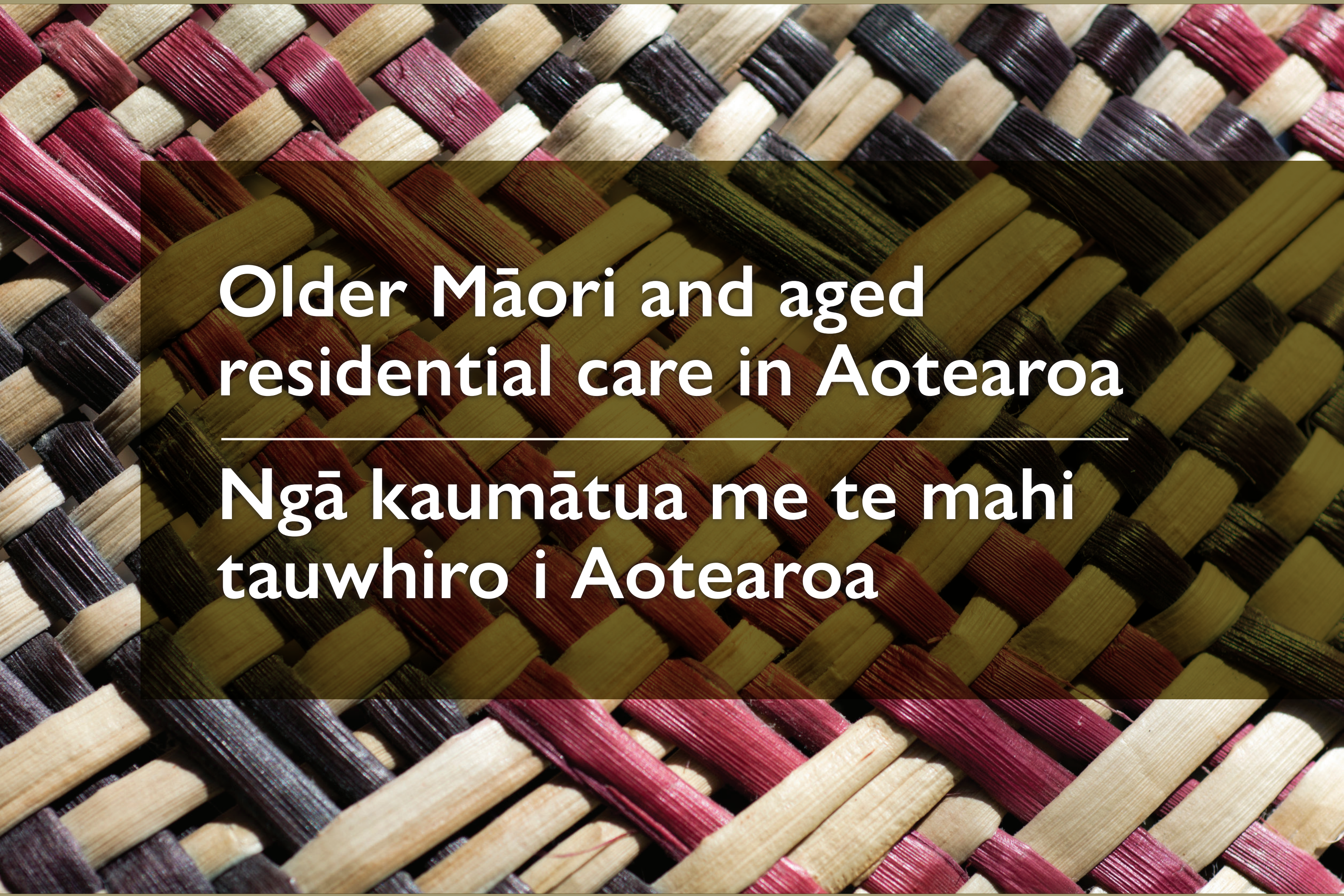
Joanna Hikaka & Ngaire Kerse DECEMBER 2021 | HAKIHEA 2021



Older Māori and aged residential care in Aotearoa

Ngā kaumātua me te mahi tauwhiro i Aotearoa

REPORT PREPARED FOR
HEALTH QUALITY & SAFETY COMMISSION NEW ZEALAND
HE PŪRONGO I TUHIA MĀ
KUPU TAURANGI HAUORA O AOTEAROA

He wāhi kōrero

He aro tahito
He aro tipua
E Io-matua-te-waiora
Ko koe anō hoki te uru-tapu-nui
Te kura wānanga i te Toi-o-ngā-rangi
Nāhau te kupu i whakaae
Kia uru ai ki roto ki te puku
o te tangata
Tāwhia mai i waho, rawea mai i roto
Te wawana, te horonga, te hiringa
I te Pū-ao-whio-whio-nuku
I te Pū-ao-whio-whio-rangi
Te mārama ahu nuku
Te mārama ahu rangi
Kua takoto i te hau-o-Tū
Tū-te-winiwini
Tū-te-wanawana
Tū te ihiihi o Tū
Haumi e
Hui e
Taiki e

Foreword | Kupu whakataki

This report was commissioned by the Health Quality & Safety Commission New Zealand (the Commission) as a 'thought-piece on Māori and aged residential care (ARC)'. This report includes the published literature as well as the thoughts from just some of those, Māori and non-Māori, who work and research in the ARC sector. For some, their professional experience is mixed with personal whānau experiences of Māori realities of ageing and ARC.

Given the timeframe for this work to be completed, wide engagement with the sector and communities impacted by this topic was not possible. The contributors to this work are clear that future dialogue needs to be centred on Māori voices; to be centred on the voices of those with experience being, and caring for, our kaumātua, our pakeke, our koeke, our whānau, as they move into the stage of life where ARC living may become an option. Time needs to be given to developing trusting relationships with those who want to share their stories of the ARC sector – what has been, what is, and aspirations of what it could be.

Joanna Hikaka (Ngāruahine), is a pharmacist and health researcher, living and working in Tāmaki Makaurau. She has experience in older adult health, Māori health and health services research and has spent a decade working as a pharmacist in the aged residential care sector. Joanna's research focuses on equitable access to health services for Māori and considers how we can develop pro-equity, anti-racist health services in Aotearoa.

Ngaire Kerse is the Joyce Cook Chair in Ageing Well, a GP delivering services in ARC for over 20 years and health researcher specialising in clinical gerontology, primary care, equity and studies in the aged residential care setting.

Acknowledgements | He mihi

E tuku mihi ana mātou ki te whakanui I te hunga I whai kaha ana ki te tautoko I tēnei mahi pūrongo. Rātou ko:

We would like to acknowledge and thank those who contributed to, and supported, this work including:

Georgina Martin, WaiResearch, Te Whā

Rangimahora Reddy, Rauawaawa Kaumātua Charitable Trust

Mary Simpson, The University of Waikato

Geraldine Boyd, Rauawaawa Kaumātua Charitable Trust

Kay Shannon, Auckland University of Technology

Tiakina Te Kare, Goodwood Seadrome

Kelly Te Kare, Goodwood Seadrome

Tina Chivers, Goodwood Seadrome

Hayley McElwain, Northern Regional Alliance Limited

Thérèse Jeffs, CEO, The CARE Village

Rebecca Abey-Nesbit, Research Fellow, Christchurch School of Medicine, University of Otago

He mihi hoki ki ngā kaumātua e noho ana ki te ARC, ki tō rātou whānau, me ērā e manaaki ana I a rātou.

We also acknowledge the kaumātua who live in ARC, their whānau, and those that care for them.

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Glossary | Kuputaka

ARC – Aged Residential Care
ADLs – Activities of Daily Living – a measure of ability to function independently
Hapū – sub-tribe
Hākari – feast
Hauora – health and wellbeing
Hīmene – hymn
Hui – meeting, gathering
Iwi – tribe
Kai – food
Kaiako – teacher, tutor
Kaimahi – worker
Kapa haka – Māori performing arts
Karakia – prayer
Kaumātua – Māori elder/s
Kaupapa – activity, agenda
Kaupapa Māori – Māori way/approach/ideology
Koeke – Māori elder/s
Kohanga reo – literally a language nest, Māori language total immersion early childhood centre
Koroua – older male
Kotahitanga – working together, unity
Kuia – older female
Kura Kaupapa – Māori language total immersion primary school
Mahi māra – working the garden
Mana motuhake – autonomy and control
Manaaki – caring, hosting, reciprocity, supporting
Manaakitanga – the act of support, hosting
Marae – area outside the wharenui (meeting house), often used to describe the collective area including buildings
Māramataka – Māori lunar calendar
Mātauranga Māori – Māori knowledge/wisdom
Mate wareware – dementia
Manu tukutuku – bird kite
Oranga – welfare, health
Pākehā – New Zealander of European descent; white New Zealander
Pakeke – adult, elder
Pepeha – personal introduction, usually including reciting of some whakapapa
Pōwhiri – formal welcoming ceremony
Pūoro – Māori musical instrument
Pūrakau – story, legend

Rangatiratanga – sovereignty, the right to exercise control or authority, self-determination
Raupatu – confiscation
Rohe – territory, region
Rongoā – methods of healing
Roopū – group
Taiao – environment, natural world
Tangata whai i te ora – Māori mental health service users
Tangata whenua – people of the land, Indigenous people, Māori people
Te Ao Māori – the Māori world
Te Tiriti o Waitangi – the Māori language version of the Treaty of Waitangi
Te reo – Māori language
Te wā Māori – Māori time
Tikanga – practices, lore, the customary system of values and practices
Tititorea – traditional stick game
Tūpuna – ancestor/s
Tūrangawaewae – standing place
Wāhine – women
Waiata – song
Waiata tautoko – song of support
Wairua – spirit
Whānau – family
Whakapakiri – cultural education development sessions
Whakapapa – geneology
Whakatau – official welcome
Whakawhanaungatanga – establishing or strengthening connections
Whanaungatanga – relationship, connection
Whare kura – Māori language total immersion secondary school

Executive summary | Whakarāpopototanga matua

This report was commissioned by Health Quality & Safety Commission (the Commission) to serve as a think piece, highlighting current knowledge of care for Indigenous people in aged residential care (ARC), present views and experiences of Māori in ARC and discuss issues of relevance with a future focused view.

This report presents:

1. Population demographic shifts and Māori access to ARC in Aotearoa;
2. Quality of care for Māori living in ARC;
3. A narrative review of the literature regarding ARC and Indigenous populations in Australia, Canada, and the United States;
4. Voices of Māori involved in research or care provision for Māori in ARC;
5. Case studies of programmes developed to support Māori living in ARC.

It concludes by identifying knowledge gaps, and areas that are important in the ongoing discussion relating to Māori and ARC, with the intention of being both practical and aspirational. Commitment to te Tiriti o Waitangi requires full information on health outcomes for Māori and inequities for older Māori have been described. Inequities in ARC access and outcomes are largely unstudied and this report summarises available information.

Currently 16% of the total New Zealand population identify as Māori, and 7.6% of New Zealanders aged 65 years and older are Māori; in part caused by a disparity of over 7 years in longevity for Māori. **Demographic ageing** will happen faster for Māori than non- Māori in the next 20 years. And with this will come a large increase in the number of Māori with a need for daily support.

Māori are **underrepresented in ARC** with currently 2.98% (1,441) of the total Māori population aged 65+ (48,372) residing in ARC, whereas 7.6% are expected by population proportion alone. If the trends in ageing and ARC access continue, the expected number of older Māori accommodated in ARC will increase 4-fold by 2038 to a total of 4,986 persons. Evidence from longitudinal studies and qualitative in-depth interviews with older Māori show half the rate of admission to ARC for Māori compared with non- Māori and that kaumātua identify the need for ARC **solutions to be co-designed**. ARC is a second choice to staying at home. Care patterns differ and government expenditure for care is lower for Māori than non-Māori, potentially increasing the informal care required from whānau, but without corresponding increases in formal support services (ARC or home care) or financial resourcing being offered.

Quality of care for Māori in ARC can be examined through the interRAI assessments, universal in ARC 6-monthly. However, limited ethnicity-based analyses hampers the identification of inequities in the quality of care. Māori admitted to ARC are younger than non- Māori, and have similar levels of independence. The quality of medication prescribing may be lower for Māori than non-Māori.

The workforce serving ARC are diverse, largely composed of unregistered caregiver staff, 40% of whom work on immigrant visas, supported by registered nurses and care managers. Pay parity for Registered Nurses is called for to ensure continuity of high-quality staff. Cultural safety training and equity approaches to care are alluded to in relevant policy but not always present. The importance of a sustainable Māori workforce in ARC, well-resourced in a way that acknowledges both clinical and cultural expertise, is highlighted.

District Health Boards (DHBs) spend $1.8 billion subsidising care, with a further $0.8 billion contributed by out-of-pocket payments from residents. Personal contributions to care costs, and the means-testing regime, can create a barrier for older people to return home. **Means-testing may have more of an impact on Māori** who more commonly live in multi-generational homes and may be more complex for Māori when considering collective land ownership and Māori land.

Internationally, literature relating to Indigenous populations and ARC reports five areas of need: ensuring services are accessible, improving social support networks, building community capacity, a wellness-based approach, and preservation of cultural values. The need for culturally appropriate care is highlighted in most available studies and the importance of same (known) language for care is underlined. Systematic under resourcing of health systems for Indigenous populations in Australia and the United States of America also contribute to the under resourcing of care for older Indigenous people in ARC.

Case studies from **two Māori service providers** add lived experience of guiding older Māori through care and support. Emphasis on changing demographics with smaller family units suggests that community and whānau support for care may not be possible at some point unless there are significant changes and development of new service models allowing for “ageing in place”. Regional and urban populations are likely to require different considerations for ARC, and the need for flexibility in approach to suit different individuals and whānau was emphasised. Older Māori, when asked, are reluctant to enter ARC due to a lack of Kaupapa Māori services. A personal journey of care highlights the lack of Māori cultural norms in ARC. **Kaumātua need to see, hear and feel the presence of Māori cultural values and practices for whānau to thrive in ARC**. The importance of Māori governance and leadership in the development and delivery of care was emphasised, as was the need for different models of service provision to meet both care and cultural needs of kaumātua and their whānau. **Maintaining autonomy of the kaumātua** during the process of admission and within the care home was seen as paramount, echoing messages from the literature.

Two examples of **successful Māori-led models of ARC** are presented from The CARE Village in Ngongotahā, Rotorua, Goodwood Seadrome Home and Hospital, a dementia care facility in the greater Auckland region. In both cases Māori staff instigated the model and way of caring; tikanga, te reo Māori, kai, karakia, waiata and Māori governance were essential to success, again emphasising the importance of developing a skilled, sustainable workforce. ARC contracting can be a barrier or enabler; at The CARE Village, a service contract change was required to deliver the new model of care. Residents wanted to be connected with Te Ao Māori, and availability of staff members who can work in ways that ensure the connection is authentically maintained are essential and part of sustainability. Ongoing co-design and education with development and 'spread' of cultural skills ensured staff and resident acceptability throughout the shifts. Residents responded with increased awareness, engagement, expressions of happiness and belonging.

Throughout the report, views and expectation of ARC as expressed were largely negative with little time to come to terms with a move to ARC and whānau considering they had 'failed' should ARC be needed. Implications for **strategies across the lifecourse** may be to socialise the idea of increased care in later years as normal, and to encourgage whānau discussions about wishes and realities throughout the lifecourse. Improving the care provided to Māori in ARC will further support these discussions, through increased access to and awareness of Māori thriving when increased care can be provided.

Several ways forward are gathered and offered for consideration by stakeholders and the sector based on the findings in all sections of the report.

- Develop pro-equity policy in the ARC setting and include the monitoring of ARC access and quality outcomes for Māori in this policy;
- Develop an ARC workforce that can deliver culturally safe care to Māori, is equitably resourced and where both clinical and cultural skills are valued and appropriately remunerated;
- Support and appropriately resource the development of kaumātua-led and Māori-led ARC and other Kaupapa Māori care models that deliver to those with similar clinical care needs;
- Incorporate tikanga Māori, te reo Māori and Māori cultural values into care models in an authentic way with the involvement, and resourcing, of appropriate expertise;
- Apply flexibility in the contracting for ARC services to allow care delivery that can accommodate more than just clinical needs of the resident;
- Recognise the diversity of Māori and that appropriate models of care will vary for different regions, different whānau and individuals and that this is likely to change as different cohorts of Māori age;
- Increase the socialisation, across the lifecourse, of the concept of ARC for Māori.

Introduction | Kupu whakataki

Aged residential care (ARC), known internationally as long-term care homes (LTC), provides a residential option for those, generally over the age of 65 years, who require 24-hour personal care and/or supervision and are unable to be safely supported in the community. ARC is home to approximately 32,000 residents in Aotearoa New Zealand (NZ), with this number increasing year on year (interRAI NZ, 2018). The acuity, complexity and care needs of residents in ARC in NZ is also increasing (Boyd et al., 2011). Providing safe, effective and high-quality care for those living in ARC is important for improving older adult wellbeing and for efficient use of health resources.

In keeping with the rest of the mainstream health system in NZ, the origins of ARC in NZ are reflective of its historical, and contemporary, settler-colonial status. In the mid-1800s large numbers of men, many single, were attracted to the possibilities that life in the 'new' country offered. By the turn of the century there were many men who required extra support but remained without family or societal connections to provide this support (Tennant, 1983). The needs of this group of people led to the development of charitable 'old men's homes' (Tennant, 1983), which eventually became the basis of modern-day ARC. Although ARC have clearly moved on in this last century, understanding the societal drivers and historical foundation for the current ARC model of care is important when we consider this sector in the context of Māori.

As is occurring internationally, NZ's population is ageing, with the proportion of older Māori increasing at a faster rate to that of the rest of the population (Te Pou o te Whakaaro Nui, 2019). The population of Māori 65-years and older is expected to almost double in the next decade, increasing from 50,000 in 2019 to 90,000 in 2029 (Te Pou o te Whakaaro Nui, 2019). As people age, they are more likely to require the support of others, including through that available in ARC.

Te Tiriti o Waitangi (the Treaty of Waitangi), is one of NZ's founding documents and guarantees Māori the right to equitable health outcomes (Waitangi Tribunal, 2019). Despite this legislative and ethical right, non-Māori continue to be privileged over Māori in relation to access to and resourcing of the social determinants of health, including employment, education and health care (Ministry of Health, 2019; Robson, 2004). This, in turn, is driven by the ongoing effects of colonisation and racism. The effects of these are ultimately actualised when we examine life expectancy, with non-Māori men and women living for over 7 years longer, on average, than Māori men and women (Ministry of Health, 2015).

In relation to health, in addition to the **right of equitable health outcomes**, te Tiriti o Waitangi guarantees Māori:

- **self-determination and autonomy** in their healthcare journey;
- that the Crown and Māori will be **well-informed** of actions and outcomes relating to pro-equity strategies and activities, and Māori health;
- authentic **partnership** in the **development**, **implementation**, **evaluation** and **governance** of health services;
- access to healthcare **options** including **culturally safe**, **mainstream services** and **Kaupapa Māori services** (Waitangi Tribunal, 2019, Hikaka et al., 2021).

These principles of te Tiriti not only set out the obligations of those working in the ARC sector but provide a clear framework with which to inform this report, and to structure future pro-equity conversations relating to Māori, ARC, and health care service provision for older Māori more generally.

OBJECTIVES

This report will present:

1. Population demographic shifts and Māori access to ARC in Aotearoa;
2. Quality of care for Māori living in ARC;
3. A narrative review of the literature regarding ARC and Indigenous populations in Australia, Canada, and the United States;
4. Voices of Māori involved in research or care provision for Māori in ARC;
5. Case studies of programmes developed to support Māori living in ARC.

It will conclude by identifying knowledge gaps, and areas that are important in the ongoing discussion relating to Māori and ARC, with the intention of being both practical and aspirational.

SECTION ONE | WĀHANGA TAHI

Setting the scene | Te horopaki

This section focuses on presenting what is known about the ageing population in Aotearoa, how the demographic is changing for Māori, and examines literature relating to access and outcomes for Māori in ARC. Literature relating to these issues in Indigenous populations in the United States, Canada and Australia is also presented. The literature was identified through searching biomedical databases as well as grey literature. Information that is yet unpublished was also provided to the authors from various people in their networks.

Māori and ageing | Māori e kaumātua haere ana

Despite comprising 16% of the total population in NZ, Māori make up just 7.6% of the population aged 65-plus, a proportion that will increase to 10% over the next 10 years; the number of Māori aged 65-plus doubling in this time (Te Pou o te Whakaaro Nui, 2019).

Older Māori occupy a revered place in Māori society, adding valuably to social and cultural capital (Durie, 2009). High proportions of Māori continue to provide care and support for whānau members and the wider community into their old age (Waldon, 2004). At the same time as contributing support and knowledge to whānau and communities, older Māori experience increased care and social support needs themselves, associated with changes in physical and cognitive abilities (Kerse et al., 2016; Lapsley et al., 2019). Care and support may be provided by family, or publicly and privately funded care services in the community. For a proportion of older Māori, this support will come from ARC.

Any discussion regarding social and health services for older Māori needs to be undertaken within the context of wellness and what it means to 'age well' for Māori. Ageing is seen as a normal, and inevitable, part of the life course and the self-agency that is expected in earlier life is expected to be continued into older age as well.

Dr Will Edwards' research for PhD thesis on Māori positive ageing found:

> ***Māori positive ageing is … concerned with older Māori ageing on their own terms, having control over their life circumstances, enjoying a high level of social engagement and being economically and culturally secure. Further, many of the concerns at the heart of Māori development efforts are likely to impact on Māori ageing. This includes centrality of Māori worldviews, strengthening cultural integrity, addressing ethnic inequalities, the importance of environmental protection, and the capacity to adapt to change*** *(Edwards, 2010)*.

These aspects are all relevant when we consider the role of ARC for Māori as they age, and the development of ARC services. The findings have been replicated in other work with kaumātua highlighting that quality of life in older age meant that cultural practices and the importance of whānau were recognised, there was the ability to make social connections, and there was the opportunity to pass knowledge on to younger generations (Allport et al., 2018). In relation to ARC specifically, kaumātua felt that ARC needed to reflect their current community. What that looked like depended on their current living situations. Kaumātua identified the need for ARC solutions to be co-designed. Independent of what the ARC solution was, ARC was positioned as a second choice to staying at home with whānau (Allport et al., 2018).

Monitoring the Crown | Te Aroturuki i te Karauna

Aotearoa is committed to equity in health and health care delivery through commitment to te Tiriti o Waitangi. Te Tiriti o Waitangi sets out both the requirement for the Crown to be fully informed in relation to health outcomes for Māori, and the right of Māori to have the information needed to monitor the Crown in relation to this (Waitangi Tribunal, 2019). Policies, nationally collected statistics, research funding mechanisms, and longitudinal studies are available to allow progress in addressing inequity in older age (Parr-Brownlie et al., 2020), however there is little work in the area of ARC. The extent to which ethnic inequities, seen in the wider health system, exist in ARC is largely unstudied. This section presents the little information that is available on the trends in access to ARC for Māori, as well as measures of quality of care. It also identifies what further information is required, and potential methods to examine this.

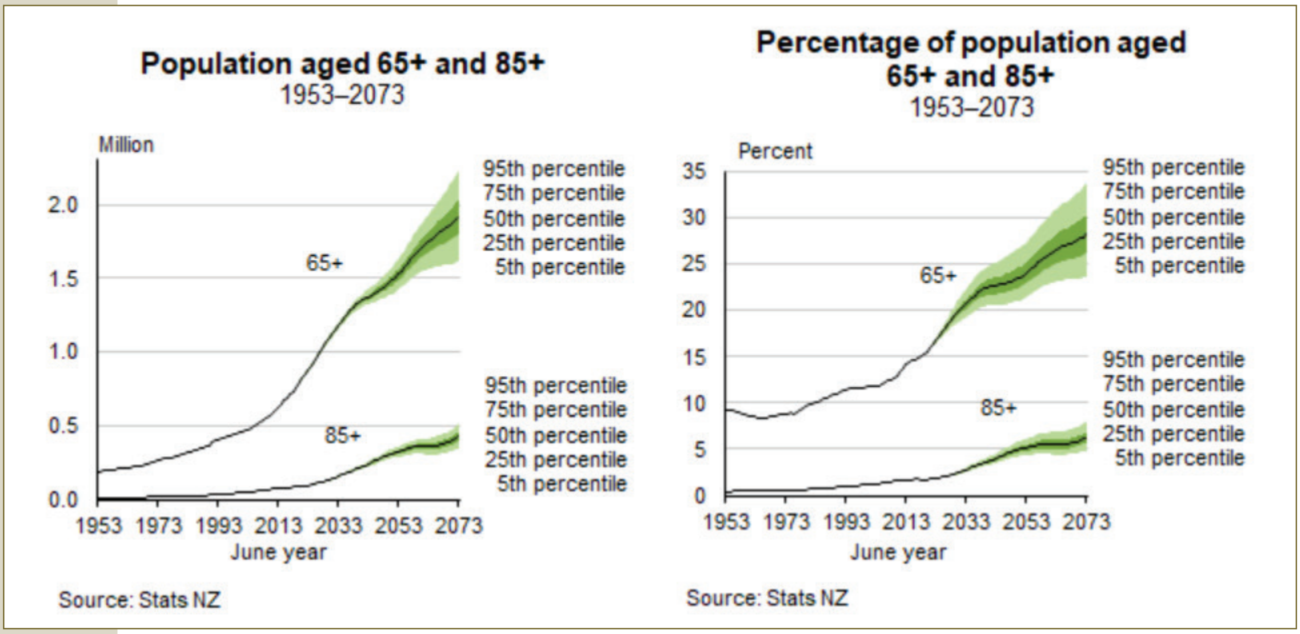
POPULATION DEMOGRAPHIC SHIFTS AND PROJECTIONS

For Māori, population ageing is causing greater and faster shifts than for the non-Māori population. Life expectancy and demographic proportional shifts contribute to this. For Māori life expectancy of those born in 1996 was 66.6 years for men and 71.3 years for women. This has increased to 73.4 years for men and 77.1 years for women for those born in 2018, a seven-year gain for men and six-year gain for women over 22 years (Statistics New Zealand, 2021a). From the same data source, the life expectancy of non- Māori born in 2018 is estimated at 80.9 years and 84 years for men and women respectively, a disparity of 7.5 and 7 years for Māori men and women respectively, one of the highest disparities for Indigenous people globally (Bramley et al., 2005).

Because of longevity and reduced fertility, the proportion of the New Zealand population over aged 65 years and 85 years are increasing rapidly.

Figure 1 shows the national population projections to 2073, showing number and proportion of the population as recorded to 2020 and estimated beyond. The black line indicates the 50th percentile and the spread of the fan depend on assumptions about mortality, fertility and migration estimates. By 2073 those aged 85 years and over may represent over 5% of the total population and up to 500,000 persons.

Figure 1: NZ total population projections for older people



From National population projections, by age and sex, 2020(base)-2073(Stats NZ, 2021a).

For Māori, population projections are available to 2038. Table 1 shows that while the total NZ population proportion for Māori increases from 17 to 22% from 2013 to 2038, the portion of Māori amongst the total NZ older population (aged 65+) doubles from 6 to 12% over the same time period and the absolute number of Māori in the 65+ age group more than triples from 34,500 to 125,900 persons.

Table 1: Population projections for total population and Māori population, total and 65+ years

Year	Total Māori population in NZ	Māori % of total NZ population	Total Māori aged 65+ yrs	Māori 65+ % of NZ population aged 65+ yrs
2013	69,2300	17.3	36,400	6.6
2018	766,000	18.0	48,400	7.6
2023	835,500	18.8	64,100	8.8
2028	905,300	19.8	85,300	10.2
2033	979,800	20.8	105,300	11.5
2038	1,059,400	21.9	125,900	12.9

Derived from the 2021 release of the National ethnic population projections (Stats NZ, 2021b) [yrs = years]

The projections for the breakdown of the older population show rapid increase in the older aged groups within the 65+ population over two decades (Table 2). The proportion of the older Māori population aged 65-69 years will decrease from 41% of those aged 65+ to 30% by 2038, while all age groups aged 75 years and over increase their proportion within the older Māori sub-population. The absolute number of Māori in the 80-84, 85-89, and 90+ years age group increase by 5, 6.5 and 10-fold respectively. This has relevance in considering the potential changes in the requirements for ARC over the next two decades.

Table 2: Older Māori population projections by 5 years age group

Year	65-69 years		70-74 years		75-79 years		80-84 year		85-89 year		90+ year	
	N	% of 65+	N	% of 65+	N	% of 65+	N	% of 65+	N	% of 65+	N	% of 65+
2013	15,000	41.2	10,200	28.0	6,100	16.8	3,400	9.3	1,300	3.6	400	1.1
2018	19,900	41.1	13,200	27.3	8,200	16.9	4,400	9.1	2,000	4.1	700	1.4
2023	25,200	39.3	17,800	27.8	11,000	17.2	6,200	9.7	2,700	4.2	1,200	1.9
2028	32,700	38.3	22,900	26.8	15,300	17.9	8,600	10.1	4,000	4.7	1,800	2.1
2033	34,200	32.5	30,200	28.7	20,100	19.1	12,200	11.6	5,800	5.5	2,800	2.7
2038	37,600	29.9	31,900	25.3	27,000	21.4	16,600	13.2	8,600	6.8	4,200	3.3

Derived from the 2021 release of the National ethnic population projections (Stats NZ, 2021b)

MĀORI ACCESS TO ARC AND PROJECTIONS OF FUTURE NEED

Access to healthcare, including ARC, involves a 'complex chain of events in a process' (Horsburgh & Norris, 2013). These start with either an individual or their whānau experiencing an acute event or a chronic increase in support requirements and identifying that ARC may be an option for care, and end with a person settling in as a resident (Figure 2). There are multiple factors that can enable or constrain access to ARC including physical location and financial resourcing through to acceptability of ARC facilities (both conceptually and as related to a particular facility). This section presents trends in access to ARC to provide a baseline to examine the bigger questions about why access may be different between Māori and non-Māori.

Figure 2: Steps in ARC access pathway

One-way to assess the proportion of Māori accessing ARC is to look at International Resident Assessment Instruments (interRAI) assessments. interRAI is a suite of comprehensive assessments, for use by trained assessors, usually health professionals. The interRAI assessments can be used to assess needs of people, with each assessment being designed for specific populations. Assessments can then be used for care planning, to tailor care to the needs of the individuals, and for administrative and planning purposes. interRAI tools are also used extensively to monitor and research populations – to both better understand characteristics of these populations and also evaluate the impact of interventions. Before interRAI tools were used in NZ, extensive consultation was undertaken with Māori to assess appropriateness to the NZ context and identify areas for adaptation (Meehan & Millar, 2014). In addition to this, the need for assessors to be culturally competent (in line with their professional requirements) to undertake the assessment in a culturally appropriate way, was further highlighted. Although it is unclear to what extent this is facilitated, monitored, or achieved.

In NZ there are five interRAI assessments used, one of which is the Home Care Assessment, used to assess the needs of community-dwellers, with one of the potential assessment recommendations being that ARC placement is appropriate. For those that are already residents in ARC, the Long-Term Care Facilities Assessment (LTCF) is required to be completed at least once every six months. The LTCF is administered to residents in ARC to evaluate their needs, strengths, and preferences. Although there is regional variation in the quality of this data (i.e. in some regions, LTCFs are completed for those that *may* require ARC placement but are not yet residents), it is likely that the variation in this aspect of data quality will affect Māori and non-Māori equally.

In 2019/2020 70,500 LTCF assessments were completed. Participants median age was 85 years and 5% of assessments were completed for Māori living in ARC (interRAI NZ, 2020). It is anecdotally known that older Māori may not feel 'safe' in mainstream ARC facilities. With 7.6% of the total population (2018) aged 65+ being Māori, and 5% LTCF assessments being recorded as those of Māori ethnicity, there is potential underrepresentation of Māori in ARC. This also assumes that the need for ARC is similar, however, given earlier onset of chronic comorbidity, increased disability across all ages, and greater prevalence of cardiovascular disease (Teh et al., 2014) for Māori compared to non-Māori, it is likely that there are even higher proportions of Māori with care needs that would make them eligible for ARC. These groups are likely to be, instead, currently living in the community with support of both informal and formal care. To explore this further we use national statistics to describe the population proportion of Māori living in ARC by age group.

Table 3: Total number of Māori in ARC over 5 years

	2014-2015±	2015-2016	2016-2017	2017-2018	2018-2019	2019-December*
55-64	67	133	186	196	184	163
65-69	75	148	168	183	195	157
70-74	116	192	244	253	243	185
75-79	143	248	286	347	351	265
80-84	125	197	289	287	301	228
85-89	77	149	191	230	244	198
90+	48	73	98	106	107	81
Total 55+	651	1,140	1,462	1,602	1,625	1,277
Total 65+	584	1,007	1,280	1,406	1,441	1,114

± Numbers may underrepresent as LTCF assessment processes were being rolled out.
*Data for a six-month period

Source: personal communication R. Abey-Nesbit from interRAI data 2021, years reported 01 July to 30 June.

This same data was used to assess mean age in ARC. For Māori, the mean age was 77.2 years [standard deviation (SD) = 9.4], and 85.9 years for non-Māori (SD=7.7) (Abey-Nesbit, 2021). The number of Māori living in ARC is fairly stable, potentially indicating a relative reduction in the proportion of Māori served by ARC. Table 3 shows total number of Māori who had interRAI-LTCF assessments from the 2014-15 year (July to July) to the first half of the 2019-20 year. This table includes those aged 55 and older. Although the numbers have increased modestly to 2018, considering the population denominator increase (Table 2) we suggest this represents a relative reduction in usage for Māori. Correspondingly, reduced (and inequitable) utilisation results in reduced – and inequitable - per capita expenditure for Māori compared to non-Māori in ARC (Ernst Young, 2019).

Using Statistics New Zealand population projections for Māori (Stats NZ, 2021b) and current interRAI data for 2019, 2.98% (1,441) of the total Māori population aged 65+ (48,372) reside in ARC. Looking ahead we were able to use the most recent population projections to identify the age group size estimated for Māori (Stats NZ, 2021b) and, assuming that the population proportion requiring ARC stays constant, estimate the projected numbers of Māori (Stats NZ, 2021b) requiring ARC by 2038 to be 4,986, an over four-fold increase on 2018/2019 residents.

Table 4 illustrates the estimated amount and rate of change over the next decades. One could pose the question as to how the increase in Māori numbers that is projected, a quadrupling, will be best accommodated in ARC? Overall, Māori are underrepresented in ARC; currently 2.98% of the 65+ aged Māori population live in ARC, whereas national estimates are 4-6% of all those aged 65+ living in ARC (Broad et al., 2013). This represents a disparity.

Table 4: Current and projected number of Māori in ARC, 2018-2038

Age group	Current			Projections 2038	
	Total Māori 65+ in ARC 2018-2019[a]	Total Māori Population 65+ 2018[b]	% Māori 65+ in ARC	Total Māori Population 2038[b]	Projected total in ARC 2038
65-69	195	20,445	0.95	37,600	359
70-74	243	12,705	1.91	31,900	610
75-79	351	8,232	4.26	27,000	1,151
80-84	301	4,302	7.00	16,600	1,161
85-89	244	1,965	12.42	8,600	1,068
90+	107	723	14.80	4,300	636
Total 65+	1,441	48,372	2.98	125,900	4,986

[a] *From 2019 interRAI data (pers comm R. Abey-Nesbit)*

[b] *From National ethnic population projections, by age and sex, 2013(base)-2038(Statss NZ, 2021b)*

STUDIES EXPLORING MĀORI ACCESS TO ARC

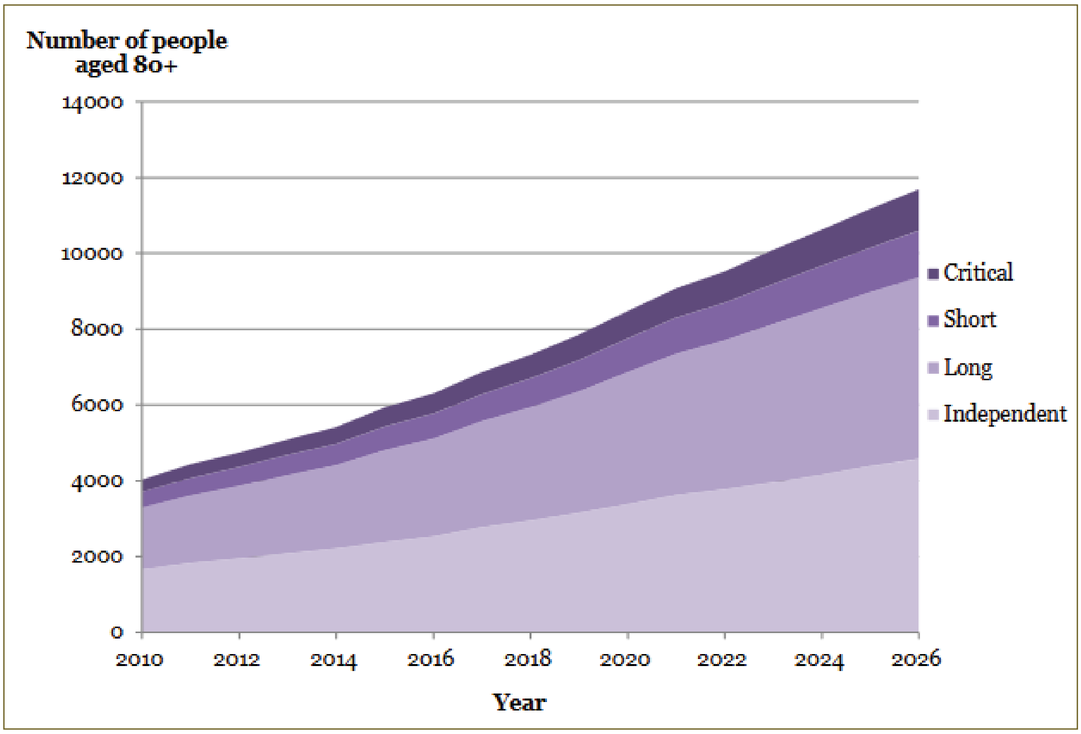
Further evidence of fewer Māori using ARC comes from the LiLACS NZ bicultural cohort study of advanced ageing. In 2020 over 400 Māori aged 80-90 years and over 500 non- Māori aged 85 years were engaged in the study using a population-based sampling frame with a 56% and 59% response rate for Māori and non- Māori respectively (Kerse et al., 2015). Complete ascertainment of follow up was achieved for 88% of the sample as participants gave permission for hospitalisation and mortality data to be accessed. Over 5.9 years of follow up, 22% of Māori and 41% of non-Māori accessed ARC at some time (Risk Ratio 1.77, 95%CI:1.39–2.23) (Holdaway et al., 2021), highlighting inequity of access. Whether the disparity represents better or worse care is not clear as the choice of intergenerational home care is consistent with Māori values (Edwards, 2010), thus this could represent better care. Supporting this idea, the risk factors associated with subsequent use of ARC differed between Māori and non- Māori, with older age and living alone predicting ARC use for Māori and dependence in more ADLs and poor/fair self-rated health predicting ARC use for non-Māori. This suggests that where there is whānau support, even Māori with high care needs are supported in the community, whereas for older Māori who are unable to access whānau support, ARC may be an option at earlier stages of the ageing process.

Considering those with dementia using ARC, analyses of data from South Auckland memory clinic shows that despite having greater severity of dementia, and more co-morbidities, Māori and Pacific patients had one third the risk of being admitted to ARC over five years compared to NZ Europeans (Cullum et al., 2021). Other studies have presented trends in ARC access and population characteristics but have not included ethnicity analysis (Broad et al., 2011, 2015; Robinson et al., 2021), perhaps because low numbers of non-Pākehā make it difficult to draw conclusions from the statistical analysis, although this was not discussed in the presentation of the report. This highlights the need to undertake work explicit in its intent in understanding access issues as relevant to Māori.

Another way of examining levels of disability and care patterns from the LiLACS NZ data is reported in the Intervals of Care Need report (Kerse et al., 2017). The frequency of need of assistance reflects the level of care required. Need for assistance was ascertained by personal interview with the participants, asking about Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) functions and the frequency with which they needed support. ADLs include activities such as toileting, feeding, dressing and showering, while IADLS include housekeeping, meal preparation, and the ability to take medications. For those with a daily need of assistance, more Māori (12%) than non-Māori (5%) were receiving neither home support nor ARC; this represents an inequity. Of Māori with a critical level of care need (requiring assistance several times daily, equivalent to hospital level ARC care), 45% lived in ARC compared with 75% of non- Māori at similar levels of care need.

Extrapolating the Level of Care Need proportions of the LiLACS NZ participants to the whole population and projecting forward to 2028 shows that the number of Māori with critical and high levels of care need will increase by 195%, and those independent by 174% (Figure 3). For non- Māori, an increase in the number of people with short, high and critical level of need over the same time period was 75% (Kerse et al., 2016). Data for the LiLACS NZ reports was drawn from earlier population projections (2011) than currently available. More recent estimates suggest even larger increases in the older Māori population. These data suggest that planning processes for appropriate investment in care processes should focus on the rapid population change with concurrent pressure on requirements for formal and informal family care for Māori. Currently the LiLACS NZ study shows inequities in access to that care, and lower use of ARC services, increasing the pressure on informal caring.

Figure 3: Anticipated changes in Level of Care Need (Kerse et al., 2016)



Source: LiLACS NZ 2010-11, Statistics NZ population projections 2011

This inequity was further explored by interviewing caregivers of participants engaged in LiLACS NZ (Kerse et al., 2016; Lapsley et al., 2019; Lapsley, 2018). More informal care was provided to Māori than non- Māori. The costs of that informal care were higher to Māori than non- Māori. This is an inequity as policies for compensation for that care, which can be argued saves the Crown up to 4.3 million annually for this small group, with costs being greatest for those caring for Māori men (based on LiLACS NZ data from 2014). Other methods and estimates of the costs of informal care estimate $7.3 bn (3.4% of GDP) to $17.6 bn (8.1% of GDP) to be the costs for the whole nation (Grimmond, 2014). The methods of calculation differed and both reports estimated that costs of informal care were higher for Māori than non-Māori (Grimmond, 2014). These findings suggest that Māori will be accessing more care in the community. However, it is unclear whether this is resourced in an equitable way and it is likely Māori make greater personal financial contributions and sacrifice to these care needs than non-Māori, for example by providing care for whānau rather than being in paid employment or undertaking education opportunities. Further research is needed to understand reasons for ethnic variation in access to ARC and an example of one current research project is included in Appendix 1.

QUALITY OF CARE FOR MĀORI IN ARC

There is limited publicly available information relating to the health outcomes associated with ARC for Māori. Information that is available has been reported here.

interRAI NZ produce annual reports that include some analysis of the data available within the interRAI data set. The areas of focus in these reports vary from year to year. From these reports alone it is difficult to understand how patterns in the quality of care may have varied, in general and for Māori specifically, however, findings from these reports which examined potential ethnic variation in quality, are reported here.

Māori ARC residents were reported as having similar levels of independence as Pākehā, with higher levels of independence than Pasifika and Asian residents (Technical Advisory Services Ltd, 2018).

In the 2017/18 reporting year, interRAI introduced the Quality Indicators for Aged Residential Care which show patterns of service delivery over time, and can be used to identify potential areas for review and improvement (Technical Advisory Services Ltd, 2018). The Quality Indicators include aspects such as pain, cognitive and physical function, medication and continence. They do not include measures such as resident satisfaction or culturally appropriate care. Reports are available to ARC facilities quarterly and provide them with the ability to monitor their own progress overtime, as well as compare to regional and national averages. Findings are separated out according to level of care. Analysis by ethnicity is not included which is understandable at a facility level as, due to low numbers of non-dominant cultures, there would the potential for reports to de-anonymise individuals within facilities. Ethnicity analysis could, however, be included in the national quarterly reports, which is not currently done.

Medications are used for therapeutic benefit to improve outcomes related to chronic co-morbidities but can also increase the risk of harm. One of the interRAI Quality Indicators was appropriate medications. The medication quality indicator 'triggers' those receiving nine or more regular medicines, and experiencing at least two pre-defined symptoms (e.g. dizziness, shortness of breath), indicating those at high risk of medicines-related harm. This indicator was more likely to trigger for Māori and Pasifika people at an earlier age than non-Māori, non-Pacific (Technical Advisory Services Ltd, 2018). This parallels findings in the general older adult population in NZ where these same groups experience polypharmacy at a younger age (Health Quality & Safety Commission, 2019a), although this finding must be viewed in the context of the younger Māori population in ARC compared to non-Māori (Abey-Nesbit, 2021).

The Commission has a focus on improving medication safety in ARC, and one particular area of focus is the use of antibiotics. In 2017, the number of residents prescribed all systemic antibiotic (per 100 people in the population) was higher for Māori than European/other (67.2 and 64.5 respectively) (Health Quality & Safety Commission, 2019b). In contrast, Māori (and Pasifika) in ARC are less likely than European/other to be prescribed antibiotics for urinary tract infections (UTI) (Health Quality & Safety Commission New Zealand, 2020a). The overuse of antibiotics for the treatment of suspected UTI in ARC is a specific area of focus for the Commission and it is unclear whether this variation represents under prescription in Māori, or over prescription in European/other.

One study explored ethnic variation in oral health and found no difference between Māori and non-Māori ARC resident rates of dental caries (Thomson et al., 2018), despite Māori ARC residents being significantly less likely to have had access to formal dental examinations than their non-Māori counterparts (Schluter et al., 2020).

Other NZ studies have presented trends in the ARC population health and functional status, and clinical outcomes but have not included ethnicity analysis (Boyd et al., 2011; Carryer et al., 2017; Chatindiara et al., 2020; Connolly et al., 2014; MacDonell et al., 2016). The Commission report 'A window on the Quality of Aotearoa New Zealand's Health Care 2019' (Health Quality & Safety Commission, 2019c) focused on equity including equity across the life course, however, did not include information relating to ARC.

As above, this highlights the need for ARC researchers, those that develop and deliver ARC, and policy makers to be intentional in their work to ensure equity of access and quality care is assessed, and measures put in place to achieve equity when disparities are found. interRAI NZ maintain an extensive database that has the potential to effectively monitor both access to, and quality of, care for Māori in ARC. If robust analysis protocols were developed, these could provide a method for understanding both current ethnic variation in the quality of care provided in ARC and to evaluating quality of care for Māori over time. These protocols will also need to take into account Māori data sovereignty and the ethical issues surrounding this (Te Mana Raraunga, 2018).

SUMMARY

The Crown has an obligation to ensure equity in access to health care and health outcomes for Māori and that information is available to adequately examine whether equity is achieved. Māori appear underrepresented in ARC, and current institutional analyses do not allow an equity focus in examining routinely collected interRAI data. The demographic ageing of the Māori population is happening faster than for non- Māori and even with the underrepresentation the number of Māori accommodated in ARC will increase four-fold over the next two decades.

Training and retaining a culturally safe workforce in ARC | Te Whakangungu me te mau i te ohumahi tika i ARC

> **Curtis et al (2019) write** *"Cultural safety requires healthcare professionals and their associated healthcare organisations to examine themselves and the potential impact of their own culture on clinical interactions and healthcare service delivery. This requires individual healthcare professionals and healthcare organisations to acknowledge and address their own biases, attitudes, assumptions, stereotypes, prejudices, structures and characteristics that may affect the quality of care provided. In doing so, cultural safety encompasses a critical consciousness where healthcare professionals and healthcare organisations engage in ongoing self-reflection and self-awareness and hold themselves accountable for providing culturally safe care, as defined by the patient and their communities, and as measured through progress towards achieving health equity. Cultural safety requires healthcare professionals and their associated healthcare organisations to influence healthcare to reduce bias and achieve equity within the workforce and working environment."*

The ARC workforce is central to the resident wellbeing and outcomes in the sector. It is important that the workforce is well-trained, and that training is relevant to needs of residents, including the needs of Māori and their whānau. During the early 2000's a survey of all ARC facilities showed that very few Māori residents were cared for by Māori staff with a large regional variation in Māori staff and residents (Kiata et al., 2005). The ARC industry profile (McDougall, 2020) is silent on ethnicity of residents and staff. It does outline that 40%, 39%, 17% and 5% of caregivers, registered nurses, clinical managers and facility managers respectively are working on migrant temporary or permanent visas. The majority of these migrant health workers come from the Philippines and India (McDougall, 2020).

Based on evidence from other health settings in NZ, to develop an appropriate workforce that contributes to achieving health equity, there should be explicit training relating to health equity, te Tiriti o Waitangi, cultural safety, Māori health and anti-racism (Cormack et al., 2018; Curtis et al., 2019; Curtis & Reid, 2013; Jones et al., 2010; Springer et al., 2018). Lack of cultural congruency between providers and patients, or in this case carers and residents, has also been shown to be to be a barrier to good quality care for Māori (Jansen, 2009; Jansen et al., 2008).

Although these expectations are well documented and evidenced, and often form part of health professional standards of practice (Came et al., 2021; Medical Council of New Zealand, 2019; Pharmacy Council of New Zealand, 2015), there is variable uptake and monitoring of action and outcomes across the health sector. In publicly available training documents for the ARC sector, there is a lack of inclusion of considerations relating to Māori and health equity. The newly developed Careerforce modules which focus, separately, on dementia, palliative care, and complex conditions, do not advertise that these contexts will be discussed in relation to Māori or health equity. This is in spite of clear evidence that culturally appropriate care is critical for older Māori palliative and dementia care (Dudley et al., 2019; Moeke-Maxwell et al., 2020), and our knowledge that Māori are more likely to experience chronic, complex comorbidity than non-Māori (Ministry of Health, 2019; Robson et al., 2007).

Clinical care guides also support workforce training. The 2019 Commission frailty care guides, designed to support nurses deliver care in the ARC (and community) setting, have used te reo Māori in the titles throughout the document. Older Māori are at higher risk of frailty than non-Māori and this increased risk is associated with worse outcomes (Abey-Nesbit et al., 2020). Recent literature has presented the multi-dimensional experience of frailty for older Māori and that this experience is characterised by an intertwining of deficits and strengths (Gee et al., 2021). Although the importance of cultural considerations in general were mentioned, the impact of frailty on Māori and the need for pro-equity solutions which are responsive to the multi-faceted needs of Māori, were not explored. Incorporating these aspects into clinical care could improve health-related outcomes, as well as resident and whānau acceptability of ARC as a care option, allowing Māori to benefit more from the care provided by ARC. There is the potential that Māori-led training organisations may be able to support workforce development in this space to ensure those that work in ARC are trained in culturally safe care, as relevant to Māori.

Nursing staff in ARC lack pay parity with nursing staff working in acute hospital and primary care settings, putting pressure on attracting and maintaining high-quality staff. ARC pay parity for registered nurses would follow a recent increase in caregiver staff rates of pay as a result of pay equity settlement in 2017 (Ministry of Health, 2017a), and would recognise the value of this workforce.

ARC funding | Te Pūtea a ARC

Many types of ‘public’ healthcare in NZ are delivered by private providers that are contracted for the services they provide. This includes general practice, pharmacy and the ARC sector. There is increasing privatisation within the ARC sector in NZ, a move to increased size of facilities which produce effective economies of scale, and the addition of ‘premiums’ to costs of living in ARC, a number of these changes driven by the fact the ARC sector funding has remained relatively stagnant despite the increasing acuity of residents that live there (Boyd et al., 2009; Ernst Young, 2019).

The evolution of ARC ownership from mainly publicly owned and run, to religious and welfare and private ownership with public subsidy (Ashton, 2000), has further evolved to care homes in NZ mainly being owned and run by private for-profit providers.

The ARC profile report for 2019 prepared by the Aged Care Association (McDougall, 2020) outlines 667 facilities with 39,568 beds with marked regional variation in bed type, facility ownership and subsidy use.

Table 5: ARC ownership by facilities and beds

Ownership	Percent facilities	Percent beds
DHB	1.3%	0.3%
Individual or minor group – Charitable	12%	11%
Individual or minor group – Private	37%	27%
Major group – Charitable	9%	10%
Major groups – Private commercial	21%	24%
Major group – Publicly listed	19%	28%

Derived from the Aged Residential Care Industry Profile 2019-20 (McDougall, 2020)

The type of beds available range across rest home (24%), hospital, dementia, psychogeriatric, and Young Persons with Disability and the ownership is mainly in the private sector, with major groups dominating the individual or minor group category. The types of bed offered by providers are predominantly rest home and hospital level care with an increasing number of beds being 'swing' or dual service beds. Care facilities are also getting larger and there is marked regional variation in size, ownership type and offering of occupational rights agreement (ORA) beds. ORA are the types of contracts that provide retirement village living and are now moving to allow ARC beds to be 'purchased' or rather purchase the 'right to occupy' the bed.

PUBLIC FUNDING OF ARC

In New Zealand, Aged Residential Care is administered through the "Aged Residential Hospital Specialised Services Agreement" (ARHSS) between each provider and their respective DHBs, and the daily rates paid (after any contributions from resident) differ from facility to facility. The corresponding document "Age-Related Residential Care Services Agreement" (ARRC) deals with those who are in non-hospital level beds. The 2019 Aged Residential Care Funding Model Review (Ernst Young, 2019), contains summary information about costs. New Zealand has a relatively high per capita use of ARC compared with other OECD nations, and spends 0.8% of GDP on ARC, less than other OECD countries.

DHBs spend around $1.1B per year on ARC for older people, with residents contributing a further $0.8B (excluding extra charges). Providers are able to charge extra fees (or 'premiums') to residents for extra services or accommodation options (premium room services up to $37.50 daily) and in 2019, most facilities offered these premium services (McDougall, 2020). Nearly all ARC residents make a contribution towards the costs of their care, with means-testing determining the level of contribution required. The means-testing regime is reported by the Aged Care Association to be relatively clear, with individuals able to understand if they will be required to make the maximum contribution or not, in contrast to the resident and whānau perspectives relating to the perceived 'hidden' costs of premium services, discussed in more detail in Section 2.

The proportion of residents making the maximum contribution towards the cost of their care is increasing up from 30% in 2010 to 37% in 2019. For the vast majority that enter ARC, the weekly payment is far in excess of their previous weekly costs of living. For those that own their own home, and do not have a partner still living in it, the costs often have to be met by the sale of their homes. The proportion of ARC facilities that have extra charge or ORA arrangements with residents is increasing and, in those facilities, around two thirds of residents pay these charges, a higher proportion than five years earlier. DHB subsidies then 'top up' any remaining difference between private contributions and the cost of an older person's care. Personal contributions to care costs and the means-testing regime can create a barrier for older people to return home, and through the interaction with DHB strategies for care of older people, create inequities across DHBs in personal contributions towards the costs of care (Ernst Young, 2019).

Health Quality & Safety Commission | Kupu Taurangi Hauora o Aotearoa

The Commission is a government agency with the vision of 'quality health for all'. The Commission's strategic priorities are:

- improving experience for consumers and whānau;
- embedding and enacting te Tiriti o Waitangi, supporting mana motuhake;
- achieving health equity;
- strengthening systems for high-quality services (Health Quality & Safety Commission, 2020b).

In 2018, the Commission began the journey of partnering with the ARC sector to support the development and implementation of quality improvement within the sector. To date, the Commission has supported the ARC sector with various pieces of work including videos showing what is important to residents and whānau when they enter the ARC system in NZ, guidance around discrete clinical issues such as urinary tract infection management and COVID-19 management, and the development of a quality improvement tool kit tailored specifically for ARC. The Commission has also supported short-term (three-month) quality improvement projects in four ARC facilities. This current report is the first piece of Commission work which explicitly looks at Māori, the role ARC plays in their lives, and looks to seek out a vision of quality care for ageing Māori.

The Commission's Aged Residential Care Quality Improvement Programme Charter (Petagna, 2018) stated some goals relating to Māori and equity. These include that 'equity is prioritised as a key domain in each workstream' (Petagna, 2018) and to advocate for multi-dimensional focus on equity in ARC. In the short-term this included understanding unwanted variation in outcomes, and suggested partnering with interRAI (TAS) to enable this. It also stated that quality improvement measures would include equity analysis.

The multi-dimension focus included workforce development to build the capability of the ARC sector to provide culturally safe care. In relation to Māori specifically, there would be Māori 'representation' in leadership group established to inform the strategic direction of the programme and enable whakawhanaungatanga (establishment of connections). Engagement with Māori providers, residents and whānau to improve the Commission's understanding of considerations required was also identified as important to address. The main way in which these have been responded to are through the sharing of stories relating to equity and Māori health from 'exemplar' facilities.

Since the initial charter was published, the programme plans have been updated twice. The programme now has the following aims:

- Promote the voice of the consumer and whānau to increase the focus on resident-centred care.
- Support better use of data and measurement for equity and quality improvement.
- Establish a quality improvement network to support a quality improvement culture.
- Develop evidence-based tools and resources for shared learning.
- Develop capability in leadership, teamwork, and communication.
- Consider the impact of equity on the ARC sector, with a focus on understanding.

During 2017/2018, the Commission conducted a series of regional workshops around NZ which enabled invited participants to contribute to the conversation regarding the future of quality improvement in ARC and the role of the Commission in supporting this. The Commission's strategic priorities (including 'improving health equity') were presented and facilitated discussions took place. The key discussions and themes have been presented on the Commission website. There is no mention of Māori or health equity in these summarised discussions (Health Quality & Safety Commission, 2018). The extent of Māori participation in these events was not documented in the corresponding site on the public website, however, this, and equity-related discussions may be available in internal reports. This current report is one of the steps the Commission has made to towards exploring Māori responsiveness in the ARC sector and the impact the sector has on health equity.

ARC and Indigenous populations in Australia, Canada, and the United States | ARC me ngā taupori iwi taketake i Ahitereiria, Kānata me Amerika

The following section explores ARC services for Indigenous people in Australia, Canada and the United States, countries where, similar to NZ, Western health care models predominate, and there are disparities in health outcomes between Indigenous and non-Indigenous populations. It presents information relating to care preferences and expectations, lived realities of Indigenous people and their whānau in care, and briefly touches on the implications of resourcing constraints.

A study undertaken in Australian Capital Territory (ACT), Australia, interviewed 98 older Indigenous people (45 years plus), at a time when there were just five residents of Aboriginal ethnicity in the state living in ARC, out of the total 1315 ARC residents (Dance et al., 2004). None of the participants reported a current need for ARC. When asked of future preferences for care options, all participants preferred community-based care to residential care options. Almost half of respondents indicated they would prefer care to be delivered by an Indigenous organisation (43%), with 24% preferring a non-Indigenous provider, and 28% with no preference (Dance et al., 2004). Similar findings were reported in a recent study involving 336 Aboriginal and Torres Strait Islanders from rural and urban regions in New South Wales which looked at access to and preferences for disability and aged care services (Larke et al., 2021). The majority of those interviewed would prefer to access Aboriginal Community Controlled Health Services (ACCHS) over mainstream services, with this preference being more significant in the rural cohort than the urban cohort. Cultural alienation was seen to be the major disadvantage of mainstream services while the preference for ACCHS was driven by the sense of Indigenous ownership and less perceived discrimination.

A more recent scoping review explored health and social care needs, preferences and priorities of Indigenous older adults (and their carers) living with multi-morbidity (Webkamigad et al., 2020). Although this review specifically excluded ARC, the findings may be of relevance when we consider future planning for Māori and ARC. The review identified five areas of need: ensuring services were accessible, improving social support networks, building community capacity, a wellness-based approach, and preservation of cultural values (Webkamigad et al., 2020). A systematic review which explored the care needs of Aboriginal and Torres Strait Islanders in ARC was undertaken (Brooke, 2011). Similar to other studies, this review found that the care provided had to incorporate cultural values in addition to physical and psychological care. The authors discussed the need for a culturally safe workforce to provide the care which included power-sharing and self-empowerment at its core. This review included a list of recommendations to ensure culturally appropriate care that was structured around the following topics: care and communication, palliative care and death, activities, and environment (Brooke, 2011). In reality, despite government policy focusing on the integration of culturally appropriate care into care practices more generally, another study found this was not seen in practice by Aboriginal Australian residents (Sivertsen et al., 2019). Participants described marginalisation of Aboriginal culture within the ARC setting (Sivertsen et al., 2019) These findings are similar to those in a study with American Indian elders and families of those in LTC where participants perceived a lack of information, understanding and respect by care providers (Hendrix, 2003). This highlights the need for explicit policy about culturally appropriate care to influence action with the hope that this will lead to improved outcomes in the ARC setting.

Te Reo Māori is one of the three official languages of Aotearoa and is spoken at a conversational level by approximately 20% of Māori, and to some extent by up to 50% of Māori, although there is wide regional variation in these figures (Stats NZ, 2020). Research exploring the importance of the use of native language in ARC has been undertaken in Wales (Martin C. et al., 2019). English acculturation of the Welsh has occurred and Welsh language revitalisation helps to inform a Te Reo Māori path in NZ. This study showed that cultural congruence positively impacted on wellbeing with language congruency having even greater positive effect on wellbeing.

The importance of a culturally competent, culturally safe ARC workforce has been discussed earlier. In Hawaii a training programme was developed to support care home operators and staff that focused on nine clinical areas (Nishita C.M. et al., 2014). The training was proactively tailored to be 'culturally responsive', utilising external consultants to develop training packages. The evaluation of the training showed that clinical knowledge improved although changes in cultural responsiveness and related outcomes were not reported.

Understanding funding structures and implications is an important part of the discussion relating to ARC and Māori. It needs to be considered within the context of the changes resulting from the Health and Disability System Review generally, as well as the funding of the new Māori Health Authority. In the United States, the Indian Health Service (IHS) operates within a budget annually approved by Congress, to deliver care for approximately 2.2 million American Indians and Alaskan Natives (Indian Health Service, 2017). This level of funding is known to be approximately half of what is needed to provide appropriate level of health services (Goins et al., 2010). Despite the increasing need for ARC in this population, funding for ARC largely falls outside the IHS budget and relies on less sustainable funding sources (Goins et al., 2010). Although IHS providers have a desire to deliver ARC to their population, lack of financial resources has been identified as a major barrier to IHS developing LTC services. Required resourcing relates to the initial start-up, as well as ongoing funding to ensure sustainable service delivery (Goins et al., 2010). Research undertaken in South Australia with Aboriginal carers and residents in ARC found that lack of resources directly impacted on care, including high turnover of Aboriginal staff members (Sivertsen et al., 2019).

SUMMARY

In considering the projected increasing numbers and need for care for older Māori, the inequity in access to and funding of community care, and lower proportion of Māori residing in ARC, the literature supports development of explicit policy ensuring culturally safe models of care as vital to the ability of Māori to thrive in ARC in Aotearoa. These care models are likely to be both inside and outside of the current ARC structures and require a skilled, sustainable and appropriately remunerated workforce that delivers clinically and culturally excellent care.

In addition, processes to ensure quality of care is assessed with an equity lens should emphasise equity in quality outcomes for Māori in all care settings. This includes the need to report cultural responsiveness of care and measure the outcomes that matter most to whānau. Measurement of cultural responsiveness and Māori flourishment have been articulated and frameworks for this type of outcome analysis have been developed (Durie, 2014; Te Pou Matakana, 2015) which could be used to guide development in the ARC sector.

SECTION TWO | WĀHANGA RUA

Experiences of care, and case studies, for Māori in ARC | Te wheako tauwhiro, he kēhi mō te Māori i ARC

In this section, people who have roles in older adult and ARC care provision and research were asked to contribute their experiences and stories on the broad topic of 'Māori and ARC'. While each contribution focuses on different aspects of this topic and raises different questions, there are also some areas where the stories come together and similar challenges and opportunities are identified.

Contributors were identified through author networks and although there is a vast collection of thoughts presented, we are aware this will not capture the broad thoughts and knowledge relating to the topic of ARC and Māori across Aotearoa. We also acknowledge that the direct voices of those that need to be centred in this conversation – older Māori and their whānau – is not captured to a great extent and recognise this is essential for future work.

Sharing experiences of caring and care for Māori in ARC | Te tuari wheako tauwhiro mō te Māori i ARC

Georgina Martin *(Te Rarawa, Te Aupouri)* has a nursing and public health background. In the early 1990s she worked alongside West Auckland-based Te Whānau o Waipareira Trust to establish a mobile medical service to all kohanga reo in the area and a GP practice in Waipareira. Those early experiences led to the development of networks for her within a Māori community intent on finding ways to improve whānau wellbeing. She has lived experiences of working with and caring for kaumātua both at home, and in ARC. In 2016, Georgina joined Waipareira's Wai Research. Their translational approach to research is about improving understanding and ensuring knowledge is used to build better services for whānau in the future. In this contribution, Georgina shares findings from work undertaken at Wai Research about kaumātua, as well as her own personal journey of engaging with the ARC sector to care for her mum and aunty.

ARC AND KAUMĀTUA CARE – TIME FOR NEW MODELS OF CARE FOR KAUMĀTUA

Māori and ARC do not sit easily together. For some, it is not an option. Pakeke Māori and kaumātua who find themselves in need of care or 24 hour supported care, really only have two options; to stay in their home and live with the support of community caregivers and whānau or alternatively when their health needs become too overwhelming for caregivers or their safety compromised, then ARC or Long-Term Care (LTC) becomes a very real possibility.

Our changing demographics with smaller family units will likely affect everyone alike be they small communities in rural areas or urban settings. This suggests that community support and whānau support for care may not be possible at some point unless there are significant changes and support provided to develop new service models allowing for "ageing in place". Scoping work completed by Te Rarawa in the Far North of Aotearoa in 2014/15 identified a preference for ageing in place and community care where possible (Henwood, 2017). These findings were also expressed in research undertaken by the Whānau Ora Commissioning Agency in 2017 and 2018 (Allport et al., 2018). If ARC is available and accessible, questions then arise for whānau about cost, choice of provider and their location, cultural support, accessibility for whānau and quality of care to meet the goals of both the resident and wider whānau.

Differing use of LTC between Māori and non-Māori and delayed entry for Māori, possibly due to care provided by whānau, has been identified in a recent study (Holdaway et al., 2021). The role of kaumātua commands special attention amongst Māori communities and their whānau. This Māori worldview of kaumātua frames the thinking behind their care as they age. It is important however to understand that urbanisation of Māori in the early 1950s and 1960s saw subsequent generations become westernised in their thinking over time whereby cultural values may have been influenced by different attitudes and learnings. In parallel, the revitalisation of the culture and language spurred by Māori academics, scholars and community leaders have reinforced Māori identity. It will be important to understand the expectations of those who have been nurtured by this revitalisation over time, as they will likely be different to other cohorts requiring ARC in the future.

Te Whānau o Waipareira Trust in West Auckland is a grassroots Māori organisation established in 1984 and initially born of the ongoing hopes and aspirations at the time of whānau who lived in West Auckland as part of urbanisation. All of those who established Te Whānau o Waipareira and who still live in the rohe are now kaumātua themselves. Many of these whānau came from remote rural areas and belong to various iwi or tribes throughout Aotearoa, brought together by the need for work, better education and the need to house their whānau (Wai Research, 2017). This happened across many towns and the main cities, particularly those that could offer work opportunities (Williams, 2015). West Auckland became home to many whānau. In 1980, prior to the establishment of the Trust, Hoani Waititi, a pan-tribal marae, was established. This came about through collective action with the help of whānau, local schools, wider community and iwi groups from around Aotearoa. This was followed by kohanga reo, the first kura kaupapa Māori, and wharekura which cater to the spectrum of education from early childhood through to secondary school. As part of the marae complex, kaumātua also lived in small whare, adjoining the marae. This model still exists at Hoani Waititi and similar models can be seen across Aotearoa in both urban and rural settings. Kaumātua participate in the day-to-day activities of the marae and are respected for their knowledge, their link to the past and the support they bring.

As you wander through the properties associated with Te Whānau o Waipareira, founding kaumātua are recognised in the photographs you see, naming of rooms, team activities and spoken history. In addition, there is a large group of kaumātua who form the kaumātua roopū and support all manner of events and functions from a tikanga perspective. These roles are also carried out in other areas across Aotearoa by various marae and organisations. This all serves to demonstrate the cultural importance of kaumātua both in the urban setting of Waipareira and wider community, from their roles in whānau to the highest level of Government, particularly where they are skilled in the practices of Te Ao Māori. The role of kaumātua is not diminished and consequently admission of a kaumātua to an ARC home can be a painful decision to make for everyone concerned and not one to be taken lightly (Allport et al., 2018). Furthermore, some urban-based kaumātua are choosing to return to their ancestral lands. These are often remote, with reduced access to quality housing, a lack of public transport and health and social services, yet rich in social, cultural and spiritual connection (Allport et al., 2018). Waipareira has extended its reach through a wider network underpinned by the Whānau Ora Government policy platform to the North Island wide Whānau Ora network. Waipareira has established backbone services including Wai Research, servicing Waipareira Trust and the Whānau Ora Commissioning Agency.

A study undertaken in 2017-2018 by Wai Research on behalf of the Whānau Ora Commissioning Agency, was a chance to check what was happening across the Whānau Ora network of 80+ providers in relation to kaumātua services and kaumātua aspirations for ageing well. Having been established in 2014 exploring what was happening for kaumātua was a new journey for the Whānau Ora Commissioning Agency.

A literature review showed a lack of Kaupapa Māori services in general and no such services for ARC. Māori have no choice when accessing services to be cared for in a predominantly westernised model of care (Wood, 2017). Other findings showed that there was lack of Whānau Ora funding across the network of Whānau Ora providers for specific kaumātua services. A few providers received time-limited programme funding for some initiatives such as exercise but little else, thus limiting opportunities to create a range of supportive services. Furthermore, kaumātua views about ARC showed a predominant resistance to care in such facilities, independent of whether kaumātua resided in urban or rural areas (Allport et al., 2018). In a recent study, predictive factors for Māori entering LTC were living alone, and older age, with European entered LTC at almost twice the rate of Māori (Holdaway et al., 2021). Research to date highlights the need for ARC models of care that understand and support Māori values and needs (Allport et al., 2018). Having had the opportunity to discuss care with whānau across the North Island, there are clearly different needs between urban and rural areas (Allport et al., 2018).

A PERSONAL JOURNEY

Speaking from personal experience, as someone who has cared for kaumātua and supported them in ARC, it is very difficult for kaumātua to enter a setting that is devoid of cultural and spiritual elements. One of the most difficult aspects of kaumātua entering ARC particularly is when they are cognizant of their surroundings. Comments such as "there are no Māori here" highlight the social, and cultural, isolation that can occur when Māori are removed from their normal place of living. The loss associated with not hearing Māori spoken around them can be profoundly sad and difficult for both the kaumātua and whānau to reconcile. The importance of visitors who can share familiar kōrero becomes crucial to helping manage the grief process that goes with entering the ARC setting.

Should current ARC homes incorporate different ways of working to accommodate kaumātua needs? Potentially, yes. ARC facilities could enhance their practices with the appropriate support; however, it isn't the only solution. What the Kaumātuatanga research showed was there is a need for more Kaupapa Māori services to be developed (Allport et al., 2018). Thought needs to be given to accessibility both geographically, cost-wise, and in the community support aspect that is required to keep kaumātua in the community for as long as possible, if that is their wish.

Currently ARC operates as a public/private partnership. My lived experience of supporting kaumātua in ARC is that this funding partnership is not particularly transparent. Higher needs lead to additional costs which need to be met by the resident. There are also a number of other potential barriers for whānau.

Assessment for care

Before entering ARC, a person needs to undergo a comprehensive assessment to determine their eligibility for care. It is not a given that a kaumātua will be seen as eligible for ARC, so then the question arises about community care and support. What that looks like can vary in much the same way that ARC facilities can vary.

Choosing an ARC facility

If someone is assessed as requiring ARC care, some decisions need to be made about a suitable ARC provider. This is essentially a time to assess the quality of providers. In the case of my whānau, this entailed seeking recommendations, talking to administrators at various ARC providers and viewing facilities. However, whānau may not have the ability to travel around viewing providers or may have a limited understanding of the approaches being taken in care. Options may also be limited for care therefore compromises might have to be made, balancing things like location, and the quality of facilities or the quality of care delivered.

Location of ARC services

Those in rural areas have limited ARC options if any and may have no choice but to be cared for some distance from whānau and their homes. In areas such as the Hokianga, whānau may have to travel long distances to visit whānau in ARC. Urban areas may offer more options closer to whānau.

Means-testing

Prior to kaumātua moving into ARC, 'means-testing' occurs. Kaumātua are assessed on their financial means to determine who should receive a subsidy. This is based on factors such as the extent of their assets, such as owning a home, and whether they have a living spouse who resides in that home. This does not just relate to current assets; if the home has been sold at some point, the Ministry of Social Development (MSD) can still claw back the value and use it as a determination of eligibility for subsidy. If a kaumātua owns a home, it may need to be sold to meet the mandated weekly contribution costs of care.

Through the course of work undertaken by Te Whānau o Waipareira repairing homes for kaumātua, we noted there were often additional generations of whānau living in the same home due to the costs of renting elsewhere (WaiResearch, 2018). The means-testing effectively applied to *whānau*, could result in the loss of their key asset and lead to displacement of younger generations of whānau from their homes. It is not unusual to find Māori living collectively in one home with multiple generations. This is exacerbated further by the shortage of housing or costs of renting and, if the multi-generational home is required to be sold, whānau are returned to this situation. There may be little choice in those instances, but for kaumātua to remain in their homes with the support of their whānau around them. This, however, would require appropriate community support to be available.

Our whānau flagged that the home in which our mother lived was situated on whenua Māori (Māori land) handed down and in a Trust to protect the land from easy alienation. History would show that the Māori Affairs Amendment Act 1967 legislation had required a change of Māori land title to General land which opened the land up to alienation. These details are not recognised by MSD in assessing ownership of property for the purpose of determining whether a subsidy can be claimed for care. In fact, we were treated as though we were hiding assets despite presenting all documentation to show why the land was in Trust for future generations as part of a cultural succession of land. Land in this case was not treated as a commodity to be sold, if at all possible. We were left with two options: to consider the sale of land to pay for our mother's care or for the members of our whānau to personally pay for the costs of ARC.

Hidden costs

While subsidies are available for those who do not have assets, the level of care is likely to be the most basic available, such as a basic room and shared bathroom facilities. In a facility with mixed genders and residents with varying cognitive conditions, dignity can be difficult to maintain. Any further additions such as a bigger room or ensuite, if available, would incur extra costs. A resident would also have the majority of their superannuation

payments paid to the provider. For those that need to pay, the cost could be an additional $1100+ per week. What the information fails to clearly lay out is that ARC is a privatised system where all extras come at a cost and these can be numerous and over and above the outlined weekly costs for the room chosen for the resident. Our whānau were left feeling that our mother had been cut off from the general population at a time of great vulnerability – to now adapt quickly and live life in a whole new system.

An interesting phenomenon is the use of the term hospital level care. This in no way replicates hospital care in a public hospital from a lay perspective and is somewhat misleading. Doctors are not on site or readily available. It may simply mean the presence of one registered nurse on the shift. If there is a need for any extra doctor visits over and above the standard schedule at the ARC facility (and these can vary between facilities), these incur extra costs. ARC residents who are admitted to public hospital for acute illness, are not necessarily entitled to the same hospital services on discharge as a member of the general public such as dietician or dietary supplements which again can incur extra costs. In addition, any ambulance transfers must be paid for. If the resident has paid an annual subscription for ambulance services in the past, these will no longer apply.

Legal documentation

Having Enduring Power of Attorney (EPA) documentation for health and also property is important at the outset. We needed to update those for our mother and did so while she was still cognisant. Her will was also reviewed and amended. Research had shown that many whānau did not consider such documents (Allport et al., 2018). It can be stressful to have to complete these when kaumātua are under stress and more so if others such as a medical officer need to take the role because the resident is not cognisant and decisions are needing to be made. Furthermore, the paperwork to be completed for the ARC facility and MSD for subsidy is considerable. This took a significant amount of time on our part. Our mother's bank account had been made joint some time earlier so that in the event she passed away, her account would still be accessible. It's fair to say that there is a high level of trust required from those with EPA and access to her accounts.

Taking leave from the ARC facility

While we were able to take our mother for overnight stays when we had sufficient numbers who could help with her care, we did not qualify for any equipment to help manage her lifting and moving about because she was in care. The onus fell on the wider whānau to hire or buy the equipment needed. The range of equipment for hire is very limited and we were told that often it was reserved for hospitals. The whānau looked to source equipment overseas but this came at considerable cost. The whānau began to wonder about the cost and quality benefits of having our kaumātua remain at home versus the real costs of remaining in ARC.

New models of care

It seems that the time is right to explore new models of care for kaumātua. Research has shown that there are a variety of responses needed and there are differences between those in rural areas compared to urban areas. The provision of ARC services for Māori has been seen as limited but with an impending Māori Health Authority announced, there are opportunities to innovate and develop models of care that may be more appropriate. Whānau Ora offers a whānau centred approach, working in a collective way to support whānau to achieve their outcomes. In this case the focus would be on supporting whānau to ensure quality care for their kaumātua through all stages of care. Care models do exist overseas and outside the health and disability space in NZ (Maybin et al., 2019; Wai Research, 2019). The lessons learnt and stories heard of whānau caring for our kaumātua have only heightened the desire to find better ways to honour our kaumātua in care.

With the advent of new health technologies, there are opportunities to improve home care. Innovation is happening in the development of equipment but more could be done in the procurement area to secure a better standard of equipment for community use. One of the challenges for our whānau was the need to lift our mother at home and prevent damage from moving her. Her dying wish was to be at home when she passed and this was achieved with the cultural and spiritual practices that encompass the time of passing. As a whānau we were fortunate to have that happen and recognise the difficulties for others in achieving that outcome. The ARC home had to work closely with us but we remain grateful for their support of her wish in releasing her back to the whānau before she passed.

This has taught us that there have to be better ways. That ARC suits some sectors of the population but is not the full answer. Growing a much stronger care giving workforce and resourcing for "ageing in place" of kaumātua offers opportunities for qualifications and employment and recognises the informal care that already often exists within communities and whānau. The call for "by Māori for Māori" services is one long hailed as a way forward for services which better meet the needs of Māori, and the aspirations they have for whānau, including kaumātua.

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MĀORI KAUMĀTUA IN AGED RESIDENTIAL CARE: WHAT ARE THE CHALLENGES? WHAT ARE THE OPPORTUNITIES?

The challenges to Māori kaumātua using ARC relate to their own past experiences and current perceptions, as well as the lack of availability of culturally centred residential care for kaumātua. It is well known that Māori thrive in culture-centred environments such as kohanga reo, kura Kaupapa and with Māori health and social support services. In such organisations the environment, which encompasses the workforce, communication processes, art, and interior and exterior design, is welcoming for Māori. There is a place for the *care* provided by ARC but there is a need for a different model of service provision to meet both care and cultural needs of Māori kaumātua and their whānau. In this section we share stories of perceptions and experiences of ARC from kaumātua, whānau and staff members of the Rauawaawa Kaumātua Charitable Trust (Rauawaawa).

"Not at all" was a common response to the question "When is it the right time to become a resident of ARC?" Fears of being admitted to an ARC facility included being forgotten by their whānau, not being cared for properly—with kaumātua citing publicly known instances of physical abuse of ARC residents by staff, having nothing Māori to make them welcome, and being lonely because of a lack of Māori staff or residents in the ARC facility. Kaumātua need to see, hear and feel the presence of Māori cultural values and practices including whanaungatanga, kotahitanga, waiata and kai.

Some kaumātua of today remember their experience of visiting rest homes in the 1980s; they recalled a strong urine smell, a large group of what appeared to be sedated residents gathered in a "day room", as well as shared bedrooms and bathroom areas. They remember seats beside beds that (when the seat pad was removed) doubled as a commode being a common feature of rest homes at that time. Physical activity was limited to a walking group for those who were easily managed by staff. At that time, for Māori, the thought of placing kaumātua in a rest home would be seen as a failure of the whānau to provide care for those who once were their carers.

Some kaumātua expect whānau to provide care for them as their needs change. When expectations are not met, kaumātua express feelings of betrayal and being unwanted with a sense of unfulfilled cultural obligations. Whānau too feel these obligations. One whānau member spoke of the pain, shame and sense of failure they felt when putting their kuia (older woman) in an ARC facility. Such feelings were frequently experienced by whānau at the end of each visit, particularly when the kuia had repeatedly shared her wish to return home.

From a Māori health provider's perspective, the decision to move to an ARC facility would be best when one or more of the following takes place: kaumātua and their whānau mutually agree to the move; when the independence of kaumātua is best enabled with the support of professional care available in an ARC setting; and/or when whānau no longer feel well equipped to ensure the safety and wellbeing of their kaumātua with dementia, frailty or other debilitating illness. One thing that remains important is that the kaumātua concerned needs to be involved in the decision-making process from the beginning and ideally, where it is possible, to agree to the move.

When kaumātua are part of the decision-making process, the outcomes for both the kaumātua concerned and their whānau tend to be positive. Kaumātua and their whānau shared stories of how a move to ARC positively impacted kaumātua wellbeing and safety. For example, a koroua (older man) in his 70s, with diabetes and severe mobility support requirements, lived independently in a kaumātua flat. However, his mobility needs increased, as did the risk of him falling. Consequently, the koroua and his whānau agreed that an ARC solution was best for him. Since his admission, he and his whānau have reported a considerable improvement in his health status including significant weight loss, improved circulation, and mobility.

Other positive outcomes for kaumātua moving to ARC, as reported by kaumātua and whānau, have been a greater sense of companionship, more social and physical activities, better nutrition, and improved wellbeing overall. It is clear that when ARC is able to meet the needs of kaumātua, there is a higher likelihood that kaumātua will thrive.

Unfortunately, the experience of kaumātua and whānau that Rauawaawa has supported over the years have not found this to always be the case. For example, a kuia in her 70's lived independently in her family homestead until she was diagnosed with dementia. This kuia was supported by a loving whānau who expressed concern at the risk they felt she was becoming to herself by living alone. Unable to find a way to support her well themselves, with them all working, this kuia was admitted to an ARC facility with a dementia care unit. The move was done quickly, which caused upset to the kuia and her friends. At every opportunity to speak with Rauawaawa team members, the kuia expressed her wish to go home and not return to the rest home. She reportedly escaped from the rest home and made it quite some distance before being found and returned back to the rest home. In another similar situation, a koroua in his 70s suffered a condition that severely impacted on his physical stability. After being admitted to an ARC facility by his whānau in one city, he 'escaped' to another city to be cared for by a friend. After some time, he returned for a holiday to visit his whānau when, he was admitted once again to an ARC facility. He later escaped again and returned to where he had been cared for by his friend. He was encouraged to return to his worried whānau, which he did. There is the potential that a more flexible approach to care needs may have benefitted the kaumātua, his friend, the whānau and the ARC facility.

Common themes in these cases centre on two key challenges. The first is how to maintain kaumātua mana motuhake (independence and autonomy) in the face of an imposed decision to be moved to an ARC facility. Being part of the decision-making process goes some way to address this. However, the second challenge remains: how to support kaumātua living in a culturally unwelcoming environment where the systems, processes and design are not Māori-centred. One experienced hauora worker, in her 60s, highlighted the cultural risk of the growing number of kaumātua moving into ARC. Her concern was that in moving to ARC, kaumātua become separated from their whānau and culture, and mātauranga Māori (Māori knowledge), whakapapa (genealogy) and pūrakau (stories) become lost to whānau, hapū and iwi.

Many of today's ARCs offer a resident-focused, aesthetically pleasing environment, with individual bedrooms in apartment-like settings, personal services, dementia-friendly hallways, rooms, gardens, and facilities. However, care of Māori kaumātua requires more. In the context of Aotearoa, there lies great opportunity for Māori-led development of models of kaumātua care in residential settings. Recent examples of Māori-led housing developments (e.g., Moa Cres Kaumātua Village, Ngāti Whātua Ōrākei) demonstrate positive examples of kaumātua-led, and lived, communities of care. Such models of for-Māori, by-Māori and for-kaumātua, by-kaumātua housing developments, offer the ARC sector ways to better engage with Māori cultural design and processes to care holistically for kaumātua. Such models also have the potential to facilitate a cultural shift in ARC's capacity to promote kaumātua mana motuhake.

Summary of caring and care experiences

The call for by Māori, for Māori, solutions to support kaumātua with high levels of care needs came through strongly in these contributions. This approach included establishing that higher levels of care are part of the normal life course discussion, that options for care in later stages of life are discussed as a whānau well before decisions relating to care are needed, and was reinforced by other examples of Māori-led and kaumātua-led care solutions that supported Māori to thrive. Confusion about costs and hidden costs caused concern for whānau. Flexibility was also seen as key, allowing options for care that meet local needs and take into account rurality and access to other health and social services, and whānau. Intergenerational living and more complex whānau asset arrangements need to be considered within the current ARC funding model to support access without negative impacts for whānau and to prevent a 'two-tiered' system within ARC. There are examples of benefits for Māori in ARC when kaumātua and whānau autonomy were upheld and this needs to be prioritised in our approach.

Māori-led models of ARC | Ngā tauira Māori i ARC

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THE CARE VILLAGE, NGONGOTAHĀ

The CARE Village in Ngongotahā, run by a charitable trust, Rotorua Continuing Care Trust (RCCT), utilises an innovative biopsychosocial lifestyle model of care inspired by the Hogeweyk care concept. De Hogeweyk is an ARC facility in the Netherlands, built to resemble a Dutch village, with a collection of households, rather than a large facility. De Hogeweyk residents are encouraged to participate in the running of their households with the support of staff and volunteers. Additionally, they have access to facilities such as a restaurant and supermarket in the village and participate in purely pleasurable activities in clubs that cater to their interests. Residents live in apartments with small groups of peers who share similar social norms and tastes. These groups are known as lifestyle groups, and each conforms to one of seven recognised Dutch lifestyles. For example, the ‘Christian’ lifestyle is a sober lifestyle, prayer is important and religious music is played in the home (van Hal, 2014).

When RCCT needed to develop a new ARC facility due to the end of the lease on their existing premises, they chose to build a village inspired by De Hogeweyk. The aim of building the new facility, The CARE Village, was to support the guiding vision of “people living normal lives” and improve resident subjective wellbeing (Shannon, 2021). In The CARE Village, residents live in small houses, supported by universal care workers (those able to provide personal cares and household management support) known as home leads. Home leads are consistently assigned to the same house and residents and are helped by support workers, who work between two or more houses as need dictates.

As part of developing the village, the Hogeweyk lifestyle concept was intentionally reimagined to echo the ways people live in Aotearoa New Zealand. Lifestyles encompass valued lifelong identities reflected by the physical and social environments people are comfortable inhabiting, including social norms (van Hal, 2014). Whare Aroha CARE management consulted with staff, residents, family members, other visitors to the facility and board members, to develop seven lifestyles for the people who lived in Whare Aroha CARE, the original facility, at the time of planning. At that time, the management team included Māori membership and the consultation process was led by one of the Māori members.

The consultation process encompassed many conversations and a survey, asking people about how they had grown up. From the information gathered in that process, themes were developed and subsequently refined to identify seven lifestyles, one of which was the ‘cultural living’ lifestyle, which centres Te Ao Māori (Shannon, 2021). The CARE Village is located in Rotorua where 40.1% of the population identify as Māori (Stats NZ, 2021c), compared to the 16% of Māori in the general population in NZ (Te Pou o te Whakaaro Nui, 2019). The demographics of residents and staff of The CARE Village reflect this high Māori population. One house, lived in by six residents, conforms to the ‘cultural living’ lifestyle, and this became the cultural house. Residents who are comfortable and feel at home in that house have strongly identified with Te Ao Māori during their lives. Although the majority of residents identify as Māori, not all of the residents in this house do. The home lead in the cultural house also identifies with Te Ao Māori and is able to incorporate tikanga and te reo Māori in everyday practices, enabling the house to be run in a genuinely authentic way.

Home leads, who were either Enrolled Nurses or Health Care Assistants, were identified and matched with lifestyles during the planning stage of the transition from the old facility. Once the home leads were identified, management encouraged them to utilise their embodied knowledge of the lifestyle in the home to plan how they would manage the day-to-day running of the houses. The home lead role encompasses resident care and managing the usual tasks of any household such as meal preparation, cleaning and laundry. The organisation provided training to upskill staff in preparation for their expanded roles. Staff that, prior to the move, were only employed in household management-type duties, such as cleaning and cooking, were upskilled to be able to provide personal cares, such as showering and toileting. Initially, most staff found adapting to their new roles very busy and challenging, however with the support of management and each other, they adapted and established the unique rhythm of each house. This change in workforce skills is an important aspect to acknowledge. The CARE Village were required to get dispensation from the Ministry of Health, with a need to change the ARC contract, to allow all staff to be at this highly skilled level. This change was made by the CARE Village as it was essential so that, instead of living with people that had the same care needs from a biomedical point of view, residents were enabled to live with people with similar cultural values ways of living.

A few of the examples of the incorporation of tikanga and te reo Māori are provided here. Appropriately, for an ARC facility in Aotearoa New Zealand, and in accord with Ministry of Health guidelines (Ministry of Health, 2016b), the site was blessed by a kaumātua before construction began. When the new home was first established, the home lead cleaned all the furniture and other items brought from Whare Aroha CARE to ensure no transfer of energy from one facility to the other, enabling a fresh start. In the cultural house te reo Māori is naturally woven into the conversation and providing hospitality to visitors is a taken for granted aspect of daily life. Understandings about food preparation ensure tastes are familiar to residents who share those understandings, contributing to healthy appetite and nutrition, and addressing a more comprehensive understanding of wellness for frail, dependent residents (Shannon, 2021).

The six residents of the cultural house have high care needs. Most require full support with all activities of daily living, while one can take part in activities such as cooking and helping care for others (Shannon, 2021). Data from a recent PhD study provide qualitative evidence of the effect of living in The CARE Village Māori cultural home from the point of view of one of those residents. The resident described her peers (other residents) as more engaged with their environment and the people in it since the move. In contrast to seeming to spend their days sleeping at Whare Aroha CARE, kaumātua in the cultural house in The CARE Village are described as being alert, happy and talkative, including speaking in te reo Māori, as they have done all their lives. The resident who prepares food and helps care for others describes physical and emotional benefits, such as improved sleep and a feeling of satisfaction about the reciprocity entailed in being cared for while caring for others (Shannon, 2021).

Not all Māori residents live in the cultural house, and there are other ways in which Māori culture is incorporated and accessible in everyday living in the CARE Village (Shannon, 2021). Te Ao Māori is visible in an activity developed by two home leads, both of whom are Māori. A cultural club was developed, led by a Māori volunteer (a partner of one of the staff members) who has experience as a te reo Māori teacher. At the club, karakia and waiata were used to connect residents with Māori language and culture. The activity demonstrated the worth of enabling residents to experience joy and for Māori residents this provided a link to their lifelong identities through engagement with an aspect of life they value (Shannon, 2021). Unfortunately, the club is no longer running due to staff changes and the volunteer coordinator no longer being available.

The sustainability of supporting Māori culture and activities in ARC is dependent on several factors. There must be current and future residents who want to be connected with Te Ao Māori, and there must be staff members who can work in ways that ensure the connection is authentically maintained. Given the growth of the Māori older adult population, there will be a continued if not increasing demand for recognition of Māori culture and lifestyle in all aspects of life in Aotearoa New Zealand, including ARC. The sustainability of the cultural lifestyle and cultural activities at The CARE Village also depends on the staff who understand the model of care passing their knowledge on to others who follow in their footsteps. There are plans for researchers and staff to co-design a training programme to ensure the model of care is sustainable into the future.

In a recent development, staff members (including Māori staff members and management) identified the lack of a cultural advisory team at the village as a deficit that needed to be addressed. Management had also been becoming aware of the deficit, and it was mutually agreed that interested staff with appropriate skills should form a team to advise management, staff and residents on tikanga. The team is a Māori led initiative that has emerged from facility staff and is supported by management. At the time of writing, the team consists of two respected wāhine Māori who have strong backgrounds in tikanga. The formation of the team was endorsed by a kaumātua who is a village resident and supported by another kaumātua who is a community resident. Current work being undertaken by the team includes the development of a facility waiata, developing a Māori name for The CARE Village, working on an official welcome for visitors and rewriting the village's Māori Health Plan. Work is also being done to develop and advise on a kaumātua role for the village as the team continues to evolve.

(l to r) Tiakina Te Kare, Kelly Te Kare, Tina Chivers

Kelly Te Kare *(Ngāpuhi, Ngāti Hine, Te Rarawa)* is on the Commission-ARC leadership group as a consumer representative, a Māori cultural volunteer at Goodwood Seadrome, a dementia care facility, and her current position is Te Kaiarahi Ahurea, cultural team leader, Whitiki Maurea - Māori Mental Health and addictions within Waitematā DHB. Kelly is passionate about equity of care and education for tangata whai i te ora and whānau to understand their hauora and oranga journey. She has mātauranga, Te Ao Māori and lived experience of whānau being in residential care.

Tiakina Te Kare *(Ngāpuhi, Ngāti Hine, Te Rarawa, Ngāti Kahungunu, Ngāti Maniapoto descent)* is on the Commission-ARC leadership group as a consumer representative, a kaiako kapa haka at Ngā Puna o Waiorea, a Māori Health Care Assistant, and Cultural Advisor at Goodwood Seadrome. Tiakina has grown up in the values and beliefs of Te Ao Māori and has cultural knowledge that she learnt from her whānau. Having this knowledge allows her to support the tangata whenua at Goodwood Seadrome making sure to uphold and give them a place of belonging-Tūrangawaewae, and a sense of belonging- Whanaungatanga.

Tina Chivers is qualified as a psychiatric nurse NZ. After qualifying she went to work in London in the NHS specifically in Dementia care both hospital and day stay. She returned to NZ in the late 1990's, and set up Seadrome Home and Hospital - a specialist facility for people living with mate wareware (dementia). Seadrome offers alternative management and care for people with significant behavioural issues associated with mate wareware.

TANGATA WHENUA AT SEADROME

Goodwood Seadrome Home and Hospital is an ARC facility for people living with mate wareware (dementia) in Waitematā District Health Board (WDHB).

As part of our approach, we use Kitwood's person-centred practice. This process focuses on delivering care through a range of activities and includes engaging with people, working with peoples' beliefs and values, having an empathic presence, sharing decision-making and providing for physical needs. Kitwood's definition of personhood is that *'people do not exist in isolation but exist in relationship with others and to others'* (Kitwood et al., 2019).

The very essence of the Māori world view is relationships - not only between people but also between the spiritual world and the natural world.

Our journey to improve responsiveness to tangata whenua at Seadrome began when several tangata whenua came to live here. All had come from living with whānau and now found themselves in this Pākehā world. We were not meeting the cultural needs of the Māori residents in our care; they appeared displaced, disconnected, disengaged and powerless. Seadrome did not seem like a place where they could belong. For example, one of the tangata whenua residents expressed "I am not like these people here." In the dining room she would often push all the tables and chairs back to the sides of the room at the end of the meals. At the time we did not recognise this as common practice in the marae, but accepted this as part of her illness. Although we did not understand what was happening, the staff would still all assist her to push back the tables. All behaviours are a way of communicating. Without the understanding of this kuia's cultural norms, this type of behaviours could have been labelled as displaying 'disruptive' behaviour. Instead of being disruptive, this kuia was demonstrating manaaki (caring, reciprocity). She was contributing to the care of the facility and residents by helping clear things away at the end of the meal.

These types of instances made us even more aware that our staff needed more training. For two years we tried approaching several organisations for advice and practical help to no avail. Then help arrived in the form of Dianna McGregor who was a newly appointed Māori Nurse Specialist Gerontology for Waitematā DHB. One of the first things Dianna did was to help us to engage with Kelston Girls' College. She saw that there was the potential to encourage Māori high school students to engage with the Māori residents at Seadrome who were in desperate need of reconnecting to their culture and their people. From these beginnings, a partnership with WDHB, Kelston Girls College and Seadrome emerged, and Project Toru came to be.

In 2014, Project Toru was implemented at Seadrome. Project Toru was designed to support culturally safe provision of care for Māori residents, and workforce development opportunities for Māori high school students. The school students, who could speak te reo, visited once a week to talk and interact with residents on a one-to-one basis. They also learnt some basics of caregiving. Participation in this programme qualified for National Certificates of Educational Achievement (NCEA) credits for the high school students and provided potential employment opportunities. The Māori residents became more engaged with their surroundings, had improved self-esteem and awareness. Many residents began to look forward to these weekly visits and actively planned for them by doing things like choosing their best clothes to wear for the occasion (Waitematā DHB, 2014). This can be viewed as both a model of care as well as an intergenerational programme of learning.

Seadrome's intention was to enable whānau, hapū, iwi, to make meaningful decisions for their health and wellbeing and needed further development on how to put these intentions into action. After the success of Project Toru, Seadrome's next goal was to incorporate

more Indigenous knowledge and practices into the care provided for tangata whenua that lived there. We also thought that these practices may support better quality of care for our other residents too. One of our challenges (and advantages) was the diversity of knowledge within our staff. Some staff had little-to-no foundational knowledge of Māori culture. But we were in the fortunate position of having a few staff with a strong in-depth cultural knowledge who were already implementing this into their daily care practices.

A series of wānanga whakapakari (cultural education development sessions) were held at Seadrome conducted by Kelly Te Kare who was a volunteer, and staff member's mum. Kelly is very cognisant of Māori values and beliefs, and wanted to support the strengthening of cultural knowledge of staff members in tikanga, te reo Māori, Māori worldviews, Te Whare Tapa Whā (Durie, 1998), māramataka and caring for residents culturally. Each session started with karakia and sometimes a hīmene. We went through a lesson, brainstormed ideas on how the learnings could be implemented in the workplace or in their own lives, and set a challenge for the staff to complete in the following week we closed with karakia and then shared something to drink or eat. In each subsequent lesson we reflected on the previous lesson, and everyone shared their challenge experiences.

From these sessions Seadrome were able to implement Māori values and concepts relevant to their environment and practice. There were two values and concepts which resonated with all staff, tūrangawaewae and whanaungatanga. Tūrangawaewae is standing, or a place where one has the right to stand and whanaungatanga is forming relationships, sense of whānau connection and a sense of belonging. During our wānanga whakapakari, staff collectively developed an understanding of how these concepts could be applied in the context of Seadrome. Tūrangawaewae would be the idea that Seadrome was a place where people would be able to call home for a part of their life. Whanaungatanga was the fostering of strong relationships starting from the first time meeting new whānau who arrive at Seadrome, finding commonalities through conversations, sharing experiences and assisting in providing a sense of belonging.

The Te Wā Māori is a weekly hui for tangata whenua at Seadrome to not only give the mana whenua a sense and place of belonging but to help our tangata whenua keep a connection to their identity and culture. The Te Wā Māori hui starts off with a hīmene and karakia, followed by a mihi of welcome from one of the staff members, and a waiata tautoko. Everyone that is present introduces themselves to each other by saying their pepeha, we then have a set Kaupapa (activity) for the session followed by a closing waiata, karakia and hākari (feast) of different Māori kai.

Through wānanga whakapakari with Kelly Te Kare and having kōrero with our tangata whenua at Seadrome we were able to build on the structure and content of our Te Wā Māori hui, incorporating more Māori history, tikanga Māori, waiata Māori and Te Ao Māori. With the help of Tiakina Te Kare (Māori Health Care Assistant) one of our kaumātua at Seadrome was able to have input into structuring our Te Wā Māori hui by not only sharing the cultural knowledge that was passed down by his tūpuna (ancestors) but also life knowledge he had gathered over the years. This led to us being able to focus on tikanga and history from the iwi our tangata whenua whakapapa to in the Te Wā Māori hui. Examples of this relate to particular weaving activities, such as manu tukutuku and flax flowers, and learning new waiata and karakia. We were able to look at and share Māori pūoro (musical instruments), poi and tititorea (stick games), watch kapa haka, and learn about Māori rongoā (Māori methods of healing). To engage more with the taiao (environment) we have been looking at and planting native plants in the garden and having our Te Wā Māori hui under the trees next to our native garden.

Our tangata whenua play an active role in developing the content of these hui, by engaging in conversations and discussing topics they would like to have included. From this we see the contributions grow and grow each time. People are wanting to share more of where they come from each week, participate in the different Kaupapa we have and have also gained a sense of tūrangawaewae and whanaungatanga here at Seadrome. Over the years we have adapted the Te Wā Māori hui to the different levels of mate wareware we have here at Seadrome. Lately we have found our tangata whenua are more engaged in topics that involve listening, touching and seeing so we have adapted our Te Wā Māori hui to focus more on waiata Māori, kapa haka videos, using photos/videos when talking about tikanga and Māori history, holding poi and tititorea and watching Māori entertainers such as Prince Tui Teka and Billy T James. For our tangata whenua who are at hospital level of care we hold a Te Wā Māori hui for them focusing on listening to Waiata Māori and watching staff members do action songs, poi and tititorea. Every day we strive to improve our Te Wā Māori hui to give our tangata whenua not only a better quality of life but to hold a connection to their culture.

Whanaungatanga begins in the first meeting between residents and whānau and the staff at Seadrome. There are two forms of Māori cultural welcome that we use here at Seadrome. The first welcome that we use is the ‘whakatau’ which is a welcome with a mihi (speech of welcome) follow by a waiata (song) of support and then the opportunity for the whānau to respond and have a kai. The second type of welcome is known as the pōwhiri. The pōwhiri begins in the lounge where new residents and their whānau/family are welcomed by staff members and residents. A karakia is said together by all in Māori and English, a mihi of welcome is given followed by a waiata (song) which is accompanied by a staff member playing a ukulele or guitar, then there is an opportunity for anyone else to speak. A kai is then shared which is prepared in respect of the cultural background for the person coming to reside at Seadrome. During kai we continue strengthening relationships. As the residents have mate wareware we were guided by Kelly Te Kare and Tiakina Te Kare who were able to establish a (non-formal) pōwhiri which can be adapted for each individual’s needs.

There are variations of this pōwhiri for other cultures. For example, staff members gathered Samoan songs and recipes to welcome a Samoan woman who was being admitted to Seadrome. Staff members and residents waited in the lounge for her arrival. As soon as her and her aiga (family) came into the lounge, the staff and residents sang Samoan songs making them feel welcomed. During the singing, the Samoan woman was smiling and full of laughter. She then proudly stood up and started to do the siva (Samoan traditional dance). Traditional Samoan food was prepared by the Samoan staff and then shared with all. After the pōwhiri we sat in the lounge singing Samoan songs. This inspired her memories of Sāmoa and led her to not only perform her traditional Samoan dance, but to play the ukulele, something her aiga were unaware she could do. When the Samoan woman was performing her traditional dance and playing the ukulele it seemed she was back in Sāmoa. From this moment we were able to revive the Fa'a Sāmoa (The Samoan way) here at Seadrome.

Another example of a pōwhiri we had was for a Māori woman who came to live at Seadrome. She was accompanied by her mother and sister, and was shy, appearing overwhelmed. As we continued with the pōwhiri, she sat closely beside her mother and we noted her response to waiata was positive. Her head was bowed, her hair slightly over her face, she was peeping out to look at the people singing and after a few songs we noticed she joined in with the waiata. After the final karakia we invited her and the whānau to her room, where we offered kai. Some weeks after this pōwhiri she emerged from a shy reclusive person to a vibrant warm personality who joins and contributes to the Te Wa Māori hui, loves to sing, plays the ukulele and guitar, and loves the staff putting on her make up and nail polish. Much to the delight of the Samoan staff, as well as speaking Māori and English, she also speaks Samoan.

We held a pōwhiri for a Pākehā man who was accompanied by his wife. They responded with respect, and his wife had tears in her eyes throughout the pōwhiri. These appeared to be tears of relief, appreciation, and gratitude. We sang Māori and European songs which everyone knew, followed by a karakia then kai. Again, we witnessed the power of the pōwhiri.

In the last days of a resident's life, we are guided by Te Ara Whakapiri: Principles and guidance for the last days of life (Ministry of Health, 2017). The components of care relate to the dimensions of Te Whare Tapa Whā (Durie, 1998). This model is used as a blueprint for all residents, and our aim is to provide quality to life and dignity in death. Cultural and spiritual wellbeing, wairua and whānau are equally as important as physical and mental dimensions. Not all people who are dying have whānau, family, or friends to support them. In these cases, the caregiver's role is particularly important. A Care Review with the whānau/family and staff involved in the care is undertaken. This is led by the Nurse Practitioner, and recognises that the person is approaching the last days of life. Conversation includes ensuring the whānau/family are aware that the person's condition is changing. Their preferences for care are noted and acted upon, ensuring that any cultural needs are understood and implemented. This review gives an opportunity for whānau/family to discuss what is important to them, discuss any fears or concerns, and gives confidence that their beliefs and values and care after death will be respected.

After the death the whānau/family are invited to spend private time with their whānau/family/friend. The chosen funeral director is contacted, either by the whānau/family or staff and initial arrangements made. The person is washed and prepared, and whānau/family are invited to take part in this. When the funeral director arrives, the person is placed on the trolley to be taken to the hearse. Seadrome's formal farewell comprises of whānau/ family and staff with one staff member playing the ukulele and everyone singing the waiata *Te Aroha*. When the person is placed in the hearse a karakia is spoken in te reo Māori and English by everyone present. There may be variations to this practice, and some whānau may choose to perform a haka at this time. Then slowly the person leaves Seadrome to everyone singing a waiata. This ritual has evolved over time under the guidance of Kelly Te Kare and Tiakina Te Kare, and it will continue to evolve.

Caregivers form an attachment to residents, one of affection, aroha and compassion. The farewell gives them an opportunity to express their respect and sadness at the passing of the person they have cared for, often for a number of years, with whānau/family/ friends. Whanaungatanga, sense of belonging, is important at this time. One of the most important things in our lives are the relationships we have with one another, especially for people living with mate wareware. We observe that the importance of whānau connection also extends to others to whom a close friendship has developed. This model has been adapted for people of other cultures. Sometimes songs from different cultures are used; it could be that the resident's favourite songs are used. We observed that non-Māori, particularly Pākehā, are moved and feel privileged to receive karakia and waiata at this time of grief and farewell.

Ideas and plans for the future emerge from our interactions and observations of the people living at Seadrome, along with ideas from staff and whānau/family/friends. Some thoughts that we are currently pondering and for discussion in our Cultural Safety Hui include:

1. Extending the formal farewell ceremony by inviting whānau/family to join us for kai, and an opportunity to reminisce about their whānau, once the person has been taken from Goodwood Seadrome;
2. Further adapting and developing the pōwhiri within our hospital where all of our residents' experience mate wareware;
3. Extending our mahi māra (garden) including planting by the moon, planting more vegetables, flowers, and native trees and to encourage more birds;
4. Discovering more ways to support whānau/ family while they are visiting residents;
5. Find ways to increase the involvement of whānau/family in activities such as our mahi māra and Te Wā Māori roopū.

In writing this, we wish to acknowledge some special people. We will always remember Charlotte for her kindness and gentleness, Ada for showing us the benefits of being able to connect with her culture, Elizabeth for her uniqueness, Patrick for his haka and love of Māoridom, and Phil for his guidance and role as Kaumātua. With aroha they taught us so much, their spirit and presence are forever with us.

Kia whakakotahi ai tō tātou tū i runga i te aroha o tētahi ki tētahi

Let us stand in unity with compassion for one another

CASE STUDIES SUMMARY

Māori thrive in ARC when there is clear action that supports Māori to develop a sense of place and belonging within the ARC facility. The case studies demonstrate the positive benefits that can occur when there is explicit intent to incorporate Māori values and care models into practice and even more so when there is ongoing co-design with kaumātua, residents, and whānau included. The inclusion of residents and acknowledgement of their ability to contribute is vital in this process, as is having a sustainable Māori workforce to facilitate this.

WĀNANGA WITH CONTRIBUTORS

All contributors to Section Two of this report were invited to review the draft report and come together in an online wānanga to discuss future priorities and aspirations for Māori and ARC. Thoughts arising from this wānanga which are not covered elsewhere in this report are briefly included here.

ARC as part of the life course

The current ARC system seems very far removed from normal 'life', perhaps hidden from sight, only visible during times of acute change in need. There was a strong feeling from contributors that ARC, or similar levels of care, needed to be discussed as part of the potential life course for Māori in order to ensure that older Māori and their whānau have the ability to plan and be active, informed, decision-makers in this process. When discussion about ARC as an option for care came too late, contributors described a 'clumsiness' in the approach, with the removal of kaumātua agency and kaumātua often feeling like they had been tricked into care.

Kaumātua in ARC also need to still be considered as part of the general population, whereas those living in ARC are often viewed as living 'outside' of normal society. With being considered as a part of, and contributing to society, kaumātua can bring their previous experiences with them and continue to contribute to their own lives and the lives of others in this new community.

A one-way door

Contributors expressed that once a whānau member was in ARC, that seemed to be their final place of residence. They discussed that for some, a rehabilitative approach would be appropriate instead, with the potential for moving back home. There were complexities to this of course; potential sale of their private home in order to fund their ARC stay, as well as potential equipment or modifications being needed to their existing homes in order to facilitate a return. Their views also were that there should be better support for whānau who want to take residents for short stays outside of ARC.

ARC and palliative care

The issue of ARC being viewed as a one-way door has added significance when examining the final stages of life. For some, they would have liked the opportunity for their whānau members to be 'brought home' at the end.

For those 65 years and over, 38% will die in ARC in NZ, the highest rate of any of 44 other countries in an international comparative study (Broad et al., 2013), yet many staff working in ARC feel ill-equipped to adequately provide end of life cares (Frey et al., 2017). Flexibility in the approach to palliative care may mean that whānau can be better supported to take on some of these roles. Relevant support may include developing whānau orientated training modules that could be delivered proactively, rather than this feeling like an imposition when delivered very late.

SECTION THREE | WĀHANGA TORU

Using experiences to identify knowledge gaps and future aspirations | Meatia ana ngā wheako hei tautohu āputa me ngā wawata mō muri

In the previous section, contributors’ experiences of Māori and ARC were presented. In this section, we provide commentary relating to the challenges and opportunities that were identified. This section adds policy and integration to the discussion of literature and contributor’s experiences.

There is overwhelming evidence that ARC can support wellbeing in the general population, and Māori have the right to experience these benefits, but this should not be at the expense of culturally appropriate care. The clinical benefits which ARC can provide may not be benefitting Māori because of increased barriers to accessing care and an environment (which includes staff, physical buildings and culture), that does not support holistic, culturally appropriate care. Māori access to ARC is also influenced by the perceived acceptability of this as a care option. Current and historical experiences of the ARC setting influence Māori acceptability, and work needs to be undertaken to ensure Māori are well informed of ARC options, including the potential benefits and the financial implications of both at home care and residing in ARC. Māori also need to have the ability to influence and lead the development and delivery of new models of care.

Designing explicitly pro-equity policy and models of care | Te hoahoa kaupapa mana ōrite me ngā tauira tauwhiro

In line with Māori rights under te Tiriti o Waitangi and the MOH goals of health delivery in NZ, examination of health equity needs to be incorporated into every policy and quality document, with clear direction around the expectations in relation to Māori health equity. The Health and Disability System Review was billed as a once-in-a-generation review of this NZ sector (Health and Disability System Review, 2020). DHBs will be disestablished and be replaced by four localities which will manage ARC services. Although ARC is mentioned in the Health and Disability System Review it is acknowledged that the changes that need to occur in the ARC for older adults to ‘live well’ are beyond the scope of the review. The plan from government to date has been lacking in detail regarding ARC, and older age care services more generally.

Changing the ARC sector to be responsive to the needs of Māori, and to allow for Māori flourishing in later life, is not going to happen by chance. Robust policy, that is informed by the voices of Māori, especially those who have lived experiences of ARC and those that are planning for the futures of their whānau, and frameworks for *resourcing and implementation* of those policies, is required to implement change. Some recent work looking to improve ARC outcomes in general, have failed to address the need for equity of outcomes (Neville et al., 2016).

Below we have outlined some policies and organisational documents which shape the ARC sector in Aotearoa, as well as action resulting from these policies, and examine where change may be needed.

The Age-related Residential Care Services Agreement requires ARC facilities to develop a Māori health plan which includes policies and procedures which guide staff to ensure that the needs of Māori residents are met. This includes eliminating care barriers, supporting cultural practices, inclusion of whānau, and consultation with tangata whenua (Technical Advisory Services Ltd, 2020). ARC facilities undertake audits which include review of these Māori health plans. Very similar language is used across reports, potentially reflective of the nature of audit, however it is difficult to understand the explicit actions that are being taken to deliver pro-equity care and how Māori health equity is evaluated at a facility (or organisational) level (Bupa Care Services NZ Limited, 2014, 2015). The North Regional Alliance which supports the four Northern-most DHBs (Northland, Waitematā, Auckland and Counties-Manukau) to implement government health policies, have provided comment on their objectives for equitable ARC services in Appendix 2.

In Section Two of this report, some excellent examples were provided of how Māori health plans were more than words on a page and demonstrated the application of meaningful change. Reflection of action that is undertaken, and the outcomes related to these actions, are an important part in ensuring the care we offer is equitable and challenges the current structure and provision of ARC. In the CARE Village example, we also saw how the ability to adapt contracts to suit the way in which care was delivered in this ARC facility was integral to the day-to-day operation of the facility. The Commission website provides a good example of a Māori health plan at Enliven's Kowhainui Home and Village in Whanganui (Health Quality & Safety Commission, 2019d). The development of the plan included mapping of Te Whare Tapa Whā against their current philosophical model of care and was supported by an advisory group which included kaumātua, whānau, staff, residents, and cultural advisors. The plan is open to change based on feedback, although in the description provided, assessment of the impact on Māori health, and health equity was not presented.

Way forward: that the policies guiding Māori health plans are ubiquitously implemented and the action taken is monitored to access the impact on equity and Māori health outcomes.

Use of data to drive knowledge and practice | Te whakamahi raraunga hei kōkiri i te mātauranga me te mahi

The data which is available regarding ARC is largely silent on ethnicity of staff and residents, and any potential variations in outcomes. There is limited information available regarding ethnic variation between access to, and the quality of care and related health outcomes for Māori in ARC. The information which is available shows that Māori do not have equitable access to ARC facilities, and potentially experience worse outcomes than non-Māori. These impacts have flow-on effects into whānau who support those with high care needs. There are current assessment and reporting tools which could facilitate robust analysis of equity of ARC access and outcomes in the future.

Way forward: Undertake work in ageing support and ARC sector specifically examining variations in levels of disability and access to care and include ethnicity in ARC in interRAI analyses in TAS reports.

ARC workforce development and sustainability | Whakawhanake ohumahi o ARC me te whakapūmautanga

Cultural safety training for all staff is alluded to in policies and procedures in ARC, however implementation and measurement of impact of such training is not evident. A lack of pay parity means quality staff may be lured to other sectors and the current restriction on immigration puts pressure on continuity of quality staff. Workforce development, reflective of the needs of Māori, is essential to Māori thriving in ARC. The application of Māori cultural values and tikanga provides an opportunity for ARC system redesign to improve care in a way that aligns with previous ways of living in the community and which also has the potential to benefit all residents. To ensure that this approach is prioritised and valued, Māori staff need to be employed in a sustainable manner. Initiatives to centre Māori culture should be Māori-led, kaumātua-led with community partnerships.

We saw in a number of the case studies that activities relating to tikanga and te reo Māori were instigated and led by Māori staff and volunteers. However, when these staff members move on, the initiatives may no longer be offered. There needs to be intentionality in the building of a workforce that is capable of supporting such activities, and measures put in place to ensure this workforce is sustainable. Potential solutions may come from whānau themselves. We know that older Māori are more likely than non-Māori to be cared for by 'informal' caregivers, often whānau, at home (Lapsley et al., 2020). This knowledge provides opportunities for well-informed whānau members to contribute to training programmes and knowledge growth in the ARC sector. Co-design with Māori in partnership for development of training resources and programmes was seen to be essential, as was the self-identification of needs and expectations by Māori.

The Seadrome case study in Section Two is considered an exemplar of how the entire staff can be drawn into the journey of providing care that utilises Māori values such as whanaungatanga and manaakitanga, allowing new staff to develop skills when they join the organisation and upskill as they go, creating some sustainability in the model of care. An environment where Māori staff are resourced to support these initiatives, where their expertise and skills in this area is recognised, including in remuneration, and where they are authentically supported by facility and sector leadership will contribute to sustainability. These aspects have the potential to improve retention of staff, as well as care and outcomes for residents. This highlights the benefit that could be gained from true and authentic partnership in the approach within facilities and the sector, ensuring that pro-equity care is always part of the agenda.

Way forward: that Māori-led development and co-design of Kaupapa Māori programmes in ARC be encouraged, and supported, and the contribution of Māori tikanga and te reo be valued. This includes for-Māori, by-Māori and for-kaumātua, by-kaumātua housing developments. Such models offer the ARC sector ways to better engage with Māori cultural design and processes to care holistically for kaumātua and have the potential to facilitate a cultural shift in ARC's capacity to promote kaumātua mana motuhake.

Ageing in place | Kaumātua ki te kāinga

ARC is not only a health issue but a housing issue.

The concept ageing in place is promoted in national policy as well as internationally ((Ministry of Health, 2016a; Ministry of Social Development, 2019; OECD, 2003). In general terms this refers to living in your own home in the community, with support if needed, for as long as possible. Understanding of place and home may need to be viewed differently for Māori where current place of living may be some distance from the lands to which people whakapapa to. Māori urbanisation has meant that for many Māori, the community in which they live may be distinct, and some distance, from where they whakapapa to. As was discussed in the earlier contribution from Georgina Martin, for many urban Māori, despite decades of connections to urban communities, for some, living at 'home' and 'ageing in place' may actually mean a return to their ancestral whenua.

Hokia ki ō maunga kia purea ai koe e ngā hau a Tāwhirimātea.

Return to your mountains so that you may be cleansed by the winds of Tāwhirimātea.

This whakataukī speaks of how returning home, to your mountain, to your place, can restore and sustain wellbeing during times of distress and upheaval (Pihama et al., 2019). Connection to whenua and the environment is also illustrated in Tā Mason Durie's model of Te Whare Tapa Whā, where part of the strength of the whare is through its strong connection to the whenua (land) upon which it sits (Durie, 1998). It highlights the importance of connection to land and how this connection sustains wellbeing. These concepts all need to be considered in the context of ARC, or other solutions for Māori.

We can look towards Māori models of living and community such as papakāinga (a 'home base' or collections of houses on ancestral lands) to think about ARC redesign.

The need for flexibility in the approaches was mentioned across numerous aspects of this discussion. Flexibility in ARC contracting is needed to ensure that care is provided that centres a resident's culture and way of living rather than this being secondary to, or separate from, clinical care needs. There needs to be flexibility to enable Māori collectives to action rangatiratanga and mana motuhake to deliver services designed specifically for their local environment and needs. The value will only come from local communities knowing and responding to what is important to them. Flexibility is needed to respond to the needs for different individuals as they age and their different requirements which may range from rehabilitative to palliative. There also needs to be flexibility within each model to allow for the changing desires of Māori as different cohorts age through time, as they will have different ways of living, different priorities and different care needs. Barriers, enablers and solutions are likely to be different based on geographical location in NZ and the proximity to other health and social services, with different opportunities available to people in different locations. Implications for differing populations, and urban versus rural Māori will need to be further considered into the future.

Way forward: encourage regional flexibility in ARC design and encourage Māori models of living adaptations as an aspiration for ARC. Enable flexibility over time to accommodate cohorts changing preferences and needs.

Funding implications for Māori | Ngā pānga pūtea mā te Māori

For Māori, where there are higher levels of intergenerational living than in non-Māori, the policy of the main dwelling being part of the means-test has the potential for more wide-reaching flow-on effects as it does not take into account the implications of iwi land or property held in trusts for whānau collectives. Collective ownership and guardianship of land and property for Māori needs to be considered in the context of ARC. For Māori, who have endured the historical and contemporary impacts of raupatu (land confiscation), there is an added layer of complexity legally, as well as emotionally.

The premiums, referred to as hidden costs in the case studies, can increase barriers to accessing ARC and can also create a 'tiered' system within ARC where those able to pay the premiums have better access to bathroom facilities, or, quite literally, windows to the outside. Thought about sector resourcing to promote equitable experiences and outcomes for those in ARC is needed.

The 2019 Aged Residential Care Funding Model Review (Ernst Young, 2019) included a number of recommendations that are relevant to various topics discussed in this current report. A selection of the recommendations that would impact on aspects presented in the current report include:

- Funding adjustors being applied to funding contracts for ARC facilities that are deemed to be of special character and/or strategic importance, to allow for better resourcing, and targeted assistance for capital investment in these same type of facilities 'with key priorities being rural ARC providers and services that focus on care for communities with higher needs, including meeting the needs of people with lesser means';
- Increased disclosure and transparency of the premiums payable by ARC residents;
- Introduction of funding designed to support the design and trialling of cost-effective ways of working with particular attention being given to the increasingly diverse ARC population, including Māori;
- Improved measurement and reporting of resident outcomes, including the widening of relevance of wellbeing related goals;
- Policies to promote affordable living options for older adults who remain in the community but do not own their own homes.

New funding models have been suggested but are yet to be implemented or evaluated and the increasing trend towards extra charges and ORA arrangements, and collective land ownership arrangements of some Māori (taken into account in the means test process) mean that financial barriers to ARC will continue for Māori.

Way forward: Sector resourcing to promote equitable experiences and outcomes for those in ARC is needed in line with prior recommendations made in the ARC funding model review.

The Māori Health Authority | Te Mana Hauora Māori

The Health and Disability System Review (Health and Disability System Review, 2020) recommended that a Māori Health Authority be formed although it was unclear the extent of power this would have. Since this, the government have released their white paper outlining the reforms that will take place, which includes the establishment of a Māori Health Authority with full commissioning powers (Department of the Prime Minister and Cabinet, 2021). The Māori Health Authority *'will support the Ministry in shaping system policy and strategy to ensure performance for Māori, and will work in partnership with Health NZ to commission care across New Zealand, ensuring that the needs and expectations of Māori communities are also centred in design and delivery'* (Department of the Prime Minister and Cabinet, 2021).

This announcement has generally been met with hope by Māori health professionals and providers, even if this hope is somewhat restrained by previous experiences. Although much of the detail relating to this is still to be decided upon and released, many see this as an opportunity for Māori-led development and delivery of pro-equity services that will deliver equitable health outcomes for Māori. There will need to be appropriate and sustainable resourcing of the Authority in order for these visions to be met. It is important that the design and development of culturally safe *and* Kaupapa Māori services for older Māori that require 24-hour personal care support remains on the agenda of the Māori

Health Authority. It will also be of interest to understand whether the Māori Health Authority will have greater ability for cross-sectorial development than is seen within traditional central government policy and implementation. The issues remain bigger than the biomedical approach to health alone.

Limitations | Ngā whakawhāititanga

There are a number of limitations in this report. There was a short timeframe given to the production of this report which limited the extent to which the ARC sector could be engaged with. Publicly available literature was used to produce this report and, in order to include as many areas as possible that are relevant to this discussion, the literature reviews were not undertaken in accordance with gold standard best practice systematic reviews protocols. Other contributions were sought from those in the authors' networks and, this, as well as the short timeframe, has meant experiences of those in Kaupapa Māori ARC services nationally has not been included in this report. The inclusion of Māori community voices, kaumātua and their whānau, is largely missing from this report. Although it was outside the scope of this report, we acknowledge that these voices need to be central to ongoing aspirational development in this space and needs to be the focus of future work. No consideration was given to economic models of care and cost implications of changes in care.

The future | Ngā rā ki tua

The Māori population is ageing and the number of Māori that may benefit from ARC level of care services will increase in the next decade. Ageing is a natural part of the life course. Older adults are part of the general population and should not be excluded. If we normalise this discourse, the need for increased supports as we age can also be normalised. Increasing the societal acceptance of this allows for people to have discussions around what this support may look like, earlier in their life. Early, gentle discussions, with inclusion of the individuals and whānau most impacted by these decisions, will allow Māori to maintain agency in the planning as much as possible, and potentially increased engagement when the need for extra support arises. The value of kaumātua in society also needs to be recognised and has the opportunity to be utilised in the ARC setting so that residents benefit from this.

Te Tiriti o Waitangi guarantees Māori the right to rangatiratanga and the ability to partner in healthcare development and design. Indigenous-led ARC solutions have been shown as important internationally, and many Māori identify that by Māori, for Māori, solutions are needed to improve care in older age, yet Māori are not visible in the discussions and decisions relating to ARC. The success of this approach has been seen in other settings. There are Māori health and social service providers and organisations willing to try new things and this potential needs to be tapped into. Recent health sector reform, including the establishment of a Māori Health Authority, provide opportunity for appropriate, sustainable resourcing to be secured for this Māori-led rebuild of the health sector. Solutions need and will benefit from cross-sectorial collaboration and community involvement.

We cannot confine ourselves to current models and current providers. When King Tawhio was encouraging visionary thinking and unity in his people, he said *'Ki te kahore he whakakitenga ka ngaro te iwi'. Without foresight or vision the people will be lost.* By articulating the rights of Māori in relation to ARC, reviewing available literature and engaging with some sector stakeholders we have proposed a vision for the future of Māori, ARC, and related models of care.

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Appendices | Ngā āpitihanga

APPENDIX 1 – INVESTIGATING ARC ACCESS PATHWAYS FOR OLDER MĀORI AND NON-MĀORI IN WAITEMATĀ DHB

As shown in Figure 2, there are numerous steps involved in order to be able to access ARC. A person needs to be identified as having a need, a referral for assessment made, an assessment undertaken, the assessment needs to indicate that ARC placement is required, a suitable ARC facility needs to be identified (including the availability of a bed), and the person has to then enter care. At all of these steps, decisions are made by those within the healthcare system, and by older adults and whānau. There are varying levels of information available to inform these decisions and little data about whether there is ethnic variation in each of the stage involved. A research project, currently underway, will investigate Māori access to aged care services, and associated outcomes in Waitematā DHB. The study will look at ethnic variation at each step and is split into three parts.

1. Referrals for assessment: Data relating to the referrer, reason for referral, length of time from referral to assessment, assessment outcome and action taken will be collected and analysed by ethnicity.
2. interRAI assessments: All residents newly admitted to LTCF in 2018 will be included. Hospitalisation and mortality data for these residents will be collated. The association between interRAI assessments, ethnicity and clinical outcomes will be explored.
3. Decision support: A stocktake of resources available to support decision-making will be undertaken. This will identify what resources are available to potential residents and whānau and explore whether these are appropriate to support Māori to make well-informed decisions at all stages of the process, including if they accept an assessment in the first place.

Analysis is currently underway with results expected at the end of 2021. The research is funded by the Health Research Council of NZ and further information can be found here https://www.hrc.govt.nz/resources/research-repository/access-pathways-residential-aged-care-Māori-and-non-Māori.

APPENDIX 2 – NORTHERN REGIONAL ALLIANCE PRIORITIES AND COMMITMENTS: AGE-RELATED RESIDENTIAL CARE AND MĀORI

The Northern Regional Alliance (NRA) supports the four Northern-most DHBs (Northland, Waitematā, Auckland and Counties-Manukau) to implement government health policies, particularly when there is benefit working regionally to meet Ministerial priorities. The NRA works to leverage gains achieved from regional alignment while respecting varying local needs and capabilities. The NRA were approached to contribute to this report by providing their priorities in relation to Māori and ARC, and their response has been included below.

The Northern Regional Alliance (NRA) supports the northern region DHBs to progress work that needs to be undertaken in a 'joined-up' manner, working across DHB boundaries.

The Northern Region recognises variation in health outcomes of Māori compared to non-Māori, with an example of this being Māori life expectancy eight years shorter than non-Māori and non-Pacific across the Region. Health status is variable and there are significant inequities for some population groups and geographic areas as well as a large burden of ill health across the Region

Our Region has made a commitment to supporting the development of a future health system centred on individual patient need, investing in targeted inequity reduction efforts.

Frail and older people are amongst our most vulnerable population groups and they currently account for a significant proportion of the Region's health service use. As the population grows over the next 20 years, the number of people aged 75 years and over will more than double to 225,000.

The northern region spent over $388 million on Age-Related Residential Care (ARRC) in 2015/16, representing a 14.4% growth in utilisation over a five-year period (Northern Regional Alliance, 2018)*, compared to a regional population growth of 9.4% over the same period.*

The Region sees value in partnering with community providers within the residential care sector to provide enhanced care in a community setting as well as rehabilitation services and options for early supported discharge from hospital. Further development of DHB community outreach services or external contracting for similar expertise will increase access to specialist rehabilitation and aged care interventions in the community. Ideally, this will include targeted care to prevent exacerbation and deterioration of long-term and chronic conditions as well as enhancing recovery from acute episodes.

The specific planned area of focus for Māori and ARRC, as included in the Northern Region Service Plan 2020/21, detailed as part of the Northern Region Frailty and Healthy Ageing Network work programme is;

Develop strategies to address inequity for Māori associated with the services of ARRC and home based support.

This translated for the 2020/21 period into exploring data analysis opportunities to assess access to, and utilisation of, ARRC services by Māori across the region, with a goal to identify points of inequity and undertake work to address this inequity. This work will be continued into the 2021/22 year. Furthering knowledge and developing strategies to address inequities in access, as well barriers of utilisation of funded ARRC services, is a significant component of the Northern Region Frailty and Healthy Ageing Network work programme.

The Region vision for the future of health sector includes (Northern Regional Alliance, 2020)*;*

- *A **whānau controlled system** that develops and delivers accessible, culturally safe and responsive services in **localities** based on **what matters to whānau** and accountable to the local community.*
- *A focus on **closing the equity gap** particularly for Māori and Pacific populations.*
- *Full implementation of the **te Tiriti O Waitangi** and embedding **rangatiratanga** (authority, ownership, leadership) and **mana motuhake** (self-determination, autonomy).*
- *A **wellbeing and population-based** approach that emphasises **equity, prevention and wellbeing** and provides **proactive coordinated care**.*
- *Integration and collaboration across the health and social care system **with health and social care partners working together** to address inequity and the determinants of health.*
- *Service redesign will enable **more accessible, convenient, responsive** and efficient services.*
- *And **multidisciplinary team-based care, technology, new funding approaches** and **increased investment** will support the delivery of **modern, high performing,** and **sustainable services**.*

He tira kaumātua, tēnā te haere nā

This proverbial saying uses the analogy of a group elders moving on to a marae. It reminds us of how our elders moved, slow but sure and how they approached all challenges. It's a lesson for us in this modern fast-paced world to take our time when facing the challenges and give all matters the deliberation and thought that they require as did our ancestors. Kia tau te mauri.

Published in December 2021 by the Health Quality & Safety Commission,
PO Box 25496, Wellington 6146.

ISBN 978-1-98-859958-8 (online)
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