation of resources.
6. Most dementia care is provided by unpaid family carers and would cost **\$1.19 billion** if it were provided by paid staff.
7. Delaying entry into ARC by 12 months would save \$278.8 million. These savings could be used to provide culturally appropriate community care services and address inequitable allocation of resources for dementia.
8. The total economic cost of dementia is projected to increase by 24% to **\$3.51 billion** in the next 10 years, or by 51% to \$4.28 billion with inflation.

KEY RECOMMENDATIONS

1. Epidemiological studies are required to assess the true extent and economic impact of dementia and differences across ethnic groups in Aotearoa NZ.
2. Aotearoa NZ needs a dementia action plan, ratified by the NZ Government and resourced for implementation.

8.1 Introduction

Dementia is a global public health priority. The populations of every country in the world are growing older, and as age is the greatest risk factor for dementia, the worldwide prevalence of dementia is increasing exponentially. Aotearoa NZ is no exception to this phenomenon, but unfortunately we are unable to evaluate the extent of the problem as there has never been a community-based dementia prevalence study. Instead, we have relied on estimates of prevalence that have been provided by the DEIRs.(4, 13, 14) These reports applied prevalence data from international research studies to the Statistics NZ population projections based on census data to obtain estimates of dementia prevalence. This approach differs from approaches adopted elsewhere around the world, where community-based prevalence studies have provided more robust evidence on which to base policy. This area is the main weakness of these reports. The DEIR estimates do not account for the unique demography of Aotearoa NZ, and the possibility of differing dementia prevalence across the major Aotearoa NZ ethnic groups. Research evidence published since DEIR 2016(4) suggests dementia prevalence may be higher amongst Māori and Pacific peoples,(5, 16) and possibly amongst all major Aotearoa NZ ethnic groups as Aotearoa NZ has higher prevalence of risk factors for dementia (e.g. deafness, diabetes) than most other high income countries.(5)

This 2020 *Dementia Economic Impact Report* provides estimates of the prevalence and the economic costs of dementia in Aotearoa NZ. It provides a snapshot of the current situation and projections for the future. Although we were limited to replicating the previous DEIR methods for the estimation of dementia prevalence, we were able to use real data for the measurement of most costs. In addition, we were able to present our findings by ethnicity to demonstrate the differential effects on the major NZ ethnic groups.

This section summarises the main findings and reflects on some of the implications for Aotearoa NZ.

8.2 Prevalence of dementia

The prevalence of dementia is rising fast. The estimated number of people living with dementia in Aotearoa NZ has increased by 11.9% from 62,287 estimated in DEIR 2016 to 69,713 in 2020. The number of people living with dementia is projected to be 167,400 by 2050, comprising 2.7% of the total population and 10.8% of the population aged 65+.

The proportion of people living with dementia accounted for by Māori, Pacific and Asian people is expected to triple by 2050, compared to a 76% increase in Europeans. These differences are based on changing age structure of populations and do not consider any differences in dementia prevalence that may exist between ethnic groups. This is important, because, compared to Europeans, there is a higher prevalence of many of the modifiable risk factors for dementia in Māori and Pacific populations, and therefore prevalence is likely to be higher in these groups.(5) Well designed prevalence studies in these populations would supply epidemiological data to improve the accuracy of these estimates.

8.3 Total economic costs of dementia

Table 26 shows the total economic cost of dementia in 2020 and the change in costs since DEIR 2016. DEIR 2016 projected a 14% increase in total costs by 2020, however costs have increased by 43% in four years, from \$1.72 billion to \$2.46 billion.

The increase is mostly due to a 42% increase in the cost of ARC, a 50% increase in hospital costs and a 61% increase in unpaid care.

The cost of unpaid care in 2020 is estimated to be \$110.7 million, an increase of 61% in the last four years. If unpaid care is estimated at the cost of paid care, thus the total cost of unpaid care may be ten-fold higher, at \$1.19 billion, and the total economic cost of dementia may be \$3.62 billion.

Table 26. Summary of total economic cost of dementia DEIR 2016 to DEIR 2020.

Health budget costs	Cost (\$ millions)		% change
	DEIR 2016	DEIR 2020	
Hospital costs			
Inpatient	159.9	237.1	48.3
Outpatient	13.8	22.5	63.0
Social care costs			
Aged residential care	849.2	1,206.8	42.1
Community care	67.3	131.7	95.7
Other health care costs			
General practitioner	3.4	4.3	26.5
Pharmaceuticals	0.8	0.6	-25.0
Pathology and imaging	0.4	0.2	-50.0
Research	4.8	*	
Allied health	5.6	9.5	69.6
Total health budget costs	1,105.2	1,612.7	45.9
Other costs			
Reduced employment	207.4	213.3	2.8
Absenteeism	17.4	3.7	-78.7
Premature mortality	16.2	15.1	-6.8
Unpaid care	68.6	110.7	61.4
Respite and carer support	21.9	38.8	77.2
Mobility aids and modifications	5.5	*	
Travel costs	6.5	14.8	127.7
Income support	50.7	82.4	62.5
Deadweight losses	226.9	373.5	64.4
Total other costs	621.1	851.8	37.1
Total economic cost	1,726.3	2,465.0	42.8
Cost projections			
2030	2,827.3	3,509.1	24.1
2030 with 2% inflation		4,277.6	
2050	4,717.4	5,921.7	25.5
2050 with 2% inflation		10,726.3	

Note: * = missing data.

Source: University of Auckland calculations.

8.4 Main drivers of the economic cost of dementia in Aotearoa NZ

Fifty percent of total economic costs of dementia in Aotearoa NZ are due to ARC. Even with some private payers, ARC constitutes the greatest cost to the NZ Government. Aotearoa NZ has more ARC beds per capita than any other OECD country,(42) which may mean we are over using ARC as a resource.

Compared to Europeans in Aotearoa NZ (\$20,530), the social care cost per person with dementia is lower for Māori (\$15,870), Pacific (\$16,020) and Asian (\$10,090) populations. This is predominantly due to the lower utilisation of ARC by these ethnic groups. This results in the NZ Government spending less on dementia care for Māori, Pacific and Asian peoples compared to Europeans, as alternative (and culturally appropriate) support in the community is not available.

People from all major NZ ethnic groups report a preference for living independently in their own home for longer if this option were available to them.(43) We have demonstrated that delaying entry to ARC would provide about the same resource as 7 extra hours of community support per day. It might therefore be more cost-efficient to provide people living with dementia and their families with more community support that delays entry into ARC. This would require evidence-based reform of the current health and social care systems as well as development of a mechanism that would allow savings (ARC contracts are with District Health Boards) to be redirected to a different part of the health sector (community support services).

8.5 Unpaid care

Dementia is increasingly being viewed through a social justice lens, and it is important that we recognise the contribution of unpaid carers, even if the contribution is not currently a cost to the NZ Government.

If only those carers who would otherwise have been in employment are counted in the estimation of this cost (i.e. the cost to the NZ Government), then unpaid care constitutes only 4.5% of the total economic cost of dementia. But if all unpaid care is valued at the same level as paid care (whether or not the carer would have been in employment) then it constitutes almost half (48%) of the total economic cost of dementia. The cost of unpaid care is higher in Māori, Pacific and Asian families due to these populations' lower rates of utilisation of ARC. Acknowledging the importance of this support for people living with dementia and their families and whanau and addressing equity in how care is accessed and distributed will lead to new health and social policy directions.

8.6 Projected costs of dementia

DEIR 2016 projected an increase in costs of dementia of 14% by 2020, but the actual increase in the 2020 estimates that we have provided was 43%, partly due to use of different methods for estimation, but mostly due to an increase in the utilisation and cost of health care services and ARC. We have provided costs for 2030/2050 with the caveat that these too are likely to be an underestimate.

This report projects costs for 2030 and 2050 to have increased by around 25% to \$3.51 billion and \$5.92 billion respectively since the last report.

To obtain a more realistic estimate, we added inflation estimated at 2%. With inflation, the total economic cost of dementia for 2030 and 2050 are estimated to be \$4.28 billion and \$10.72 billion respectively.

These projected costs are important if the NZ Government is to plan for adequate dementia care in the next few decades.

8.7 Key recommendations

It is inevitable that the numbers of people living with dementia in Aotearoa NZ will increase, as they will in the rest of the world, and the cost of dementia will increase. Dementia impacts not only the individuals affected, but also their families, whanau and communities. In this report we have chosen to emphasise the inequitable allocation of public resources, focussing on the impact on communities (in particular, Māori and Pacific peoples).

8.7.1 *Aotearoa NZ dementia prevalence study*

Building on the call of previous DEIRs, there is urgent need for a community-based dementia prevalence study in Aotearoa NZ to obtain real data about the extent of dementia in our country. Such a study could also establish the societal economic impact of dementia, both by collecting data on service utilisation of health and social care services, and also by evaluating the financial impact on families, particularly Māori, Pacific and Asian peoples, who provide a greater proportion of care for people living with dementia. Accurate prevalence data are essential to plan services for people living with dementia and the families that care for them.

8.7.2 *National Dementia Plan for Aotearoa NZ*

This report will assist the NZ Government in finalising and implementing a national dementia action plan. A Dementia Action Plan 2020–2025 has been developed by New Zealand Dementia Foundation, Alzheimers New Zealand and Dementia New Zealand.(44) Resourcing for such a plan by the NZ Government will be guided by information in this report.

In 2017, the WHO called on member states to produce a national dementia plan or strategy by 2025.(45) The WHO *Global Action Plan on the Public Health Response to Dementia 2017–2025* identifies seven action areas: (i) dementia as a public health priority; (ii) dementia risk reduction; (iii) dementia diagnosis, treatment, care and support; (iv) dementia awareness and friendliness; (v) support for carers; (vi) information systems for dementia; and (vii) dementia research and innovation.

A *Dementia Action Plan for Aotearoa NZ*(44) has been developed in alignment with the seven goals set out in the WHO *Global Action Plan*. (45) In this section we highlight the findings of this report that provide evidence to support the need to implement each of the seven action areas of the *Dementia Action Plan for Aotearoa NZ*.

(i) *Dementia as a public health priority*

The total economic cost of dementia in 2020 is estimated to be **\$2.46 billion** dollars, or \$3.62 billion dollars if all unpaid care is valued as if it were provided by paid carers. This is substantial and we recommend this is addressed by the NZ Government as an urgent public health priority for Aotearoa NZ.

Resources for dementia care in Aotearoa NZ are finite and are best allocated cost-effectively. This report has demonstrated a reliance on ARC and inequitable allocation of resources across ethnic groups. Addressing inequities in health care is a NZ Government priority and changing models of care will require consideration of funding and development of community and ARC options.

(ii) *Dementia risk reduction*

Māori, Pacific and Asian populations in Aotearoa NZ are ageing rapidly. This report has estimated that the proportion of people living with dementia accounted for by Māori, Pacific and Asian people will triple by 2050, compared to a 76% increase in Europeans.

These future projections do not consider the higher prevalence of risk factors for dementia in Māori and Pacific peoples,(5) so are likely to underestimate dementia prevalence in these groups.

The higher prevalence of modifiable risk factors in Aotearoa NZ gives us an opportunity to develop tailored interventions that may prevent or reduce the prevalence of dementia. While an increased public understanding of ways to minimise dementia risk is important, these need to be tailored and targeted to different ethnic groups.

(iii) *Dementia diagnosis, treatment and care*

Many people living with dementia do not get a diagnosis because their symptoms are regarded as part of normal ageing.(17) Receiving a timely diagnosis is important for both the person living with dementia and the whānau/family and unpaid carers to access appropriate care. It can be a gateway to information, support services, and pharmacological and non-pharmacological interventions to delay or manage symptoms and help improve functioning and quality of life.

The *World Alzheimer Report 2015*(46) presented the global costs of dementia in terms of direct medical care costs, social care costs and unpaid care costs (valued as if it were provided by paid carers). Globally, most of the cost of care was due to social care (40%) and unpaid care (40%), with only 20% being due to direct medical care. Cost estimations for Australasia were 50% social care, 43% unpaid care and 7% medical care costs.(46)

The total economic costs of dementia in this report cannot be directly compared with those of the *World Alzheimer Report 2015*, because we included productivity costs and deadweight losses. However, if we compare like-for-like costs, then we find that the distribution of costs is very similar to that reported for Australasia at 48% social care costs, 42% unpaid care costs and 10% direct medical care, which adds credibility to our analyses and reported findings.

The greatest driver of the economic cost of dementia in Aotearoa NZ is the cost of ARC (**\$1.21 billion**), which is 86.6% of all social care costs. Many people living with dementia in Aotearoa NZ prefer to live independently at home but may not be adequately supported by community support services.(43) Māori, Pacific and Asian peoples are less likely to use ARC , resulting in the average government spend per person being less in these groups. Thus, compared to Europeans, the social care cost per person with dementia is lower for Māori, Pacific and Asian populations. This constitutes an inequity in allocation of resources and is not in line with Treaty obligations. The solution is not to increase the numbers of ARC beds for Māori, Pacific and Asian populations, but to instead provide adequate community support for these populations, and also for Europeans who may also prefer to stay at home and receive care there.

This report estimates that by delaying entry into ARC by 3, 6 and 12 months, the costs saved would be \$69.7 million, \$139.4 million and \$278.8 million respectively. These costs savings could be used to develop evidence-based alternatives to enable independent living for as long as possible.

Most dementia care is provided by unpaid family carers and would cost \$1.19 billion if it were provided by paid carers (valued as replacement cost). Only a tenth of this amount (\$110.7 million) is a direct cost to the NZ Government, but it is important to consider the full cost to families and communities. Families that choose to look after their relative with dementia at home, rather than use ARC facilities, will bear more of the financial burden of care as community care is a limited resource.

(iv) *Dementia awareness and friendliness*

The WHO *Global Action Plan* describes a dementia supportive society as “an inclusive and accessible community environment that optimizes opportunities for health, participation and security for all people, in order to ensure quality of life and dignity for people living with dementia, their carers and families”. (45, p. 14) In addition to providing support for unpaid carers and people living with dementia, actions for member states include safeguarding the human rights of people living with dementia, tackling the stigmatisation associated with dementia, and promoting greater involvement of people living with dementia in society. These actions require a response to dementia from across government departments that is yet to be achieved in Aotearoa NZ.

In this report, we noted that the contribution of modifiable risk factors for dementia is higher (than worldwide estimates) for each of the main ethnic groups in Aotearoa NZ.(5) Many of these risk factors are also associated with lower socio-economic status, or clustered in areas of greater deprivation (e.g. greater rates of obesity and smoking and lower levels of education).(47) This suggests that social disadvantage and exclusion heighten the risk of dementia, and thus widen health inequity. National policies need to consider how key contextual factors such as poverty, inequality and limited resources impact on the risk for dementia and access to health services.

Stigmatisation also contributes to the experiences of people living with dementia, impacting mental health, quality of life, social support and participation.(48, 49) Carers and relatives are also exposed to the indirect consequences of stigmatisation.(50) Public attitudes and the stigma that exists around dementia contribute to fear and reluctance to obtain a diagnosis,(51) and can lead to social withdrawal of the person living with dementia and their carers.(50, 51) Policies that help to raise public awareness of dementia and reduce stigmatisation, especially in Māori, Pacific and Asian communities, will facilitate more timely diagnosis and ensure that support is in place before crises arise.

With an ageing workforce in Aotearoa NZ, the impact of dementia on employment trajectories could be substantial.(52-54) This report has shown that Māori, Pacific and Asian populations have a higher proportion of people living with dementia in the younger age groups, which suggests that they will be disproportionately affected in the workplace.

Furthermore, the financial disadvantages experienced by carers due to the opportunity cost of lost income has longer-term consequences. The impact of lower contribution to pension schemes and retirement savings further perpetuates poverty in these already disadvantaged groups.

(v) Support for carers

The third action plan (Mahi Aroha Carers' Strategy Action Plan 2019–2023(23)) under the Carers' Strategy 2008, recognizes the need to support carers including providing financial support and help to impact on wellbeing. The cost of dementia for carers has been highlighted above. Research has demonstrated that caregiving incurs a high economic burden.(55, 56) However, little is known about the costs incurred by carers of people living with dementia in Aotearoa NZ.(57) Carers may experience out-of-pocket expenditure on goods (e.g. bedding, mobility aids and incontinence products), home adaptations to improve accessibility, increased heating, laundry and transportation fees.(58)

The need to develop evidence-based interventions to support carers has been highlighted as imperative, and is at the heart of government policies and programmes from Europe to India.(59) Traditionally, interventions have been targeted at unpaid carers.(60-63) More recently, research suggests that it is important to implement interventions that provide support to the unpaid carer *and* the person living with dementia, recognising that each member of the dyad will have an influence on the other member's wellbeing.(64)

(vi) *Information systems for dementia*

The WHO *Global Action Plan* recommends “routine population-level monitoring of a core set of dementia indicators to guide evidence-based actions to improve services and to measure progress towards implementing national dementia policies”.(45, p. 30) Aotearoa NZ has good systems to collect routine health and social care data (for example, interRAI data), some of which has been used to compile this updated report. Routinely collected health and social care data could be used as a proxy measure for surveillance,(16) but would need to be validated against a community-based prevalence study to ensure accuracy and utility for use in modelling estimates. If shown to be a useful proxy measure, the NZ Government could use these data collection systems to demonstrate policy effectiveness, whether it is meeting its policy goals or its Treaty obligations to ensure Māori have at least the same level of health as non-Māori.

(vii) *Dementia research and innovation*

The WHO *Global Action Plan* notes that research priorities should be identified so that “social and technological innovations can increase the likelihood of effective progress towards better prevention, diagnosis, treatment and care for people living with dementia”.(45, p. 32)

Aotearoa NZ needs a robust evidence base to inform policy. To plan services, research is required to capture accurate data on dementia in Aotearoa NZ, including prevalence and the financial and social impact of dementia on whānau/families, potential health inequities and the projected future needs for good dementia care and supportive social and physical environments in Aotearoa NZ. This will require substantial investment into dementia research, and an integrated research strategy that prioritises not only epidemiological and clinical research, but also research aimed at optimising the quality of life for people living with dementia and their whānau/families and communities.

The WHO *Global Action Plan* recommends that each country commits a minimum 1% of the societal cost of dementia to funding dementia research covering basic science, care improvements, prevention and risk reduction, drug development and public health.(45) Based on this recommendation, the NZ Government should be allocating \$36 million per annum (1% of \$3.62 billion) to dementia research in Aotearoa NZ.

It currently invests around \$5 million per annum. To establish whether dementia incidence and prevalence changes in the future (and to establish whether dementia policy has an impact), funding for epidemiological research is required. Continually basing policy upon census estimates is likely to result in a mismatch between resourcing and true need.(66)

In allocating dementia research funding, good practice would include involving people living with dementia and other relevant stakeholders in setting research priorities (e.g. James Lind Alliance in the UK – www.jla.nihr.ac.uk), developing national standards and methods for involving people living with dementia in research (e.g. nihr.ac.uk/pi-standards/standards), and developing the research infrastructure for developing co-created dementia research (e.g. www.joindementiaresearch.nihr.ac.uk). These approaches would empower and engage people living with dementia and their carers, and are more likely to meet their needs, expectations and human rights.

8.8 Conclusions

This report has highlighted the ways in which the needs of people living with dementia and their families are not being met. The long-term care system comprises support to unpaid carers, community home care, respite care, ARC and palliative care, but these components do not provide a seamless continuum of provision, and many people feel forced into avenues of care that are neither cost-effective nor culturally appropriate. This is important, as the current and future costs of long-term care will be driven to a large extent by dementia, yet there are limited opportunities for people living with dementia to express their preferences for how they would like to be supported and cared for.(67) An integrated policy approach is required to develop, deliver and promote innovative, evidence-based and culturally appropriate programmes, services, goods and environments.

Meeting complex care needs requires service integration and co-ordination, advanced planning and monitoring. Success in designing and implementing cost-effective strategies for the prevention of dementia and identifying interventions that can alter the course of the disease and that impact on quality of life will require investment in cross-sector research disciplines. It will also be important to monitor progress and cost-effectiveness of programmes and policies, that can be facilitated through the use of information and communications technology and validated routine health and social care data.

Overall, Aotearoa NZ needs an integrated and holistic approach to dementia that focuses on supporting capabilities, cultural identity and meaning, as well as risk reduction, diagnosis, treatment, care and support for dementia carers. Some societal challenges need to be tackled at a national level, such as creating age-friendly communities, raising public awareness and challenging stigmatisation of dementia. An integrated cross-sectoral approach will help to ensure that Aotearoa NZ creates a society “in which dementia is prevented and people living with dementia and their carers live well and receive the care and support they need to fulfil their potential with dignity, respect, autonomy and equality”.(45, p. 7)

The prevalence of dementia in Aotearoa NZ is likely to more than double in the next 30 years. It is a condition that affects not just the individual, nor just their family. It affects all of society and we are not prepared. We cannot afford to delay any longer.

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APPENDIX: DATA SOURCES AND METHODS

TECHNICAL DETAILS

This section provides details on the methods used in the calculations of the prevalence and costs found in the main report. A rationale for all data sources used and underlying assumptions is provided, with acknowledgement of their limitations.

Where data allows, calculations are disaggregated by ethnicity. Ethnicity data is reported using Statistics NZ level 1 categories(1) and is presented for the four largest ethnic groups – European, Māori, Pacific peoples, and Asian. Totals may sum to more than 100% as individuals can identify with more than one ethnicity. Total cost is then converted to a cost per person living with dementia to allow comparison across the groups.

PREVALENCE, MORTALITY AND BURDEN OF DISEASE

In the five years since the publication of the most recent Dementia Economic Impact Report (DEIR 2016)(2) there has still not been an epidemiological study on dementia prevalence in Aotearoa NZ. The estimates of dementia prevalence in DEIR 2016 used data from a systematic review and meta-analysis of four Australasian dementia prevalence studies published in the *World Alzheimer Report 2015* for those aged 60+, (3) a UK based prevalence study for the 0–59 year age group, (4) and age and sex relativities were derived from a combination of published epidemiological and meta-analysis studies. (5) These rates were then applied to the Aotearoa NZ population structure by five year age bands to estimate the prevalence of dementia in Aotearoa NZ. The prevalence estimates used by Deloitte Access Economics in the previous report are presented in Table 27.(2)

Table 27. Dementia prevalence in Aotearoa NZ by age and sex, 2016 (%).

Age	Male	Female	Total
0–59	0.03	0.02	0.03
60–64	2.4	1.2	1.8
65–69	3.2	2.4	2.8
70–74	4.6	4.4	4.5
75–79	7.2	7.8	7.5
80–84	12.1	12.9	12.5
85–89	18.6	21.5	20.3
90+	33.6	40.5	38.3

Source: Deloitte Access Economics (2016).

Aotearoa NZ is a multicultural and ethnically diverse country, so the studies upon which DEIR 2016 prevalence estimates are based on are unlikely to be generalisable and applicable to the Aotearoa NZ population. (4, 6–9) Furthermore, the estimates have been applied to all ethnicities so do not take into account the differential risk of dementia between ethnic groups, with Māori and Pacific populations shown to be at greater risk due to a higher prevalence of many of the modifiable risk factors for dementia.(10) However, in the absence of any Aotearoa NZ epidemiological studies, the DEIR 2016 prevalence estimates are considered the best available for Aotearoa NZ. As such, the prevalence estimates in this updated report have applied the same DEIR 2016 methods to the updated Statistics NZ population projections for the country based on census 2018 projections to 2050(11) as well as by European, Māori, Pacific and Asian ethnicity population projections to 2040.(12)

PREVALENCE BY AGE AND SEX

Prevalence rates derived in DEIR 2016 were applied to the updated Statistics NZ population estimates and projections (based on census 2018) by age and sex from 2020 to 2050.(11)

PREVALENCE BY STAGE OF DEMENTIA

There is little research on the prevalence of dementia by stage from mild to severe. However, three studies in the US and UK(13-15) are consistent in their estimates of the proportions of people living with dementia in each of the broad stages. These are:

Mild dementia: 48.4%–55.4%

Moderate dementia: 30.0%–32.1%

Severe dementia: 12.5%–21.0%

For this report, we have used the Australian Institute of Health and Welfare (AIHW) 2012(16) estimates for stage of dementia by age band due to the similarities between Australia and Aotearoa NZ. The AIHW 2012 estimates are:

Mild: 55.0%

Moderate: 30.0%

Severe: 15.0%

PREVALENCE BY ETHNICITY

The same methods were used as those for prevalence calculations by age and sex, but using the updated Statistics NZ population estimates and projections (based on census 2018) by age, sex and ethnicity from 2020–2040.(12)

MORTALITY

The MoH reports on the number of deaths attributable to dementia as the primary underlying cause of death, with the most recent data disaggregated by International Classification of Diseases (ICD) three character codes available for 2017.(17) It is acknowledged that not all individuals with a diagnosis of dementia die as a result of their dementia, and there is also evidence that dementia is under-recorded as a primary cause of death.(18)

For this reason, we have also used data provided by McLeod et al(19) who linked mortality data to other health data sets (including interRAI, National Minimum Dataset (NMDS), PRIMHD mental health data (PRIMHD) and Disability Support Services (SOCRATES)) to identify all who had a diagnosis of dementia at the time of death in 2015.

Due to concerns about the impact of COVID-19 on the accuracy of mortality estimates for 2020,(20) our mortality estimates for dementia in 2021 were calculated using data from McLeod et al(19) who provided updated mortality projections to 2043, using the more recent “Update 2020” projections from Statistics NZ for the MoH. All deaths attributable to dementia as the underlying cause of death (ICD-10 codes F01, F03, G30 and G31) were identified and adjusted for population growth by age and sex.

BURDEN OF DISEASE

Using the disability weights for dementia severity from the Global Burden of Disease 2017 study (Table 28),(21, 22) a weighted total of years lived with disability (YLD) was calculated. Years of lives lost (YLL) were calculated using the life expectancy at each age band from Statistics NZ Life Tables.(23) Disability-adjusted life years (DALY) were calculated as the sum of YLD and YLL.

Table 28. Disability weights for dementia, by dementia severity.

Severity	Disability weights
Mild	0.069
Moderate	0.377
Severe	0.449

Source: GBD (2017).

Waka Kotahi, the New Zealand Transport Agency, put the VSL in 2019 at \$4.53 million(24) and the Treasury puts the value of a statistical life year (VSLY) at \$181,000.(25)

The economic cost associated with the burden of disease is calculated as the product of the total number of DALYs and the VSLY.

HEALTH CARE COSTS ASSOCIATED WITH DEMENTIA

Public and private hospitalisations

Number of hospitalisations

The MoH provides information on the number of discharges by primary discharge diagnosis, from public and private hospitals throughout the country, with the most recent data being for 2018.(26) Individuals with a diagnosis of dementia have a longer duration of stay in hospital, regardless of whether dementia is the primary reason for admission.(27) Therefore, a more accurate estimate of the cost of admissions related to dementia should be based on the number of hospital admissions where the individual has a diagnosis of dementia, even if it is not the primary reason for admission. A special information request to the MoH provided data on the number of public and private discharges with dementia identified as a secondary diagnosis. It is also known that not all dementias are identified during hospital admissions. A recent study(28) linking other MoH datasets (including mortality, pharmaceuticals, SOCRATES, interRAI, PRIMHD) to public and private inpatient discharges identified the number of individuals with a diagnosis of dementia who were discharged from hospital.

There were an estimated 3,728 hospitalisations with dementia present as the primary diagnosis and 14,823 discharges where the diagnosis of dementia was coded on discharge. Data from the linked health datasets identified 25,827 hospitalisations where a diagnosis of dementia was present in in any other health data set (Table 29). These are the estimates that we have used in our calculation of hospital costs.

Cost

The MoH utilises the New Zealand Casemix Framework for Publicly Funded Hospitals(29) to calculate the cost of an average hospital admission. The weighted inline equivalent separations (WEIS) cost weights released by the MoH calculate the average cost of case-weighted discharge in 2020 to be \$5,216.21.

Dementia weighting

Compared to those without dementia, the cost of a hospital stay for individuals diagnosed with dementia is higher, due in part to a longer average length of stay.(27) To account for this, a case weighting is used, with the WEIS 2020 case weighting of 1.76x for "*Dementia and other chronic disturbances of cerebral function*".(29) This estimate is in line with international literature that report case weightings for dementia admissions between 1.7x and 3.5x.(3)

Using the ICD-10 codes pertaining to dementia (Table 30), all public and private discharges with dementia as a primary diagnosis in 2018 were identified and adjusted for prevalence growth to 2020. All public hospital discharges with dementia as a secondary diagnosis using the same ICD-10 codes were provided by the MoH for 2020. All private hospital discharges with dementia as a secondary diagnosis were provided by the MoH for 2019 and adjusted for prevalence growth to 2020.

The number of discharges was then multiplied by the average case-weighted discharge cost and dementia weighting to estimate the total hospitalisation cost attributable to dementia.

Table 29. Hospitalisations with a diagnosis of dementia and associated cost, 2020.

	Dementia as the primary discharge diagnosis	Dementia as one of the diagnoses on discharge	Dementia diagnosis present but not coded at hospital discharge
Number	3,728	14,823	25,827
Total cost	34.2 million	136.1 million	237.1 million

Source: University of Auckland calculations.

Table 30. ICD-10 codes for dementia.

ICD-10-AM code	Description
F00	Dementia in Alzheimer's disease
F000	Dementia in Alzheimer's disease with early onset (G30.0+)
F001	Dementia in Alzheimer's disease with late onset (G30.1+)
F002	Dementia in Alzheimer's disease atypical or mixed type (G30.8+)
F009	Dementia in Alzheimer's disease unspecified (G30.9+)
F01	Vascular dementia
F010	Vascular dementia of acute onset
F011	Multi-infarct dementia of acute onset
F012	Subcortical vascular dementia
F013	Mixed cortical and subcortical vascular dementia
F018	Other vascular dementia
F019	Vascular dementia unspecified
F02	Dementia in other diseases classified elsewhere
F020	Dementia in Pick's diseases (G31.0+)
F021	Dementia in Creutzfeld-Jakob disease (A81.0+)
F022	Dementia in Huntington's diseases (G10+)
F023	Dementia in Parkinson's diseases (G20+)
F024	Dementia in human immunodeficiency virus [HIV] disease (B22.0+)
F028	Dementia in other specified diseases classified elsewhere
F03	Unspecified dementia
F051	Delirium superimposed on dementia
G30	Alzheimer's disease
G300	Alzheimer's disease with early onset
G301	Alzheimer's disease with late onset
G308	Other Alzheimer's disease
G309	Alzheimer's disease unspecified
G31	Other degenerative diseases of nervous system not elsewhere classified
G310	Circumscribed brain atrophy
G311	Senile degeneration of brain not elsewhere classified
G318	Other specified degenerative diseases of nervous system
G319	Degenerative diseases of nervous system unspecified

Source: ICD-10.

Non-admitted care costs

The MoH does not capture the diagnosis code for outpatient hospital visits, so the outpatient costs associated with dementia cannot be directly calculated. Secondary care in Aotearoa NZ is similar to Australia, so in line with the methodology of previous DEIR(2, 5, 30) and other disorders(31) in Aotearoa NZ, the ratio of inpatient to outpatient costs from the AIHW report(32) was used to estimate the cost of outpatient care in Aotearoa NZ, calculated at 9.5% of total medical costs.

General practitioner visits

The MoH does not collect information on GP consultations by diagnosis code. However, the *New Zealand Health Survey (NZHS) 2019/20* reported an average of 2.9 GP consultations per person per year.(33) It is not known what proportion of GP consultations were for dementia. Two Australian studies(16, 34) estimated that 0.5% of all GP consultations were for dementia, but there is also evidence that the number of GP consultations per year reduces as dementia progresses.(35)

The average out-of-pocket cost of a GP consultation without a community services card (CSC) in 2020 was \$42.83.(36) Those aged 18 years and older who hold a CSC or high use health card qualify for a subsidy of \$15.33 per visit.(37) It is not known what the average out-of-pocket cost was to the individual or if the subsidy was accessed.

In line with the DEIR 2016(2) the total cost of a GP consultation was calculated as the sum of the subsidy and out-of-pocket costs (\$58.16). The cost associated with GP consultations was calculated as the product of the number of GP consultations for those with dementia multiplied by the cost per visit.

Pharmaceuticals

There are four dementia specific medications approved for use in Aotearoa NZ – donepezil, rivastigmine, galantamine and memantine. The MoH publishes dispensing data for all community dispensed pharmaceuticals that are funded by the State, with data currently available to 2019.(38) Of the four dementia medications licensed for use in Aotearoa NZ, two are funded – donepezil tablets (5mg and 10mg) and rivastigmine transdermal patches (4.6mg and 9.5mg). It is not known how many prescriptions of the unfunded medications have been issued, but this is likely to be a small fraction given the availability of the two funded medications.

The available pharmaceutical data gives the number of dispensings for each medication. The PHARMAC schedule(39) recommends donepezil is dispensed as a one-off three-month supply, while rivastigmine patches are dispensed monthly. The cost of each medication was sourced from the PHARMAC community pharmaceutical schedule(39) that lists the price of all medications and therapeutics subsidised by the government (Table 31).

The total cost of dispensing was calculated by multiplying the number of dispensings by the cost of the recommended dispensing duration.

Table 31. Pharmaceutical dispensing for funded dementia medications.

Medication and dosage	Price	Number dispensed*
Donepezil 5mg	\$4.34/90 tablets	40,975
Donepezil 10mg	\$6.64/90 tablets	41,437
Rivastigmine 4.6mg patch	\$48.75/30 patches	1,722
Rivastigmine 9.5mg patch	\$48.75/30 patches	2,551
Total		86,685

Note: *Number of times the pharmaceutical product was dispensed from a pharmacy to the named person on all occasions including repeats (except for administrative dispensings such as owed balances) during the year.

Source: Ministry of Health.

Allied health

Data on the allied health utilisation or their cost is not available for Aotearoa NZ so needs to be estimated. The cost of allied health expenditure for dementia has been previously estimated at 3.5% of the total health system costs (excluding ARC)(30) and was the assumption used in DEIR 2016.(2)

Pathology and imaging

As with allied health expenditure, the utilisation and cost of pathology and imaging for people living with dementia is not available, with DEIR 2012 and DEIR 2016(2, 5) extrapolating these costs from DEIR 2008.(30) For DEIR 2008, the MoH provided data on the number of laboratory tests performed on people living with and without dementia, by age and sex, allowing the number of *additional* tests people living with dementia received to be derived. The number of tests was then multiplied by the cost of an average laboratory test to calculate total cost. Subsequent reports have inflated the number of tests based on prevalence growth and historical health inflation costs. There is no data available to estimate the cost of imaging for people living with dementia.

For this report, the MoH provided information on all funded laboratory tests for 2020 by the type, number and costs of funded laboratory tests. This calculated the average weighted cost of a test at \$9.44. The number of *additional* tests for people living with dementia has been inflated from the 2008 data based on prevalence growth by age band.

SOCIAL CARE COSTS ASSOCIATED WITH DEMENTIA

Aged residential care

Total aged residential care occupancy and cost

The Central Technical Advisory Service (TAS) Aged Care Demand Planner⁽⁴⁰⁾ provides an estimate of ARC bed numbers and occupancy, and projected future demand for each level of care in each region. By using the Aged Care Demand Planner 2021 update,⁽⁴⁰⁾ it was estimated there were 38,998 ARC beds across all four levels of care in 2019/2020, accounting for 12.3 million occupied bed days.

The daily cost of an ARC bed varies by level of care and territorial local authority (TLA). Using the negotiated minimum daily rates for the year commencing July 2020,⁽⁴¹⁾ Table 32 reports the average cost across all TLAs for each level of care.

The average cost of a bed-day across all regions for each level of care was multiplied by the number of occupied bed days to calculate the total cost of ARC. The total spend on ARC across all levels of care for people with and without dementia was estimated at \$2.54 billion.

Table 32. Aged residential care occupied bed days and cost by level of care, 2020.

Level of care	Cost per day (\$)	Bed days per year (\$ millions)	Expenditure (\$ millions)
Rest home	159.77	5.6	901.2
Hospital	256.68	4.8	1,221.5
Dementia	215.51	1.5	331.0
Psychogeriatric hospital	287.09	0.3	88.7
Total		12.3	2,542.4

Source: TAS (2021) and NZACA (2020).

Aged residential care occupancy and cost attributable to dementia

All individuals entering ARC require an interRAI Long-Term Care Facility (LTCF) assessment, a comprehensive clinical assessment designed to support clinical decision making and care planning with a focus on a person's function.(42) The LTCF assessment collects information on all diagnoses identified at the time of assessment. Using interRAI-LTCF data for the 2019/2020 year,(43) 48.7% of residents had a diagnosis of dementia, with 39.6% of assessments identifying dementia as the primary reason for the assessment (Table 33).

Table 33. Proportion of interRAI Long-Term Care Facility (interRAI-LTCF) assessments with a diagnosis of dementia present and with dementia as the primary reason for assessment by ethnicity, 2020.

Ethnicity	% of LTCF assessments	% of all LTCF assessments with a diagnosis of dementia	% of all LTCF assessments with dementia as primary reason for care
Māori	4.5	54.1	44.4
Pacific	2.0	55.2	43.8
Asian	3.3	40.8	31.7
European	89.6	48.6	39.5
Total*	99.4	48.7	39.6

Note: *0.6% of assessments did not identify with one of the four ethnic groups so their total does not sum to 100%.

Source: interRAI (2020).

While entry into dementia level of care in ARC usually requires a diagnosis of dementia, people living with dementia are more often placed managed in other levels of care. As such, it was assumed that all those in dementia units were placed there primarily because of their diagnosis of dementia. For the other three levels of care, the proportion of LTCF assessments with dementia as the primary reason for care were applied to the number of occupied bed days for each level of care (to calculate the number of ARC occupied bed days attributable to dementia). Using interRAI data for the 2019/2020 year,(43) 18,992 residents had a diagnosis of dementia and 15,443 residents were in ARC primarily because of their dementia diagnosis.

As with the calculation of the total cost of ARC, the number of bed days was multiplied by the average minimum daily rate for each level of care to calculate the cost of ARC attributable to dementia.

Aged residential care occupancy and cost attributable to dementia by ethnicity

To calculate ARC cost by ethnicity, the proportion of LTCF assessments for each ethnicity was applied to the number of occupied bed days in each level of care to estimate utilisation. The proportion of assessments identifying dementia as the primary reason for care was then applied to the previous calculation to estimate the number of bed days attributable to dementia for each ethnic group.

Community care

Community care and cost attributable to dementia

As with entry into ARC facilities, access to publicly funded community care requires an interRAI Home Care (HC) assessment.(42) Using the same approach as interRAI-LTCF, the HC assessment collects information on all diagnoses identified at the time of assessment as well as the diagnosis that was the primary reason for assessment. Using interRAI-HC data for the 2019/2020 year,(43) 27.7% of all assessments for home care had a diagnosis of dementia, with 22.7% of assessments reporting dementia as the primary reason for the assessment (Table 34).

An information request to Central TAS estimated the total spend on home care support services for older people was \$580 million. The proportion of HC assessments with dementia as the primary reason for care was applied to the total spend to estimate the community care spend attributable to dementia.

Community care and cost attributable to dementia by ethnicity

To calculate community care cost by ethnicity, the proportion of interRAI-HC assessments for each ethnicity was applied to the total community care cost. The proportion of assessments identifying dementia as the primary reason for care was then applied to this figure to estimate the cost attributable to dementia for each ethnic group.

Table 34. Proportion of interRAI Home Care (interRAI-HC) assessments with a diagnosis of dementia present and with dementia as the primary reason for assessment by ethnicity, 2020.

Ethnicity	% of HC assessments	% of all HC assessments with dementia	% of all HC assessments with dementia as primary reason for care
Māori	8.0	28.0	22.4
Pacific	4.0	30.5	22.4
Asian	4.2	22.9	16.8
European	83.4	28.8	24.1
Total *	99.6	27.7	22.7

Note: *0.4% of assessments did not identify with one of the four ethnic groups so their total does not sum to 100%.

Source: interRAI (2020).

Carer support and respite services

Carer support and respite services are funded by the NZ Government to assist the unpaid, full-time carer of a disabled person to take a break from caring for that person. Options include having family or friends provide oversight, access to an activity or day programme, employing a support worker to spend time with the person, or facility-based respite. (44) Not all carers utilise the support or respite services they are eligible for, with an Australian study(16) estimating that only 39% of carers for people living with dementia access these services.

The only way to estimate carer respite for dementia on a national level would be to link MoH invoices for respite care with interRAI data. We were unable to obtain these data in the timeframe required for this report.

While acknowledging the limitations of the DEIR 2016 approach, our report replicates the methods they used to estimate the costs associated with respite and carer support. DEIR 2016 used the following assumptions:

- Only 39% of carers would access respite care
- Care would be accessed for four weeks per year

Care would be provided for the average weighted number of care hours an individual living with dementia needed (for calculation of the weighted number of care hours see “estimating the hours of unpaid care”, p. 112).

Using this approach, we estimated that there were 50,721 people living with dementia in the community, of whom 19,781 (39%) were assumed to access respite and carer support for 86.8 hours (4 weeks x 21.7 hours per week). This equates to 1.72 million hours of carer support.

To estimate the cost associated with respite and carer support, the cost of paying a carer was used; the average hourly rate for a carer being \$22.60.(45)

Travel and transport

The total mobility scheme set up by Waka Kotahi (NZTA), funded by both central and local government, provides travel assistance to those who have disabilities or long-term health conditions and includes subsidising transport fares by 50%.(46)

The *New Zealand Household Travel Survey 2015–2018*(47) reports the average car trip is 9km. Based on current Auckland taxi fares of \$3.50 base fare and \$2.60 per km,(48) the average journey is estimated to cost \$27.00, of which \$13.50 is subsidised. Previous dementia reports(30) have estimated the number of trips a person living with dementia takes is two trips per month, so this equates to a cost of \$324 per individual per year.

UNPAID CARE FOR PEOPLE LIVING WITH DEMENTIA

Estimating the number of unpaid carers

The number of individuals living with dementia in the community was calculated by subtracting all people living with dementia in ARC identified in the previous section from the total numbers of people living with dementia in Aotearoa NZ. This approach estimated the total number of people with dementia living in the community as 50,721.

It is not known how many people living with dementia receive unpaid care in the community. However, the AIHW 2012 report estimated that 92% of those living with dementia in the community received unpaid care from one or more carers.(16) Applying this proportion to all individuals living with dementia in the community, equates to 46,663 individuals. Using a conservative estimate of one carer per person living with dementia results in an estimated 46,663 carers providing some form of unpaid care.

Estimating the hours of unpaid care

People with dementia in the community require increasing assistance and oversight as their dementia progresses. The Dementia Worldwide Cost Database (DWCD)(49) estimates the costs associated with unpaid care for people living with dementia, with mild cases receiving 1.6 hours/day for oversight with activities of daily living; moderate dementia receiving 3.7 hours/day; and severe cases receiving 7.4 hours/day for both oversight and supervision.

To calculate the number of hours of unpaid care being provided, a weighted average of the weekly hours of unpaid care provided was derived based on the DWCD estimates of care requirements for each level of dementia severity.(49) Table 35 presents the total hours per week by severity and estimates that on average, a person living with dementia receives 3.1 hours a day (21.7 hours a week) of unpaid care, totalling over 1 million hours per week or 52.7 million hours a year.

Table 35. Estimates of the number of hours unpaid care a week by dementia severity.

Severity	Proportion (%)	Number of carers	Hours of care day	Total hours per week
Mild	55.0	25,665	1.6	287,400
Moderate	30.0	13,999	3.7	362,500
Severe	15.0	6,999	7.4	362,500
Weighted average			3.1	1,012,500

Source: University of Auckland calculations.

Estimating the cost of unpaid care

There are different approaches to assigning a monetary value to the hours of unpaid care, each with their own set of assumptions.(50)

The **replacement cost method** measures the cost of buying the same amount of care from the formal sector if unpaid care was not available. The replacement cost is therefore a rough estimate of the cost of care borne carried by families and whānau.

Previous dementia reports as well as international studies(49, 51) have used the **opportunity cost method** to estimate the costs associated with unpaid care. This approach weights the calculated replacement cost by the probability the person providing unpaid care would otherwise be in employment. This weighting has been calculated at 9.3% based on Statistics NZ data(52) and we applied the same rate in the main report to calculate the opportunity cost associated with unpaid care.

To estimate the cost associated with unpaid care, the replacement value of paying for someone to provide the care was chosen. This was costed as the average hourly rate for a carer of \$22.60.(45)

Estimating the cost of informal care by ethnicity

The cost of unpaid care by ethnicity was calculated using the same methods as for the total population.

PRODUCTIVITY LOSSES AND INCOME SUPPORT COSTS ASSOCIATED WITH DEMENTIA

Reduced employment

Estimating the number of individuals not in employment due to dementia

People living with dementia are employed at lower rates compared to those without dementia, and leave the workforce early due to the progression of their cognitive difficulties.⁽⁵³⁾ The *2003 Access Economics Dementia Report for Australia*⁽⁵⁴⁾ presented data that showed only 2.3% of people living with dementia over the age of 65 years were employed compared to 8.5% of those without dementia, an employment rate 27.1% that of people without dementia. Previous dementia reports for Aotearoa NZ^(2, 5, 30) have applied this relative employment proportion when calculating the economic costs associated with reduced employment due to dementia.

However, the *2016 Dementia Economic Report for Australia*⁽⁵⁵⁾ calculated the cost of reduced employment based on the assumption that all people living with dementia were not employed. Table 36 presents the number of people living with dementia expected to be in full or part-time employment based on employment rates⁽⁵⁶⁾ and those who would actually be employed based on those with dementia being employed at 27.1% of those without dementia. By using this assumption, there were 2,637 full-time, and 603 part-time employees with dementia who were not in employment because of their dementia.

Table 36. Number of people living with dementia expected to be employed and actually employed by age, sex, and employment type, 2020.

		Full-time employment			Part-time employment		
Ethnicity and age	Prevalence	Rate (%)	General population	With dementia	Rate (%)	General population	With dementia
Male							
30–60	605	79.5	481	130	5.8	35	9
60–64	3,386	64.4	2,179	591	9.4	317	86
Female							
30–60	399	54.2	216	59	21.7	87	23
60–64	1,798	41.2	741	201	21.6	388	105
Total	6,188		3,617	980		827	224

Source: Statistics NZ (2020).

Calculating the economic cost of reduced employment

Employment figures calculated above were then multiplied by the average weekly earnings (AWE) for 2020(56) to calculate the lost earnings due to dementia under two different scenarios:

1. The *2016 Dementia Economic Report* for Australia assumption that all individuals living with dementia are not in the workforce
2. The *DEIR 2016* assumption that individuals living with dementia are employed at 27.1% the rate of those without dementia, where the difference between the number expected to be employed and those actually employed is therefore the number of people who would have been employed if they did not have dementia.

Table 37 presents the cost of reduced employment due to dementia. Under the first scenario where all people living with dementia are out of the workforce, the economic cost of reduced employment is **\$292.6 million**. Under the second scenario where some people living with dementia are still employed, the economic cost of reduced employment is estimated at **\$213.3 million**.

Table 37. Cost of reduced employment by age and sex, 2020.

Sex and age	AWE (\$)	None in employment (\$ millions)	Some in employment (\$ millions)
Male			
30–60	1,539	39.5	28.8
60–64	1,464	174.6	127.2
Female			
30–60	1,389	18.1	13.2
60–64	1,299	60.4	44.1
Total		292.6	213.3
Cost per person		4,200	3,060

Source: University of Auckland calculations.

Absenteeism

Dementia is associated with increased absenteeism from work. Previous dementia reports(2, 5) have reported that people living with dementia are absent from work for an estimated 12 additional days compared to those in employment without dementia. This has been multiplied by the AWE to estimate costs associated with absenteeism.

Income support

Estimating the number of individuals receiving income support

People living with dementia are eligible for superannuation from the age of 65 years, a non-means tested universal payment available to all eligible Aotearoa NZ residents.(57) Those who are not yet 65 years old require alternate avenues of income support if they are not in employment. This support is in the form of a supported living payment (SLP), an income support payment overseen by the Ministry of Social Development for those who are unable to work due to a health condition, injury or disability.(58) The Ministry of Social Development spend on SLP for the year ended June 2020 was \$1.556 billion for 94,144 recipients,(59) at an average cost of \$16,527 per person.

Calculating the cost of income support

It is not known how many people living with dementia receive the SLP as eligibility is means tested. In line with DEIR 2016, the cost of income support for people living with dementia was calculated on the assumption all individuals under the age of 65 years with dementia who were not in employment were receiving the SLP. As in the previous section, we have calculated the income support due to dementia under two different scenarios:

1. The *2016 Dementia Australia* report assumption that all individuals living with dementia are not in the workforce
2. The *DEIR 2016 NZ* report assumption that people living with dementia are employed at 27.1% of the rate of those without dementia, where the difference between the number expected to be employed and those actually employed is therefore the number of people who would have been employed if they did not have dementia.

Premature mortality

The losses associated with premature mortality comprise of the amount of income a person living with dementia would have earned had they remained alive, did not have dementia and were in employment. This was calculated by multiplying the mortality attributed to dementia at each age band by the respective employment rate and AWE, then added together to estimate lifetime earnings. The lifetime earnings were then discounted back to present values at a rate of 3%.

TOTAL ECONOMIC COST OF DEMENTIA

Economic costs due to lost tax revenue

Lost tax revenue due to reduced productivity and the opportunity cost of unpaid care were calculated at the average personal tax rate of 24%. Employee losses due to absenteeism were calculated at the company tax rate of 28%. The losses incurred by the NZ Government due to the reduced indirect tax take was modelled as 15% of after-tax income using goods and service tax. Deadweight losses were calculated as 20% of the total costs incurred by the NZ Government (Table 39).

The revenue forgone by the NZ Government due to lost taxes includes the taxable income lost from reduced productivity (due to reduced employment and the opportunity cost of unpaid care), employer losses due to absenteeism, and the reduced indirect tax take.

Table 38. Taxation revenue forgone due to dementia, 2020.

Revenue	Tax rate (%)	Taxation revenue forgone (\$ millions)	Lost income tax (\$ millions)
Pre-tax income lost due to reduced employment	24 ^a	221.6	53.2
Opportunity cost of in-formal care	24 ^a	110.7	26.6
Employer losses due to absenteeism	28 ^b	3.7	1.0
Indirect tax	15 ^c		38.3
Total		336	119.1
Cost per person		4,820	1,705

Note: ^a average personal tax rate ^b company tax rate ^c modelled as 15% (using goods and services tax).

Source: University of Auckland calculations.

Table 39. Components of deadweight loss, 2020.

Cost	Expenditure (\$ millions)
Health care costs borne by government	274.2
Social care costs borne by government	1392.1
Income support	82.4
Lost taxes	119.1
Total	1867.8
Rate of deadweight loss	20%
Deadweight loss	373.5

Source: University of Auckland calculations.

Cost–benefit analysis of delaying aged residential care

Estimated survival time for dementia and duration in aged residential care

Dementia is a degenerative disease known to increase morbidity and mortality and there is evidence that some dementia subtypes are associated with longer survival times than others.(60) Furthermore, dementia is not always diagnosed at the onset of symptoms, but at some later stage in the disease process. Because of this, the estimated survival time for dementia varies between studies depending on the population studied, duration of follow up, and whether the survival time was calculated from the time from disease onset or from time of diagnosis.

The median survival times from diagnosis in the literature range from 1.1–8.5 years,(61, 62) and a recent study calculated the median time from placement in ARC to death for people living with dementia at 2.5 years.(63) Due to the wide range of survival estimates, we have chosen to calculate the benefit–cost ratio (BCR) of delaying institutional care using the 2.5 years (30 months) median survival time from entry into ARC to death, but will also present the BCR calculations using median survival times of 3.3 years (39 months) and 6.6 years (78 months) to allow comparison with DEIR 2016.

Costs savings due to not being in aged residential care

To calculate the costs savings due to not being in ARC, the proportional delay in the duration of care was first calculated. For example, if entry into care is delayed by 3 months; this is 10% of a 2.5 year placement in ARC, so the reduction in aged care costs will be 10% for this 3 month delay. Table 40 presents the proportional reduction in care for different survival times assuming a 3, 6, and 12 month delay in entry into ARC. Table 41 presents the number of reduced bed days and associated cost savings assuming a 3, 6, and 12 month delay in entry into ARC.

Table 40. Percentage reduction in aged residential care at 3, 6 and 12 months under different assumptions for duration of institutionalisation.

Duration of care (years)	Percentage reduction in duration of care		
	3 months	6 months	12 months
2.5	10.0	20.0	40.0
3.3	7.60	15.20	30.40
6.6	3.80	7.60	15.20

Source: University of Auckland calculations.

Table 41. Number of bed days and aged residential care cost associated with a 3, 6 and 12 month delayed entry into aged residential care, based on an average duration of care of 2.5, 3.3 and 6.6 years.

Duration of care (years)	3 months		6 months		12 months	
	Bed days (millions)	Cost (\$ millions)	Bed days (millions)	Cost (\$ millions)	Bed days (millions)	Cost (\$ millions)
2.5	0.58	120.7	1.16	241.4	2.32	482.8
3.3	0.44	91.9	0.88	183.9	1.76	366.6
6.6	0.22	45.9	0.44	91.9	0.88	183.9

Source: University of Auckland calculations.

Calculating the informal care requirements if not in aged residential care

If a person living with dementia is not in ARC, they will require care and oversight in the community, and it is also likely their dementia is at the more severe end of the spectrum given they would otherwise have been in ARC. The amount of unpaid care required in the community is calculated as the number of hours a person would need unpaid care for at home for the duration.

To do so, it was assumed that all people living with dementia who delayed entry into care would have a severe dementia and be requiring the DWCD estimate of 7.4 hours of care and supervision per day (51.8 hours per week).

Table 42 presents the number of unpaid care hours required in the community and the opportunity cost associated with this care.

Table 42. Number of hours of unpaid care required and the opportunity cost of carer time for a delayed entry into care of 3, 6 and 12 months, based on an average duration of care of 2.5, 3.3 and 6.6 years.

Duration of care (years)	3 months		6 months		12 months	
	Care hours (\$ millions)	Cost (\$ millions)	Care hours (\$ millions)	Cost (\$ millions)	Care hours (\$ millions)	Cost (\$ millions)
2.5	4.29	9.0	8.58	18.0	17.17	36.1
3.3	3.26	6.8	6.51	13.7	13.02	27.4
6.6	1.63	3.4	3.26	6.8	6.51	13.7

Source: University of Auckland calculations.

Estimating other community care costs associated with living at home

Being cared for at home will also incur other community costs. These costs were calculated using the proportion of unpaid care hours relative to the annual total (Table 43) to weight the cost of community care, respite and carer support, and travel. Deadweight losses were then calculated as 20% of community care costs.

Table 43. Costs incurred for community care due to a delayed entry to care of 3, 6 and 12 months, based on an average duration of care of 2.5, 3.3 and 6.6 years.

Duration of care (years)	3 months		6 months		12 months	
	% of annual informal care hours	Community care cost (\$ millions)	% of annual informal care hours	Community care cost (\$ millions)	% of annual informal care hours	Community care cost (\$ millions)
2.5	8.1	28.8	16.3	57.6	32.6	115.2
3.3	6.2	22.2	12.4	44.4	24.7	88.8
6.6	3.1	11.1	6.2	22.2	12.4	44.4

Source: University of Auckland calculations.

Calculating the net benefit and benefit–cost ratio

The net benefit of delaying entry into ARC is calculated by subtracting the costs associated with being managed in the community (the costs of community care, respite, travel, unpaid care costs and associated deadweight losses) from the cost of being in ARC for the same amount of time. The BCR is the ratio of costs associated with ARC to the costs associated with community care, with the calculated ratio representing the amount saved on ARC costs for every dollar spent to keep the person living with dementia in the community.

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