



# AGEING WELL

*Kia eke kairangi ki te taikaumātuatanga*

## REVISED RESEARCH AND BUSINESS PLANS

8 JUNE 2015

National  
**Science**  
Challenges

AGEING WELL

*Kia eke kairangi ki te taikaumātuatanga*





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## EXECUTIVE SUMMARY

The Vision is to add life to years for older New Zealanders, by pushing back disability thresholds to enable all New Zealanders to reach their full potential through the life course with particular reference to the latter years of life. This will be achieved through a programme of world class research, underpinned by an environment of collaboration, continuous engagement with stakeholders and a programme infused by *Vision Mātauranga*.

*Vision Mātauranga* is critical to *Ageing Well* because of Māori culture of valuing older people's knowledge, the disproportionate burden of ageing that falls on Māori populations and communities and the commitment of Māori communities to supporting older people ageing positively in place. Delivery of *Vision Mātauranga* will be supported across this, and the other Health Challenges, by the Kāhui Māori (advisory group) and the Tira Rangahau Hauora (Māori researchers and scientists). The research is strongly aligned with hauora/health and Mātauranga and includes research involving Māori and Māori-centred research and Kaupapa Māori research opportunities will be actively sought.

The Challenge has five research strands to direct research outcomes, which have been co-created between stakeholders and researchers. The strands are:

- Enabling independence and autonomy/rangatiratanga of older individuals and their whānau and families
- Ensuring a meaningful life through social integration and engagement
- Recognising at a societal level the value of ongoing contributions of knowledge and experience of older people
- Reducing disability
- Developing age-friendly environments.

These strands have directed development of the initial portfolio of ten research projects encompassing research on maintaining social integration, including staying in work, on housing tenure and independence, dying well, healthcare needs of retirement village resident, reducing impacts of polypharmacy, preventing stroke and cardiovascular disease through coaching and reducing stroke impacts through new technology.

The Challenge will utilise a Knowledge Exchange Transfer framework which is based on the principles of co-creation and knowledge exchange between researchers and knowledge users. There is little more critical to the success of the Challenge than involving the organisations and individuals who will implement the new knowledge delivered by the Challenge. The Challenge has already consulted with policy makers and over 50 organisations who provide healthcare, accommodation or other support to older people and will work with these groups to create a Knowledge Exchange Partners Group of stakeholder representatives.

Research will be linked by the use of big and collaborative data. New Zealand has near unique data infrastructure, including the National Health Index and linked administrative datasets. New Zealand participates in two very significant international data collection exercises, which will be available to the Challenge - we were the first country to institute mandatory use of the interRAI, an internationally-aligned ageing assessment and we are also part of the International Life and Living in Advanced Age (LiLACS) study, which includes a significant Māori cohort.

The Challenge is a collaboration between the Universities of Otago, Auckland, Canterbury, Massey, Waikato, Victoria and Auckland University of Technology together with the Centre for Research Evaluation and Social Assessment and AgResearch. The researchers are a multidisciplinary mix, involved in social, demographic, policy, health services, public health, clinical and biomedical research. Their international linkages, together with the advice and support of a highly experienced International Science Advisory Panel, will ensure the Challenge delivers high quality research that is well linked with international activities.

The University of Otago will be the contract holder for the *Ageing Well* Challenge. An independent Governance Group, with four members and an independent Chair, has been established to oversee the strategic direction of the Challenge and support the Director, Science Leadership Team (SLT) and Management Directorate (a subset of the SLT with responsibility for operational activities).

Dynamism and refresh will be ensured through renewal in the Governance Group and SLT, research colloquia and contestable funding and support of a portfolio of research including research with considerable stretch. In addition, upskilling of researchers at all stages in their careers will contribute to refresh throughout the *Ageing Well* research community.

The Challenge will link closely with *Healthier Lives* and *A Better Start* and has team members in common with *Rangahau Roro Aotearoa/Brain Research New Zealand* for Brain research and *Building Better Homes, Towns and Cities*. The proven track record of the *Ageing Well* research teams, together with the proposed research strategy and collaborative approach, will ensure that *Ageing Well* will make a significant positive difference to the experience of ageing in New Zealand.

# OVERVIEW

# 1. OVERVIEW

## 1.1. The Ageing Well Challenge

### 1.1.1. Vision and Mission

The **vision** of *Ageing Well* is to:

- add life to years for all older New Zealanders

This will be achieved by harnessing science to sustain health and wellbeing into the later years of life, in ways that:

- Allow personal dignity to be preserved into old age by mitigating mental, cognitive, and physical disability;
- Support health, wellbeing and independence for all New Zealanders as they age;
- Recognise the resourcefulness of older people and their on-going social, economic, and cultural contributions to society; and,
- Enable *Ageing Well* through mutual respect, support, and reciprocity amongst people of different ages.

The **mission** of *Ageing Well* is to:

- push back disability thresholds to enable all New Zealanders to reach their full potential through the life course with particular reference to the latter years of life.

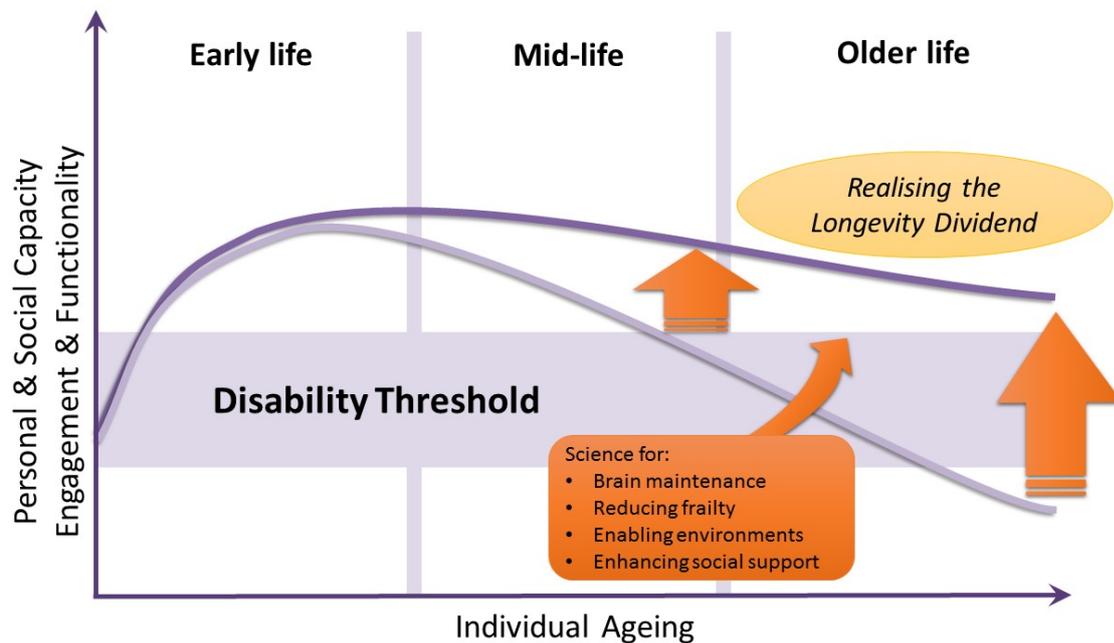
This will be achieved through delivery of our programme of research, underpinned by:

- Creating an environment that encourages collaboration between researchers who specialise in ageing research, so as to develop the innovative strategies needed for realising the potential of the longevity dividend (five interlinking strands of research);
- Engaging continuously with consumers and stakeholders from the health and disability, voluntary and community services sectors who are at the front line of support for New Zealand’s older people in an increasingly diverse and complex ageing society (the emphasis on co-production of research and an integrated knowledge transfer model);
- Infusing the research programme with the principles of *Vision Mātauranga* which seek to transform the burden of poor ageing that falls disproportionately on Māori and give expression to the long and rich tradition of Māori valuing and using older people’s knowledge and wisdom.

**Table 1 The Ageing Well National Science Challenge**

<b>Vision</b>	Add life to years for all older New Zealanders				
<b>Mission</b>	Push back disability thresholds to enable all New Zealanders to reach their full potential through the life course with particular reference to the latter years of life				
<b>Strands</b>	1	2	3	4	5
	Enabling independence and autonomy/ rangatiratanga of older individuals and their whānau and families	Ensuring a meaningful life through social integration and engagement	Recognising and enabling the value of older people	Reducing & preventing disability	Enhancing age friendly environments

**Figure 1 Functional capability over the life course now (lavender line) and as a result of Challenge outcomes (purple line) – pushing back the disability threshold (adapted from Kalache, 2013:16).**



### 1.1.2. 10 Year Plan – Research Strategy

The context of *Ageing Well* in New Zealand is the intersection of three unprecedented global trends in the developed world - increasing longevity, declining fertility and accelerating human mobility. Humanity is entering uncharted territory with ageing societies and increasing burden of age-related disorders. Therefore new approaches are required to address health and wellbeing. Realising the full benefits of the ongoing longevity dividend is not simply about reducing the fiscal burden and costs of ageing, it requires proactive measures that identify and realise the larger societal gains that can accrue from successful ageing. It is in this context that *Ageing Well* seeks to achieve the best personal and social outcomes for all New Zealanders. This will be achieved through *integrated* research that focuses on ways to push back the disability threshold by optimising brain and body health, and social and physical environments, for older people.

Integration is fundamental to this programme and will take place in many dimensions – our research will integrate:

- across multiple individuals, multiple organisations, addressing all the different aspects that contribute to individuals crossing the disability threshold,
- with mātauranga Māori, Pacific and pakeha cultures,
- with our consumers and stakeholders from health and disability, voluntary, and community service sectors.

*Vision Mātauranga* is fundamental to the Challenge vision of adding life to years for all older New Zealanders. *Ageing Well* recognises that a transformative approach is needed to address the significant inequities experienced by Māori in older age and the distinctive needs and circumstances of older Māori and their whānau. It also acknowledges the unique knowledge and world view of Māori can inform approaches to ageing well applicable to all older people. By integrating Māori knowledge systems, people and resources across our Challenge portfolio and processes, we seek to ensure that we ask the appropriate questions, and adopt the best approach, that will deliver the greatest benefit for older Māori.

The Challenge has identified five Research Strands to deliver on the *Ageing Well* mission. These five Strands capture the themes specified in the Gazette notice, while facilitating integration, and a focus on the specific needs and opportunities for New Zealand. Many of the research projects funded at the start of the Challenge deliver to multiple strands.

**Table 2 Research strands**

Research Strand long title	Short title
Enabling independence and autonomy/ rangatiratanga of older individuals and their whānau and families	Maintaining independence & autonomy
Ensuring a meaningful life through social integration and engagement	Social integration & engagement
Recognising and enabling the value of older people	Valuing older people
Reducing and preventing disability	Reducing disability
Developing age-friendly environments	Age-friendly environments

To make significant impacts on Challenge Outcomes requires collaboration between researchers in a wide range of disciplines. Neurodegeneration, stroke, gerontology, physical function, osteoarthritis, fracture prevention, primary health care, economics, demography/epidemiology, geography and social science all have a role to play in addressing the diverse social and economic drivers of *Ageing Well*. This is a fundamental step-change in the approach to research on ageing in New Zealand; rarely have interdisciplinary teams, spanning the medical, health, and the social sciences, attempted an integrated approach to address the challenges of ageing. The strategy that is being pursued is to continuously leverage interdisciplinary opportunities to generate new knowledge by new enquiry, through harnessing existing datasets and through collaborations, contributing to all three Challenge themes simultaneously through the 5 Research Strands.

Our strategy for the 10 years is:

- Support projects which align with the Research Strands outlined in Section 1.1.4.
- Support an initial core set of research projects as described in Section 2.1, prioritised using a set of principles (Section 1.4.7) which will be reviewed through the course of the Challenge. These projects will be delivered over Years 1-5 and included in the regular evaluation and review process of the Challenge.
- Run a contestable funding round in years 1-2, expanding the scope and potential impacts from the initial portfolio of research projects, while ensuring new people and ideas are incorporated into the Challenge's work.
- Carry out a major review during Year 5, documenting delivery to the Challenge outcomes, to the Challenge benefits (Section 1.6) and contributing to the external Challenge review process which will occur by the end of Year 5.
- Develop the set of research projects to be funded through Years 5-10, based on revised priorities and achievements/outcomes as defined through both the internal and external review processes.

### 1.1.3. Vision Mātauranga

*Vision Mātauranga* and mātauranga Māori are crucial to the *Ageing Well* Challenge. The detail of *Vision Mātauranga* is provided in Section 1.3. *Vision Mātauranga* is critical to *Ageing Well* because:

- Māori have a long, rich and innovative culture in which older people's knowledge is actively valued, recognised and used.
- The current burden of poor ageing falls disproportionately on Māori populations and communities both in urban and rural areas.
- Māori communities have shown a particular commitment to developing formal and informal processes, services and practices to support older people to age positively in place and those pathways have potential for New Zealand as a whole in the context of structural ageing.
- Iwi and hapū, urban Māori organisations, Māori businesses, and Māori individuals have long been service providers in social service and health service provision to older people as well as in the provision of older people's housing solutions.

Māori cultural commitments to Manaaki Tangata are strongly articulated, particularly around older people. However, there is considerable evidence that Māori older people are under-served by health, social, and housing services in the public and private sectors. Inequalities in access and material resources are reflected in the persistently smaller longevity dividend available to Māori. This reflects the current challenges for Māori of ageing

well. Moving the Māori disability threshold is critical for achieving the cultural, social and economic aspirations of Māori and optimising Māori potential for Māori. It is also critical for New Zealand.

Māori, in common with Pacific Peoples in New Zealand, have a relatively young population structure. Their ability to age well is crucial to New Zealand’s economic and social vibrancy in the context of current dynamics of Pākehā structural ageing. Māori have cultural traditions of elder respect and traditional authority, which have and are being innovatively developed in the context of significant changes, particularly around intergenerational relations associated with globalisation and migration. The issues for many towns and communities of social, cultural and economic adaptation to depopulation associated with out migration of young people and low fertility levels in the remaining population are only starting to be acknowledged. But Māori rural communities have dealt with those dynamics for many generations and have been finding innovative ways in which to value and build from the knowledge of older Māori.

#### 1.1.4. Research Strands and their fit in the national research landscape

Our Research Strands are intimately interlinked with the Gazette Outcomes as shown in Table 3. These goals are themselves interlinked: physical mobility and cognition are inherently linked, functional ability and social engagement go hand in hand, while economic participation and good mental and physical health are strongly related.

The range of potential research that could be pursued within the ambit of the *Ageing Well* themes in the Gazette Notice is vast. The 5 research strands are designed to highlight interdisciplinary research areas that span the three themes, resulting in outcomes that will ultimately allow older people the ability to remain active and engaged in society and the stay in their homes longer. In each strand we have selected priority areas for research; this will be reviewed and gaps filled in the contestable funding and second tranche of research project selection for Years 5-10. Each Strand has a designated coordinator from the Science Leadership Team.

**Table 3 Challenge Research Strands as related to the Gazette themes**

Challenge Themes	Maintaining brain health	Dealing with physical frailty	Enhancing the role of older people in society
Maintaining independence & autonomy	Living environments that recognise physical and mental realities for older people  Limiting major neurological disorders and their consequences	Living environments that recognise physical and mental realities for older people  Interventions to slow down onset and reduce impact of frailty	Interventions to slow down onset and reduce impact of frailty  Interventions to reduce social isolation  Sustaining participation in paid and unpaid work
Social integration & engagement	Interventions to reduce social isolation  Sustaining participation in work	Social integration is strongly linked with better health outcomes i.e. reduction of frailty	Interventions to reduce social isolation and improve integration  Sustaining participation in work
Valuing older people	Improving neurodegenerative end-of-life care	Recognising the negative impact frailty, falls and neurodegeneration have on older people and developing effective interventions	Sustaining participation in work  Enabling civic engagement
Reducing disability	Limiting major neurological disorders and their consequences	Reducing frailty, falls, stroke and major illnesses and their consequences  Living environments that recognise physical and mental realities for older people	Interventions to slow down onset and reduce impact of frailty on social isolation  Sustaining participation in work

Age-friendly environments	Living environments that recognise physical and mental realities for older people	Living environments that recognise physical and mental realities for older people	Enabling and valuing participation
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The Challenge notes that the Gazette themes do not easily encompass dying well. This concept is important as an integral part of living, and thus ageing well. In this context dying well is consistent with the mission of adding life to years. In particular the Challenge identifies that the research strand “valuing older people in all settings” should encompass research activities relevant to end-of-life care.

#### 1.1.4.1. Enabling independence and autonomy/rangatiratanga of older individuals and their whānau and families

Independence in old age is determined by physical and mental abilities and the context in which older people live (1-4). Autonomy and the ability to make decisions and chose activities to undertake on a daily and episodic basis are part of independence (1, 2, 4-7). However, there are difficulties in characterising the conceptual and interrelated features of autonomy and independence (5, 8). Recently, the term independence was reported as having multiple meanings for older people although certain features were common to all living situations. These were: accepting help at hand, doing things alone, having family, friends and money as resources; and preserving physical and mental capacities. Interestingly, a broader definition also emerged, which included concepts of relative, spatial and social independence (4).

As noted above, maintaining brain function and cognition is essential to independence and autonomy and a key component of this strand. Strategies to prevent degeneration and the impact of degeneration on function and independence are important (6, 8-10). Dementia due to neurodegenerative disorders (such as Alzheimer’s disease and Parkinson’s disease), and stroke, are the major brain disorders affecting cognitive decline and are primary contributors to mental and physical disability (6, 10, 11).

Over 95,000 New Zealanders (2% of the population) are currently living with dementia and/or stroke and this number is projected to reach 150,000 (3%) by 2026, adding significantly to an already \$955 million in direct costs (12-14). Stroke and dementia are interrelated, and having a stroke doubles the risk of dementia (15). Likewise, cognitive impairment is an independent risk factor for stroke (16). Determining strategies to prevent or moderate the cognitive impact of brain pathology is essential to alter the current trajectory of burden and disability related to dementia. Linked to dementia and autonomy is physical health, requiring efforts to maximise physical health, reduce harms from inappropriate treatments, reduce disparities in health outcomes, reduce institutionalisation, and understand the risks for situations characterised by low levels of autonomy (2, 8, 11, 17-19).

Within this strand, efforts to maximise physical and mental health, reducing harms from inappropriate treatments, and reducing disparities in health outcomes, reducing institutionalisation, and understanding the risks for low autonomy and independence are paramount to the research to be undertaken. The keys to maintaining independence and autonomy are good physical and mental health, which are inextricably interlinked with management of care (5-7). In addition, location and age-friendly housing are a fundamental part of independence (1). Functionality can be affected by socio-cultural settings, as well as policy and service settings, the age-friendliness of the environments in which people live, and the material circumstances of individuals (1, 7, 10, 18).

##### *State of the Art Research*

Stroke is preventable in over 80% of cases, while delaying the onset of dementia by 5 years would reduce its prevalence by 50% (20). Effective preventative strategies and predictive biomarker strategies are needed specific to our New Zealand population and that take account of our ethnic diversity and environmental uniqueness (17, 18). Using big data strategies to harvest and interrogate our existing longitudinal data sets, such as the world-renowned Dunedin Multidisciplinary Health and Development birth cohort study, the LiLACS NZ cohort, which includes over 400 Māori over 80 years old, as well as the InterRAI dataset and PREDICT or similar cardiovascular prediction screening tool, are key opportunities to explore novel questions that may impact on planning strategies and policies for older New Zealanders

### *Research Gaps*

The wide range of potential research areas means that there is a need to identify more immediate research gaps and longer term research areas. Immediate research gaps that have been identified, where relatively quick gains can be made, are:

- Identifying methods to ameliorate loneliness for older people of different cultural backgrounds, given that loneliness is a key negative determinant for wellness. Amelioration of loneliness includes active participation in society, both in paid and unpaid work;
- Reducing the incidence of primary stroke and cardiovascular disease in older people through coaching, rather than medical measures and identifying new ways to return people to independence after stroke;
- Reducing the negative impact of polypharmacy on wellness.

In addition, there are a considerable number of other research gaps appropriate to this Strand. Neurodegenerative disorders leading to cognitive decline and dementia have a major impact on wellness and independence. Being able to monitor the course of decline and predict the transition from early cognitive decline to dementia are crucial, as are interventions implemented early enough to modify disease. There is potential to develop biomarkers which monitor decline. Developing and testing home-based cognitive interventions for people with stroke, mild cognitive impairment and early Alzheimer's would reduce the stress related to travel to intervention sites.

New models of service support as well as care are being developed, emphasizing resident-centred approaches, new structural arrangements (including buildings) for care, and new ways to deliver food, and health care (telemedicine) that encourage participation and autonomy (1, 6, 10, 19, 21). However, operationalisation of these in New Zealand is low and their acceptance by older New Zealanders across different ages and cultures is largely unknown until interventions are put in place and assessed.

#### 1.1.4.2. Ensuring a meaningful life through social integration and engagement

Ageing is as much a social process as it is a physical and psychological one. The ability to remain integrated and engaged in society is crucial to ageing well. The benefits of social engagement across the lifecourse are well established. This research strand focuses on understanding and enabling social integration and engagement to maintain and enhance wellbeing at older ages.

Social relationships influence the health and wellbeing outcomes of older adults. Supportive social networks (including family, friends and work colleagues), participation in social groups, and a sense of belonging and purpose, have been linked to a broad array of mental health and health outcomes (22). Engagement through contributions to family/whānau, community and society, by working, volunteering, or caregiving, are also important aspects of health for older people. There is considerable evidence that participation in meaningful and appropriate work is beneficial to the wellbeing of older people (23). In addition to paid work, volunteering offers health benefits that facilitate successful ageing (24), and provides a major resource for communities by leveraging intergenerational capital to create shared purpose. Informal care is an essential part of the health care system and provides many benefits including improved patient outcomes, reduced unnecessary re-hospitalisations and residential care placements, and considerable savings in health care expenditure. However, caring for a relative or friend can also be burdensome and have negative impacts on health and wellbeing.

Barriers to contributing to family, community and society through work or volunteering, may include lack of resources such as income, transport and time, inflexible workplace practices, ageist attitudes and poor health or disability (25, 26). Such factors prevent desired contribution, cause discomfort and distress, and exclude some older people (27, 28). People who are unable to contribute experience isolation and alienation from communities and the wider society (28, 29). Participation, including contribution to family/whānau, community and society by working and volunteering, contributing to marae activities and governance, or caregiving in the home, is an important aspect of health for older people (30).

This strand recognises that the social environments in which older adults are embedded are instrumental in enabling them to develop and maintain supportive social relationships; and in facilitating participation in formal and informal volunteering. The key goal of this strand is to increase opportunities for social engagement for older New Zealanders by developing strategies that enrich social environments to reduce social isolation; remove barriers to participation; and enhance and mobilise social and cultural capital across communities, whānau, families and organisations.

### *State of the Art Research Nationally and Internationally*

Social integration is conceptualised as a multidimensional construct consisting of social engagement across a wide range of social activities and relationships (31). Considerable international evidence demonstrates that various aspects of social engagement are associated with better health and health outcomes (32), including better quality of life (33) and lower levels of loneliness and discrimination (34, 35). Conversely, social isolation and social disengagement in older adults impacts on health, well-being and quality of life (36).

Older adults are at greater risk of being socially isolated and rates of loneliness in older New Zealanders are comparatively high compared to other countries (37). Both paid and unpaid work (including formal and informal volunteering), are also important aspects of social integration for older adults and facilitate social engagement. Older New Zealanders generally want to contribute to society but many face barriers such as poor health, low income or ageist attitudes (38). Thus, those who could most benefit from social engagement are also those in most need of support to participate.

There are a number of relevant current and ongoing research projects and programmes in New Zealand that inform the direction of this research strand. The Dunedin Multidisciplinary Health and Development Study has tracked the social relationships of their participants (now aged 42-43 years) over time and provide information regarding social engagement in early life and early to mid-adulthood. The ongoing Health, Work and Retirement (HWR) study and the Life and Living in Advanced Age study (LiLACs NZ) continue to explore the influence of social engagement on health and wellbeing with longitudinal cohorts in the young-old and old-old age groups respectively. These studies provide the opportunity to explore the distinctive social engagement landscape in New Zealand due our unique demographic and cultural profile. In particular, the design and sampling of these studies make them strongly placed to inform research in this strand as it addresses theme three of Vision Mātauranga – Hauora/Oranga: Improving Health and Social Wellbeing.

The positive effect of social integration and social relationships has been demonstrated in some circumstances to be as impactful as well-established risk factors for chronic disease and mortality such as smoking, hypertension, obesity and physical activity (22), suggesting the possibility of a powerful tool for beneficial intervention. However, previous interventions to enhance social integration have often been of poor quality and report disappointing results (39, 40). New Zealand has a unique cultural profile with a large indigenous population and large numbers of overseas-born residents from European, Asian and Pacific Island countries. To enhance social environments for all older New Zealanders, we need sound understandings of how social networks function in the context of rapid ethnic diversification and how new models of social integration can be practically supported.

### *Research Gaps*

Despite consistent evidence over many decades for the health benefits of social engagement, we still understand little about *how* social connections and the social environment in which they are embedded actually influence health and well-being (41). Perhaps reflecting this lack of understanding, only a small number of interventions aimed at enhancing social integration (39, 40) and reducing isolation or loneliness (42, 43) have been effective. We also lack detailed understanding of the mechanisms by which volunteering benefits health, including the optimal “dose response” of those benefits (24).

This strand of research will therefore investigate:

- The risk factors that can be identified that indicate likelihood of reduced social engagement in older people.
- How to ameliorate social isolation as understood and experienced by older New Zealanders.
- How to facilitate inclusion of older people in both paid and unpaid work and the relationships between participation in work and loneliness, isolation and health.

Research foci for this Strand include:

- Use of existing and ongoing data collected from a mandated service assessment tool, the International Residential Assessment Instrument (InterRAI), to determine the complex interplay of factors that lead to reduced social engagement in older New Zealanders.
- Exploring the impact of Age Concern’s Accredited Visiting Services on social isolation and loneliness amongst older people to better understand the mechanisms mediating impact on wellbeing.
- Use of existing public datasets to identify important predictors, investigate the effects of aspects of participation on social isolation and health for different groups and statistically model the outcomes of projected policy applications.

There are areas where further research investment in this research space would be productive. For example, older New Zealanders are increasingly adopting computer networking and the associated technologies (44). It is important to examine how these technologies may be used to enhance supportive social networks and social engagement. In addition there is evidence that the internet is being used to provide support for those with chronic or stressful conditions (22), however evaluation of internet social support resources for health conditions in older adults is limited.

Constructed communities such as retirement villages are very popular in New Zealand and may provide more socially supportive environments. However, they are often limited to those with sufficient financial resources to pay a large capital sum and may segregate older adults from the rest of the community (45). A focus on understanding housing arrangements in terms of their ability to support social integration may be a key aspect of supporting the health of an ageing population in New Zealand.

#### 1.1.4.3. Recognising at a societal level the value of ongoing contributions of knowledge and experience of older people

In societies where population ageing is occurring, the policy priority has been on finding ways to reduce the economic and social burden associated with ageing-related disease and dependency (46). Fiscally-driven solutions have focused on the mitigation of costs associated with pensions, healthcare and social care, while prolonging the period that older people remain in paid work. Implicit is the notion that, as people reached advanced age, the cost of support outweighs the value of the societal contribution they make.

Recent studies quantifying the contributions of older people have begun to challenge this assumption, suggesting that older people not only represent a net gain financially through tax contributions and consumer behaviour, but also contribute ‘hidden’ value in terms of their knowledge, experience, and commitment (47). A key challenge for ageing policy is to move beyond a deficit model of cost reduction to a more expansive concept of value as it relates to older people in diverse contexts, and to put in place structures and processes that enable the full value of those contributions to be realised. The goal of this strand is to effect a major step change in the social and economic valuing of older people in New Zealand, so that their roles and contributions are enabled and sustained within their culture and communities. In particular it focuses on the pathways that enable the smarter utilisation of older peoples’ experiences, wisdom and mātauranga in the labour market, civil society, and in whānau/family contexts. This includes the development of innovative methods that leverage the expertise and knowledge of older people as catalysts for realizing the longevity dividend.

##### *State of the Art Research*

Population ageing in high-income countries has stimulated a great deal of interest in policy solutions that lower the costs associated with ageing while maximising the potential benefits. The concept of value is largely driven by fiscal considerations, with research focused on the relative costs and savings of adjustments to age-related pensions, health care provision, and time spent in paid work (48, 49). Recent research has extended this concept of value to quantify the formal and informal contributions of older people, taking account of the growing ‘silver economy’ (50), volunteering, altruistic giving and caring for others. Efforts to monetise the value of older peoples’ contributions have identified a largely untapped potential for communities and businesses to more effectively utilise the skills and experience of older people.

In New Zealand, the labour market engagement of older people is among the highest in the OECD (51). In 2013, nearly one third of the usually resident male population aged 65 years and over were in the labour force; for older women the share was one in six (52). Rates are typically higher for older Māori especially at ages 65-74 years (53). Rather than focus on increasing participation rates, the challenge for NZ is to improve the quality and benefits of working for longer through closer alignment between older workers’ resources and the demands of the job (39-41). The psychosocial characteristics of the work place are key aspects of job satisfaction for employees. One source of dissatisfaction is inflexible work policies that make it difficult for older workers to balance their often significant caregiving responsibilities with the demands of paid work (54).

The value of older peoples’ contributions extends beyond the monetary. In many communities, particularly those where accelerated population ageing has occurred, older people provide the “social glue” through volunteering, leadership, being good neighbours, skills and experience, advocacy and underpinning the viability of local services. The benefits of engaged social participation are reciprocal, benefiting both communities and the older people, as also noted in Strand 2.

New Zealand is fortunate in that cultural models of older people as a resource are readily available. Māori have a long, rich and innovative culture in which older people's knowledge is actively valued, recognised and used within whānau, in institutions such as marae, and through particular roles (e.g., kaumātua) (55, 56). This valuing not only provides older Māori with pathways for engagement, but also strengthens intergenerational relations. Pacific Peoples and Asian communities also have traditions of venerating older people. Leaders and spokespeople in the meeting houses in different Polynesian, Micronesian and Melanesian communities are invariably older men. In Chinese families, filial piety has a significant impact on the support for older family members, although restrictions on immigration of elderly parents, which is becoming a common feature of immigration policies in most developed countries, can create severe tensions for families living transnational lives.

#### *Research Gaps*

Leveraging the value of older people in an ageing population involves rethinking the intergenerational contract – the implicit expectation that future generations will be willing and able to provide the services and supports to those generations that have gone before them. In many countries there are indications of change in 'mentalities' or tastes around intergenerational reciprocity, as well as misalignments between these and service provision and practice and the capacity for mutual support. In New Zealand, there is evidence of ongoing mutual support between generations of all cultural groups. Equally, however, there is emerging evidence of assumptions that some ethnic groups maintain 'traditional' practices of piety, authority, and support, which appear to diverge from the reality of the experience of both older and younger generations.

It is unclear how changes in the intergenerational contract may impact on the demand for health and social services or housing adjustments that may need to be made to ensure that older people can maximise independent living, continue to make social and economic contributions, and optimise their health through to end of life. In the context of paid work, we know that older people often have significant caregiving responsibilities to spouses/partners, elderly parents and sometimes children and grandchildren, and that these can act as barriers to engagement if not matched with flexible workplace policies. Likewise, the capacity to give to others through volunteering and other acts of reciprocity is diminished where resources are limited and there is poor health or disability.

*Ageing Well* will incorporate research on 'Enhancing the role of older people', addressing the factors that enable the participation of older adults in paid and unpaid work (see strand 2). A key strategy for realising the potential of the longevity dividend is the "development of policies to foster the active participation of healthy individuals over age 55 in formal work and informal volunteering" (57). This research will provide new knowledge about the participation needs of increasingly diverse groups. This knowledge will be used to develop and enhance 'best practice' to support older citizens to continue to make contributions to family, community and society through paid and unpaid work for longer. Drawing together epidemiological and social policy research will enhance our understanding of the ways in which older adults, and the large cohort of "baby boomers" as they enter old age, will be living in our society across the next 30 years.

*Ageing Well* will also address how we, as a society, can better value our older people at the time of their greatest vulnerability and need; when they are dying. The vast majority of people die in their later years, hence ageing well includes dying well. Supporting the best quality of life (QoL) possible even in the face of severe disability and impending death is critical to older people's wellness. In New Zealand and internationally there is a lack of evidence on what individualised interventions work that can improve QoL and reduce suffering for people with end-stage neurodegenerative conditions in aged residential care (ARC). In Aotearoa New Zealand, approximately 45% of people over 65 years old live in an ARC facility at time of their death, the highest rate of death in ARC facilities of any country worldwide (Broad, et al. 2013). It has been suggested that ARC facilities serve as a 'de facto' hospice for many older people due to the extensive palliative care they provide (58). Māori have higher rates of risk factors for dementia such as cardiovascular risk, depression, head trauma and substance use issues and very little is known about their use of care as well as their end of life experience in ARC (59).

This Challenge will identify best methods of delivering palliative care to older people in the health system, through the course of an illness rather than in the last phases of dying. It recognises the cultural context of dying, and the cultural and spiritual needs and the challenges faced by older Māori, their whānau, and those involved in their care. There is currently very little information about palliative care experience of Māori and Pacific Peoples with neurodegenerative conditions and this project hopes to provide valuable evidence to inform best care practices for Māori and Pacific Peoples and their families/ whānau.

Within the ambit of *Ageing Well*, there is considerable scope for innovation in terms of the ways in which research is designed and carried out with and for older people. *Ageing Well* will provide explicit opportunities for older people to shape the research through processes of co-construction and engaged participation that are sensitive to

cultural context as well as methodological innovation through closer collaboration with older Māori participants and stakeholders. This methodological component will be developed across the 10-year lifespan of the challenge and, consistent with *Vision Mātauranga*, will leverage well-established models of co-construction within Kaupapa Māori research accessed through Te Tira Rangahau Hauora.

One of the major gaps in New Zealand is that little research has been undertaken on the different ways in which older people are valued, and how that value is expressed. Within Te Ao Māori, as well as in Pacific societies and some other ethnic communities, there are well-defined structures and norms for valuing the contributions of older people. However there is a generally poor understanding of the factors and conditions that enable these expressions of value to be fully realised, and the ways in which these valuing systems might provide a protective buffer against the inequities that older peoples from underserved communities generally face.

#### 1.1.4.4. Reducing disability

All ageing New Zealanders will face some level of disability as the ageing process impairs their abilities. Physical disability is a risk factor for development of depression i.e. disability and depression may feed on each other, creating a self-reinforcing spiral of increasing psychological and physical decline (60) (which impacts on independence and autonomy – Strand 1, as well as social integration – Strand 2).

Disability can be thought of as at one end of a spectrum with well, active ageing at the other. Both ageing processes (61) and disease processes (62, 63) contribute to the disability cascade. Steps along the way can be defined with frailty being part of the complex vulnerability that puts older people at risk of developing disability. Specific events related to diseases cause disability directly; stroke is a good example of this, also injury from falls (64) or multiple comorbidities limiting function (65). Sometimes these disease-related events are sudden and sometimes gradual in onset. In contrast, development of frailty and disability from ageing processes can be hidden and more difficult to define in time.

Three of the major contributors to disability are problems with mobility (66), dementia (67) and depression (63). Depression modulates the experience of disability, such that someone with significant arthritis and no depression may be able to ‘box on’ and complete their activities necessary for independent living, thus not exhibit disability, whereas another person with significant arthritis and depression may feel overwhelmed and be unable to complete the same activities and thus require physical assistance and be ‘disabled’. Mental disability is an under researched area and can accompany ageing-related cognitive decline and dementia.

Mobility problems from falls, bone and joint problems and arthritis are the leading cause of physical disability requiring daily assistance among older people (68). Stroke is also a leading cause of adult disability. Multimorbidity is the accumulation of chronic conditions, constrains function, independence and can create disability (62). Multimorbidity increases with age, and is present in 60% of people aged 65-74 years; over 90% of the Life and Living in Advanced Age: a Cohort Study in New Zealand (LiLACs NZ) cohorts (Māori and non-Māori octogenarians) have more than two conditions (69). A consequence of multimorbidity is polypharmacy and potentially the inappropriate use of many medications, which is one of the most pressing prescribing challenges (70). Older people are particularly vulnerable to adverse consequences of inappropriate prescribing and compliance because of their many pills and conditions, which are associated with disorders at older age (71).

#### *State of the Art Research*

Reaching full potential at all stages of life is the mission of the *Ageing Well* Challenge. Preventing disability is essential, and managing disability with an emphasis on enablement and rehabilitation will also promote the realisation of potential for function and independence. The World Health Organisation (WHO) developed the International Classification of Functioning, Disability and Health (ICF) which provides a useful way to use terms and language and navigate the important relationships between bodily structures and functions and activities (72). Participation in life is the epitome of not being disabled and the constraint on participation is disablement. Contextual factors, psychological, personal and environmental, all impact on the experiences of participation in life and the activities of individuals as shown in Figure 2 (73).

Prevention and reduction of disability requires:

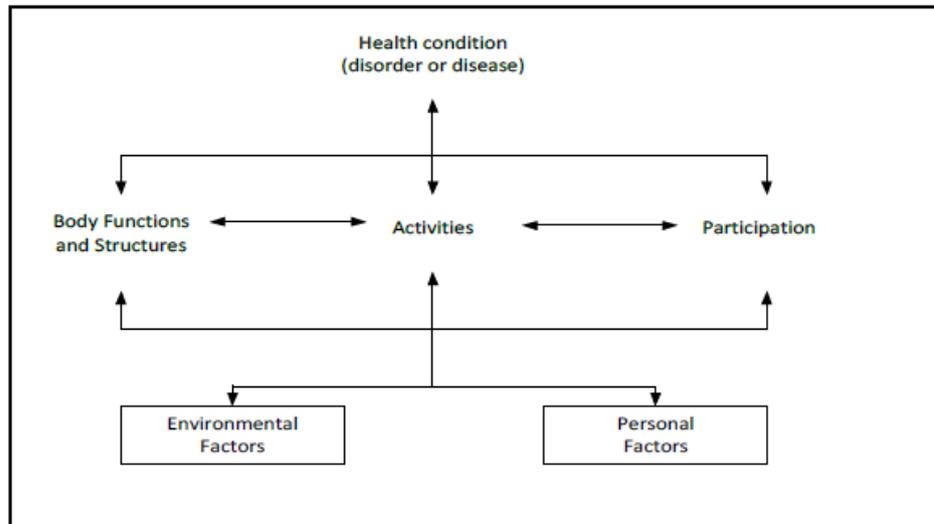
- a) accurate identification of disease processes leading to physical disablement – such as development of arthritis, bone fragility, stroke, falls, multi-morbidity;
- b) approaches to reduction in frailty and falls and increasing physical activity levels recognising that frailty is a vulnerability and any activity contributes to disability reduction;
- c) prevention of injury and rehabilitation from injury;

d) maximising function in those with disability such as those in residential aged care and those cared for in the community with disability.  
While there is considerable understanding of the disability pathways, more research is needed in specific areas.

#### Research Gaps

Given the issues with frailty, stroke and multimorbidity, priority areas of research for the Challenge are development of methods to sustainably impact frailty and falls and improve rehabilitation outcomes after stroke, focusing on reducing inequalities in levels of disability in older ages. As stroke is a leading cause of disability, sustainable ways to reduce stroke and improve cardiovascular outcomes are also of paramount importance.

**Figure 2 Impacts on experiences of participation in life**



#### WHO 2001, 18

In addition, with increasing longevity, the risk of developing osteoarthritis, osteoporosis and sarcopenia are significantly increased. Bone fragility, loss of skeletal muscle and function (sarcopenia) and joint disorders (osteoarthritis) contribute substantially to disability and the risk of frailty. The progression of these changes and risk of falls and hip fractures is assumed, but not well understood. A whole systems approach into the complex relationships between OA, osteoporosis, sarcopenia, frailty and falls are needed. Considerable research is needed in the area of disease processes involved in development of disabling arthritis, management of arthritis, the interplay between mental and physical disability and the additional disability related to both mental and physical problems.

Addressing these gaps will require focus on:

- Bone fragility, fracture and disability
- Relationships between OA, development of frailty and falls risk
- Interventions to treat OA, sarcopenia and loss of physical function
- Investigating a frailty index (FI) derived from InterRAI to personalise treatment of hips post-fracture

Depression, anxiety and addiction complicate disability. Mental health promotion, including lifestyle interventions and assistive therapies to reduce drug and alcohol addiction, are needed to improve function, reduce disability and increase participation in life. Cognitive decline due to neurodegeneration or sensory deficit compromises communication and participation in life and contributes to depression and social isolation. A whole of system approach to sensory deficit and cognitive decline will include better understanding of how ears hear and eyes see, how the mind processes and interprets sights and sounds, and the impact of devices to assist poor hearing and vision.

Addressing these gaps will require:

- Reducing multisensory deficit in combination with poor mental health
- Understanding the processes of cognitive decline and dementia and delaying their effects on physical function (Shared with Strand 1)
- Enhancing ongoing projects with attention to mental health measurement and investigation.

#### 1.1.4.5. Developing age-friendly environments

The development of age-friendly environments is recognised internationally as a critical requirement for ageing societies, if they are to optimise the productivity of people of all ages, value their contributions and enhance social integration. For older people affected by physical, sensory or cognitive impairment, age friendly environments can help compensate for those losses of personal functionality (74-84). The age-friendly environment strand of *Ageing Well* consequently weaves together and contributes to all the other Challenge strands. It also gives New Zealand researchers an opportunity to be at the cutting edge of significant advances in thinking internationally around age-friendly environments.

##### *State of the Art Research*

The primary objective of research, policy and innovation seeking to achieve age-friendly environments is to redesign elements of our world which are universally used by people of all ages, but which fail to meet the needs and functionality tests of people who face age-related constraints. As the framework for age-friendly environments has emerged over the last decade or so, the research platform has broadened to explore the barriers presented to people by the environments in which they live. The international framework for transforming our communities into age friendly environments focuses on four key dimensions. These involve developing:

- Existing and future built environments and settlements in ways that make them functional to people of all ages and capacities across all life stages (85-88).
- Building new, and retrofitting existing, dwellings to make them functional to people of all ages and capacities across all life stages (87, 89-97);
- Products with packaging that can be accessed easily and then used effectively and safely by people of all ages and capacities across all life stages (88, 98); and,
- Services that deliver effectively and responsively to people of all ages and capacities across all life stages (88, 99, 100).

At the core of research into age friendly environments is readjusting the built, product or service environments to ensure optimisation of older people and children, needs, functionality, engagement and independence. This dovetails with and complements research ensuring that the wellness, independence, autonomy and capabilities of individuals are maximised through improving gerontological health assessments and interventions with individual older people.

The age-friendly environments strand, then, contributes to older people maintaining their independence and autonomy (Strand 1), reducing the incidence of accidents and thus slowing progress of disability (Strand 4) removing barriers to interaction and enhancing social integration (Strand 2). The development of age-friendly environments allows the contributions of older people to be made and to be valued (Strand 3). Research on age-friendly environments focuses on ensuring that products, services and systems that are used by people of all ages are functional for older people as well.

New Zealand has lagged behind both in research and in solutions across all the dimensions of age-friendly environments. The NZ National Science Challenge initiative provides an opportunity to progress research across all relevant dimensions through synergistic links between the *Ageing Well* Challenge, which focuses on age-friendly services and age-friendly products, and Challenge 11 *Better Homes and Cities*, which is concerned, amongst other things, with research that promotes functional physical built environments, city systems, including transport systems, and dwellings.

##### *Research Gaps*

The importance of place is recognised as being a critical aspect of experience and transformational opportunities in age-friendly environments. Transformational goals, opportunities and research-based solutions will often be governed by specific spatial, material and cultural conditions in which people live. All the research projects in strand 5 are required to address the impacts of rural, urban or provincial contexts of age-friendly environments both in terms of experiences, opportunities and transformational solutions. This also applies in the cases of cultural and material contexts.

Research on age-friendly environments will be multi-method and will address issues at a range of scales from the individual through the household and community to national policy and service settings. The initial research programme that focuses on age-friendly environments is characterised by extensive use of national datasets and surveying which allow spatial factors to be understood, as well as careful selection of case studies to elucidate meaning and experience in specific material, place and cultural contexts.

It is expected that further research related to age friendly environments will be sought through the refresh and contestable funding processes over the life of the *Ageing Well* Challenge. The first project to be funded within this strand focuses on rental provision for older people into the future and what an increasing reliance on rental tenure will mean for ageing well. This has been prompted by three considerations:

- New Zealand is facing a profound change in housing tenure which is already affecting young cohorts and starting to affect older people as well. That tenure revolution involves falling rates of owner occupation across all age cohorts and the prospect that within the next few decades half the older people reaching retirement age will be renting (101-104).
- Rental tenure has been associated, here and overseas, with poor health and wellbeing outcomes. Understanding the tenure revolution and impacts on older people is critical for future policy and service planning, particularly as overseas research suggests that rental tenure is associated with higher probabilities of moving from living within their communities to high dependency living and residential care (89-91, 104-107).
- New Zealand research shows that income and living standards for older people are reliant on mortgage-free owner occupation. It is also likely, but yet to be demonstrated to what extent, that current health, informal and formal care, and other services assume high levels of mortgage-free owner occupation among older people. Falling rates of owner occupation are likely to make the efficacy of those settings increasingly questionable (104, 108-114).

This research project is at the cutting edge of research internationally around tenure as part of age friendly (or unfriendly environments). To date, both in New Zealand and overseas, housing-related research around older people has tended to focus on supported housing care models, opportunities for familial support within multi-generational households and equity release mechanisms for owner occupiers. More recently, attention has been given to accessible and functional housing through universal design and reducing barriers to take-up (87, 89-97). Little attention has been given to housing tenure transformation. Indeed, here and overseas, research into older people's housing frequently assumes that the macro-conditions, the distributional and institutional structure and characteristics of the housing market and housing sector will remain relatively stable.

But New Zealand faces not only structural ageing but also a housing tenure transformation shock - effectively a tenure revolution. It is that combination which raises critical questions about ageing well in New Zealand into the future. To what extent will reliance on the rental market inhibit or support older people's wellbeing and independence; promote or reduce older people's on-going social, economic and cultural contributions and reciprocities; and, reduce or support the mitigation of mental, physical, or cognitive disability to maximise engagement and personal dignity? The four year research programme selected for funding explores the impacts and dynamics of the tenure revolution and identifies adaptive strategies in a country with a geographically dispersed and culturally diverse population.

Overseas research on age-friendly environments is currently broadening our understanding of the following products and services (82, 83, 115-119):

- ICT-based services and businesses, particularly given that there is an increasing array of electronic services that older people find they need to rely on including insurance and banking, payment of rates and use of online portals in primary healthcare, and accessing of basic information such as public transport timetables.
- Innovation in the silver economy including lifelong banking and finance products and processes and universal designed products and packaging.
- Age-friendly access to public services and amenities including:
  - Justice and preventative services around elder abuse and family violence.
  - Transport and communications.
  - Leisure and recreational amenities.
  - Age-friendly hospitals, health services and treatment design and practice (linked with Strand 1).

None of these is currently prominent on the research agenda platform the ageing of New Zealand's population, or around the well-being, productivity and engagement of older people in their communities and the workforce. However, there is a pool of researchers in New Zealand with capabilities that can contribute to exploring and

resolving those issues across not only the social science disciplines but also design, engineering, ICT and management. The Ageing Science Leadership Group will encourage new collaborations that address these issues through responses to contestable funding rounds and refresh opportunities in the Challenge.

## 1.2. The Ageing Well Team

### 1.2.1. Science Leadership

**Professor David Baxter** has been Interim Director through the Commencement Phase. The Challenge will be led by a Science Leadership Team, including a permanent Director, all of whom will be formally appointed by 31 December 2015. It is currently intended that this Team will be comprised of the members of the interim Science Leadership Team (Table 4 and Appendix 5) who have taken the Challenge through its development process.

In addition there will be a formal executive for the Challenge, the Science Management Directorate, which will be appointed by 31 December 2015. This group will be a subset of the Science Leadership Team and will comprise the Director (0.5FTE), a Deputy Director (0.2FTE) and two additional members (0.1FTE each). The roles of the Science Management Directorate and Science Leadership Team are outlined in Section 3.3.1.

The interim Science Leadership Team has demonstrated its commitment to working together constructively to take corporate responsibility for development of the Research Plan. The team was designed to ensure a broad base of research expertise and experience across the many research areas and disciplines relevant to the five research strands of the *Ageing Well* National Science Challenge (Table 1). No single member of the team possesses the requisite expertise across all of the five research strands; rather, individuals are committed and able to synergistically contribute across the strands, as well as having extensive track records in research within their respective fields.

**Figure 3 Interim Science Leadership Team members**



**Professor Dave Baxter** (Director)  
University of Otago



**Professor Fiona Alpass**  
Massey University



**Professor Richard Bedford**  
Auckland University of Technology



**Professor Martin Connolly**  
University of Auckland



**Professor Valery Feigin**  
Auckland University of Technology



**Professor Ngaire Kerse**  
University of Auckland



**Dr Tahu Kukutai**  
University of Waikato



**Associate Professor John Reynolds**  
University of Otago



**Ms Kay Saville-Smith**  
Centre for Research, Evaluation and  
Social Assessment



**Associate Professor Debra Waters**  
University of Otago

**Table 4 Interim Science Leadership Team strand contributions**

Name	Research focus	Strand Coordination
<b>Prof David Baxter (Acting Director)</b>	Rehabilitation for chronic pain & musculoskeletal diseases, physical activity & health, medical devices for rehabilitation	
<b>Prof Fiona Alpass</b>	Health, mental health & wellbeing of older adults	Coordinator 2 Contributor 1, 3, 4, 5
<b>Prof Richard Bedford</b>	Population dynamics & movement, immigration policy related to population movement in context of ageing NZ society	Coordinator 5 Contributor 2, 3
<b>Prof Martin Connolly</b>	Geriatrics & gerontology, long term condition management, organisation of care (particularly residential aged care), the frailty syndrome	Contributor 1, 2, 3, 4, 5
<b>Prof Valery Feigin</b>	Epidemiology, prevention & management of stroke & traumatic brain injury	Contributor 1, 4
<b>Prof Ngaire Kerse</b>	Gerontology, primary health care with respect to maximising health for older people, fall prevention, quality of life, predictors of successful ageing	Coordinator 4 Contributor 1, 3
<b>Dr Tahu Kukutai</b>	Demography; Māori and Indigenous population dynamics; Quantitative and qualitative research design	Coordinator 3 Contributor 1, 2
<b>Associate Prof John Reynolds</b>	Brain disorders, learning models, behavioural analyses, disease models for Parkinson's and stroke, neurostimulation & drug delivery techniques	Contributor 1, 4
<b>Kay Saville-Smith</b>	Cross-sectoral, quantitative & qualitative research design, evaluation & policy analysis.	Contributor 1, 3, 4, 5
<b>Associate Prof Debra Waters</b>	Gerontology, body composition, physical functioning/frailty, community-based models for falls prevention & chronic conditions	Coordinator 1 Contributor 3, 4

\*Professor Richie Poulton (University of Otago, Director of Dunedin Multidisciplinary Health Study) has acted as Advisor to the Group.

### 1.2.2. International Science Advisory Panel

An International Science Advisory Panel of seven members (Figure 4) has been established comprising senior scientists with expertise covering the breadth of science of the *Ageing Well* Challenge. It is planned that membership of this Panel will be reviewed on a biennial basis, and will change over the life of the Challenge as it evolves. Review will principally be based upon (expertise) needs analysis, as well as the need to balance continuity with refresh through rotation of membership.

The International Science Advisory Panel's draft Terms of Reference are provided in Appendix 6 and their profiles in Appendix 7.

**Figure 4 International Science Advisory Panel members**



**Dr Ger Craddock**  
Centre for Excellence in Universal Design



**Professor Leon Flicker**  
UWA Perth



**Professor Jacobijn Gussekloo**  
Leiden University Medical Centre



**Professor Thang Leng Leng**  
National University of Singapore



**Professor Suzanne McDonough**  
University of Ulster



**Professor Christine Milligan**  
Lancaster University



**Professor Peter Schofield**  
Neuroscience Research Australia

The Panel will provide:

- an independent perspective on research plans and strategies,
- reviews of the quality and potential impact of research, as well as translational activities,
- confirmation that the science is innovative, meets international best practice,
- advice on new or evolving research opportunities,
- connections with international research programmes and networks.

### 1.2.3. 'Wise Heads' Group

A Wise Heads Group was set up in the Commencement Phase and the members are shown in Figure 5. They form a representative sample of knowledge exchange partners who have been consulted regularly in the process of creating the Challenge and this document. Their role is to:

- Act as a group independent of the Challenge.
- Give independent review of research proposals submitted for contestable funding (including those described in this Plan).
- Provide an independent perspective on the New Zealand context of research and identify gaps in the portfolio to be targeted through future contestable funding.

It is intended that the Wise Heads Group will form the basis for the Knowledge Exchange Partners Group.

**Figure 5 Wise Heads Group members**



**Mr Len Cook**  
Victoria University of Wellington



**Ms Wendy Fleming**  
Alzheimers New Zealand  
Charitable Trust



**Dr Malcolm Menzies**  
Commission for Financial  
Capability



**Professor Les Oxley**  
University of Waikato



**Ms Trina Tautau**  
Ministry of Health

#### 1.2.4. *Kāhui Māori*

The *Kāhui Māori* will support the three health and wellbeing challenges and will comprise representatives from key Māori groups, including iwi/hapū, working across the health, social, and education sectors. For *Ageing Well* the *Kāhui Māori* will provide advice and direction on:

- Realising Vision Mātauranga
- Strategic direction
- The research plan for feedback to the Science Leadership Team and the Governance Group.
- Reducing Māori health inequalities
- Capacity and capability building
- Implementation pathways and knowledge translation through engagement of communities in co-production of knowledge.

The *Kāhui Māori* Terms of Reference are provided in Appendix 8. At present an Interim *Kāhui Māori* has been created, comprised of 4 members (Figure 6). These members will consult with the Challenge Directors and propose the membership of the ongoing *Kāhui* (*Kāhui Tuturu*), to be established within 3 months post commencement. The Health Challenge Board Chairs will approve this membership. The appointment of a Chair of the ongoing *Kāhui* will be agreed with the Challenge Board Chairs.

**Figure 6 *Kāhui Māori* members**



**Professor Helen Moewaka Barnes**  
(Chair), (Ngāti Wai/Ngāti Hine/  
Ngāti Manu)  
Massey University



**Garrick Cooper**  
(Ngāti Karaua (Hauraki),  
Te Pirirākau (Tauranga Moana))  
University of Canterbury



**Distinguished Professor  
Richard Faull**  
(Ngāti Rahiri, Te Atiawa)  
University of Auckland



**Moe Milne** (Ngāti Hine, Ngapuhi)  
Independent Consultant

## 1.2.5. Stakeholder engagement & Knowledge Exchange Transfer Framework

### 1.2.5.1. Research end users

Research end users include the public of New Zealand, as well as those who provide healthcare, accommodation and other support for the older members of the New Zealand population, policy makers and the national and international scientific communities. Our sector engagement process to date has involved meetings with representatives of the groups listed below. We have also compiled a wider list of stakeholders (Appendix 9).

- *Ageing Advocacy and Relevant Health-related Groups:* Age Concern, Stroke Foundation, Alzheimer's Association, Arthritis NZ, Osteoporosis NZ, Grey Power.
- *Central & Local Government:* Ministry of Health, National Health Committee, Ministry of Social Development, Commission for Retirement Income and Financial Capability, MBIE (Housing), the Accident Compensation Corporation (ACC), Dunedin City Council.
- *Provider organisations:* Retirement Village Association, Abbeyfield NZ, Healthcare NZ, District Health Boards.
- *Community support organisations:* NZ Council of Christian Social Services, NZ Council of Social Services, Community Networks Aotearoa, Citizens Advice Bureau, Otago Community Hospice, Christian Fellowship For Disabled.
- *Māori community leaders:* Māori Business Unit Ministry of Health, AP Papaarangi Reid, AP Jo Baxter
- *Pacific community leaders:* Tagaloatele Dr Peggy Fairbairn-Dunlop, Hilda Faasalele, Dr Ofa Dewes, Pacific Trust Otago.

### 1.2.5.2. Knowledge Exchange Transfer Framework

*Ageing Well* is developing an integrated knowledge exchange transfer framework (KETF), based on the principles of *co-creation* and *knowledge exchange* between valued partners and researchers. Central to this model is partnership in which researchers and knowledge users – including communities, voluntary agencies, health service, ministries and New Zealanders – will together make decisions to shape research direction, interpret findings, derive key messaging, and move research findings into practice. The KETF is based on those developed by Canadian Institutes of Health Research (for example that shown at <http://www.cihr-irsc.gc.ca/e/45321.html> which draws significantly on the lessons of participatory action research).

The success of *Ageing Well* depends upon engagement with Knowledge Exchange Partners through a multiplicity of strategies, many of which we have embarked on. These include:

- Creation of a distribution list of key contacts;
- Engagement of stakeholders in development, management and governance through membership of the Governance Group and Science Leadership Team and hosting of a successful Stakeholders' Meeting in Wellington (20<sup>th</sup> April 2015), scheduled alongside the annual Age Concern National Meeting.
- Involvement of stakeholders in prioritisation of research selected for support by the Challenge,
- Development of advisory groups who provide input to Challenge Management regarding Challenge activities - the Wise Heads, the Kāhui Māori. In particular these groups have already contributed to prioritisation of research projects and development of the current Research Plan. They will form the basis for a future Knowledge Exchange Partner Group.
- Instigation of a social media engagement strategy to provide a platform for dissemination to researchers and stakeholders. Social media activities include a Twitter account (@ageingwellnz) and interim web site (<http://www.otago.ac.nz/Ageing-well/index.html>). In addition, a Facebook page is being developed to promote wider engagement with our communities.

As well as continuing the activities to date, future activities will include:

- Formal institution of the Knowledge Exchange Partner Group,
- Involvement of stakeholders in facilitation and planning of Challenge-related activities in fora such as an annual colloquium. The first of these is well underway, scheduled for 14<sup>th</sup> August 2015 in Wellington. It will provide a forum for the Challenge Interim Science Leadership Team and researchers to meet with stakeholders and the wider research community.
- Dissemination of information through reports and a social media strategy. The detailed communications framework for all stakeholders is provided in Appendix 11.

Input from the Knowledge Exchange Partners Group has informed the selection and shape of the first tranche of research projects within the Challenge. Continued engagement with the various groups providing advice will sustain

the focus of the Challenge on research that matters. For example, the Challenge intends that the scope of the Request for Proposals for the upcoming contestable round is agreed with the Knowledge Exchange Partners Group and the Kāhui Māori, and that recommendations for the second tranche of funding offered from 2019 are formed after advice from the Knowledge Exchange Partner Group, the Kāhui Māori and the Science Advisory Panel.

### 1.3. Vision Mātauranga

#### 1.3.1. Governance

The Challenge will continue its relationship with the Kāhui Māori group that has been established across *Better Start, Healthier Lives* and *Ageing Well* challenges to provide strategic guidance, support the science leadership and research teams and assist with integration of research and delivery efforts. The Kāhui Māori is based on a Treaty partnership model which recognises mutual relationships, responsibilities and accountabilities. Along with the International Science Advisory Panel, the Kāhui Māori has been involved in reviewing and advising on the overall research plan, and on the development of strategies to work alongside Māori communities and organisations.

#### 1.3.2. Management

The Challenge seeks to have Māori representation at the Management level. During the Challenge development, Tahu Kukutai was recruited to the Challenge Science Leadership Team as a researcher with significant experience in Māori population demographics together with the skills to have a high level vision regarding the active involvement of Māori in the Challenge and the delivery of the Challenge to Māori. The Governance Group, in its consideration of the permanent Science Leadership Team, will look for one or more candidates who can provide leadership and perspective from a Māori viewpoint.

#### 1.3.3. Research Leadership & Research Principles

The Tira Rangahau Hauora (TRH) is a group of Māori researchers and scientists involved in the health challenges. The purpose of TRH is to provide opportunities for shared knowledge translation and scaling up of community initiatives across the challenges and to give effect to *Vision Mātauranga* through collaborative cross-disciplinary research that leverages the relationships, expertise and knowledge networks of Māori researchers, scientists and communities. The focus for TRH is on enabling indigenous-driven solutions that can begin to transform long-standing inequities faced by Māori whānau and communities at all stages of the lifecourse.

The interim TRH comprises Māori PIs involved in the first tranche of core challenge projects but the intent is to leverage existing networks to draw in new researchers and ideas throughout the Challenge process. TRH will provide a mechanism to review and share relevant project learnings as well as partner for a cross-challenge Māori focused project which will be developed in partnership with the Kāhui Māori. TRH will also lead wānanga with challenge researchers (including potential PIs) to support them to integrate *Vision Mātauranga* into their research and to better engage with Māori research methodologies. *Ageing Well* is fully supportive of TRH and has committed resources to support the group to undertake its work and sees this relationship as crucial to maintaining the engagement of Māori researchers and communities throughout the 10-year duration of the Challenge.

All funded research projects in both the current tranche and in emerging research are required to guide their method and knowledge exchange pathway development by the key principles of:

- Aroha ki te tangata (respect)
- He kanohi kitea (face-to-face communication)
- Titiro, whakarongo, korero (look, listen and then speak)
- Manaaki (looking after people)
- Kia tupato (being cautious in one's approach)
- Kaua e takahia te mana o te tangata (respecting people's dignity)
- Kia mahaki (humbleness).

Research projects will report regularly on the opportunities for as well as previous engagements with Māori to activate innovation potential.

#### 1.3.4. MBIE Framework

*Ageing Well* is clearly aligned with two *Vision Mātauranga* themes: hauora/oranga and Mātauranga. The overall goal of *Vision Mātauranga* is to enable and leverage the innovation potential of Te Ao Māori and to advance the health and social wellbeing of Māori. Our approach to *Vision Mātauranga* (VM) is underpinned by the following core principles:

- Recognising and enabling the expertise, Mātauranga and experience that older Māori can contribute to the *Ageing Well* vision;
- Empowering Māori to lead and participate in *Ageing Well* at all levels, from governance, management and research to implementation;
- Developing innovative methodologies that harness and integrate, where appropriate, Mātauranga Māori and knowledge developed through western scientific paradigms;
- Providing pathways for Kaupapa Māori research projects that partner with Māori whānau and communities to develop projects that meet their needs;
- Respecting the different capabilities of researchers to engage with VM, and providing pathways to increase their capability to improve the effectiveness and relevance of their research.

The current research plan funds research which involves Māori as well as components of Māori-centred research. The current tranche of research projects include an explicit focus on Māori participation and the impacts of ageing and inequalities for Māori. Projects (see Section 2, Table 6 for detail of projects) on housing tenure (A), reducing frailty (B), social isolation (C), older people in work (D) and stroke and cardiovascular disease prevention (I) give effect to the principle of partnership as embedded in Article 2 of the Treaty of Waitangi through their sampling and/or analytic methods. *Vision Mātauranga* (VM) is integral to projects on housing tenure (A) and social isolation (C), reflected in the use of a strengths-based approach, Māori case studies, collaboration with end users/stakeholders, and/or the use of indigenous research methods led by Māori researchers.

Māori researchers and Māori centred research components are evident in projects on housing tenure (A) and social isolation (C). The importance of *Vision Mātauranga* to this *Ageing Well* Challenge is reflected in the use of a strengths-based approach, the Māori case studies and end users/stakeholders, and indigenous research methods led by Māori researchers in a number of the research projects funded in the initial tranche.

The team includes leading Māori researchers as well as tauwiwi researchers who have longstanding relations with Māori communities and stakeholders. The development of the *Ageing Well* research plan reflects the contribution of Dr Tahu Kukutai and, in the previous management team, Dr Fiona Cram. Senior Māori researchers or practitioners involved in the first tranche of *Ageing Well* projects include Dr Fiona Cram, Dr Alan Barber, Dr Tess Moeke Maxwell, Dr Hinemoa Elder, Dr Anna Rolleston and Dr Cameron Lacey, Mr Brendan Stevenson and Eruera Maxted.

It is recognised, however, that the opportunities for developing Kaupapa Māori research have yet to be realised. Similarly, that many non-Māori researchers wish to, and must if they are to be effective, better understand how *Vision Mātauranga* can be articulated and frame research across the gamut of research endeavours, approaches and methods. To drive the *Ageing Well* Challenge forward, the Challenge also intends:

- Inclusion of Māori on the Governance Group (see Section 3.2).
- Establishing and resourcing Māori collaboration at both the governance and research development levels including in the refresh processes (see Section 1.4.8)
- Establishing a series of wānanga with Tira Rangahau Hauora to provide intense engagement and skilling opportunities between non-Māori and Māori researchers.
- Considering assistance with resourcing Tira Rangahau Hauora to facilitate the development of a kaupapa Māori research programme across the three challenges: *Better Start*, *Healthy Lives* and *Ageing Well*.
- Using the colloquia and other stakeholder engagement strategies to develop a strong Māori presence and input into building on the current research platform. It will be directed to recognising and engaging the community of Māori researchers and other researchers that work with them to address the research needs of Māori for both the immediate contestable funding process and the development of the out-years' research programme.
- Development of co-produced tools (e.g. Project A and C) is a key way to achieve VM outcomes and transformational take-up. The importance of this is recognised in relation to IP management (Section 3.8), which expressly recognises the public good nature of this research.

## 1.4. Linkages

### 1.4.1. Big data

One of the features that links several areas of Challenge work is the use of big data. This is an emerging area in social and health research in New Zealand, though there are some strong existing capabilities. The near unique data infrastructure in New Zealand (including the National Health Index, a personal identifier that allows linkage of

disparate health datasets for an individual, and Statistics New Zealand’s Integrated Data Infrastructure which allows linking of national administrative datasets from many sectors), combined with existing expertise, will provide a significant opportunity for New Zealand to develop a world leading position in using big data to inform development and evaluation of social and health policy and interventions. In addition, use of existing data creates significant efficiencies, rather than new data collection being required. In the first tranche of Challenge funding, a number of projects are utilising big data as shown in Table 5.

The Challenge acknowledges that both the Better Start and Healthier Lives Challenges intend using big data approaches to address aspects of their missions. There has been cross-Challenge discussion about maximising impact of this type of research, and making effective use of investment and capability. The Virtual Health Information Network (supported by the Healthier Lives Challenge and outlined in detail there) will create a community of interest, sharing expertise and tools to support creating value from health and social sector-related big data. The *Ageing Well* Challenge will engage with the virtual network, contributing to and benefiting from the expertise, tools and techniques available through that community.

InterRAI is worth particular note given that it integrates not only across NZ health research but internationally. InterRAI is a non-profit international organisation that has developed and improved a standardised ageing assessment. The interRAI set of assessments was designed by a collaborative group of international experts as a comprehensive assessment tool for older people. It has had extensive research-based development to confirm the data produced is reliable and valid (120-122). The homecare 9.1 version used in this study consists of 236 questions and takes approximately 90 minutes to administer. After a trial period the interRAI has now been mandated from 2015 by the Minister of Health in New Zealand for all older people who are being considered for access to publically funded community services or aged residential care. All assessments include a question regarding consent and approximately 93% of assessed people who have given consent for their data to be used for research.

There are over 1800 trained assessors now in New Zealand. In order to produce high quality data a stringent Quality Assurance programme has been established and led by the Ministry of Health. All assessors are health professionals who undergo the two day interRAI training programme. Their work is subject to continuous monitoring and there are regular online updates and competency audits to be completed. All information is recorded electronically and stored at the national data warehouse. All data has a national unique identifier (called National Health Index number or NHI) and is stored using encryption for data security.

**Table 5 Use of big data in research projects**

Databases	Projects
Health Benefits funding database (Ministry of Health)	A, G, H
Health Survey (Time Series) (Statistics NZ)	A, G, H
Health, Work and Retirement Longitudinal Cohort database	D
HES (Statistics NZ)	A
Home Modifications Funding database (Ministry of Health)	A
House Condition Survey Dataset (BRANZ)	A
Health, Work & Retirement Longitudinal Study	B
InterRai (Health)	A, G, H, E
Life and Living in Advanced Age - LiLACS	B, D
New Zealand Censuses Datalab (Time Series) (Statistics NZ)	A, G, H
NZ Births, Death & Marriages Dataset	G, H
NZ National Minimum Dataset	G, H
Older People Downsizing Database (CRESA)	A
PREDICT and similar cardiovascular risk prediction algorithms used by GPs in NZ, Ministry of Health, General Practice databases	I
Residential Care Subsidy database (Ministry of Social Development)	A, G, H

### 1.4.2. Linkages to other Challenges and CoRES

There are synergies between *Ageing Well* and the other two health-related Challenge *Better Start* and *Healthier Lives*, since some disease processes are present across the life-span. The other Health Challenges are being delivered from the same institutions as *Ageing Well*, and some individuals are actively involved in multiple health Challenges. Directors of the three Health Challenges have already instigated regular monthly teleconferences and the Chairs have maintained regular communications over the Commencement Phase for the Challenges.

The National Science Challenge *Building Better Homes, Towns and Cities* Challenge proposal has been developed over the last few months and is now has Commencement funding to undertake the Research Plan development phase. Kay Saville-Smith and Richard Bedford of the interim Science Leadership Team have been involved in the series of meetings associated with the development of the proposal. Professor Richard Bedford has been appointed the Interim Director of the NSC *Building Better Homes, Towns and Cities* and the University of Otago has been represented on the Interim Governance Group of NSC *Building Better Homes, Towns and Cities*. These existing interfaces ensure that there is complementarity between the *Ageing Well* Challenge research plan presented here and the *Building Better Homes, Towns and Cities* proposal and there is a platform for fruitful synergies between the two Challenges.

The Challenge will align with the new CoRE Brain Research NZ - *Rangahau Roro Aotearoa*, which has as its vision “*Lifelong brain health for all New Zealanders*”. The Brain Research CoRE has identified the ageing brain as a focus and will establish a nationwide network of Dementia Research Clinics. These will be at hand for testing and implementing new research approaches to minimising impact of disability arising from stroke and dementia. This will be a unique flagship resource and a key vehicle for stakeholder engagement. The CoRE Directors have indicated their strong commitment and desire to engage with *Ageing Well* to facilitate participating researchers leveraging off the capabilities offered through CoRE research networks and nationwide clinic infrastructure. Ngaire Kerse and John Reynolds are CoRE Directors and members of *Ageing Well*'s Science Leadership Team. *Ageing Well* will also integrate with specialist researchers in areas not covered by the CoRE, including experts in the effects of addiction and broad lifestyle interventions, to both maintain and enhance cognitive reserve, and reduce an individual's risk of future chronic cognitive decline.

### 1.4.3. Linkages to international research

The *Ageing Well* Challenge recognizes the importance of international linkages both to support and drive forward cutting-edge research in New Zealand and to support New Zealand's own contribution to international knowledge. The international linkages maintained in this Challenge are of four types:

- Direct Challenge engagement with international researchers. This has already been established through the International Science Advisory Panel engaged to review the research projects, which were considered as part of the first tranche in the Research Plan. That internationally linked approach will be retained.
- Dedicated mechanisms within research projects in the research plan to involve either international researchers in the research project and/or an international research advisory group. A number of the initial set of projects supported use that mechanism.
- The use of data and/or instruments that are part of a formal, international comparative study or consortium. The data from LiLACS and, to some extent, interRAI data has those characteristics.
- Individual researchers' international linkages with overseas colleagues. The extensive nature of these is evident in researcher CVs.

It is the intention of the Challenge to support and foster all these types of international relationships throughout the Challenge. The many detailed links between research activities and international researchers and research agencies are shown in Section 2.4.2 (Table 9).

A major collaboration of note is the LiLACS NZ project, from which a number of research activities in the Challenge will draw data. LiLACS is part of an International Consortium of Longitudinal Studies of Advanced Ageing with three other groups. The Towards Understanding Longitudinal International studies of older People (TULIP) consortium is a collaboration of: the Leiden 85 plus study of Leiden University Medical Centre (Prof Jacobin Gussekloo, Primary care, Professor Rudi Westendorp, Geriatrician); the TOOTH study, Keio University Medical School, (Professor Yasu Arai, Endocrinologist); the Newcastle 85+ study (Professor Stuart Parker, Geriatrician, Prof Ashley Adamson, Dietician, Prof Carol Jagger, Epidemiologist) and LiLACS NZ. Indigenous scholars in Alaska, Hawaii, Canada, and Australia, and working in the fields of Health, Education, and Indigenous Development have agreed to collaborate in LiLACS NZ and the network is available to the *Ageing Well* group. Lesley McGregor, from Canada, presented to the academics at Tamaki Campus in August 2011 on her work in Toronto.

New Zealand is the first country in the world to mandate the use of interRAI, as noted in the big data Section 1.4.1. In order to maximise the use of the interRAI dataset the challenge is pleased to have a number of world experts in healthcare delivery involved. This team of experts includes Professor Len Gray from Australia, Professor John Hirdes from Canada and Professor Vince Mor from the United States. They have assisted with the rollout of interRAI in NZ and advised on the establishment of the data warehouse and will add significant understanding to how interRAI data can be utilised to improve outcomes. All three researchers each have produced over 100 papers each on healthcare delivery and visit New Zealand regularly. They each have a strong track record of using interRAI data to guide and improve healthcare delivery in their respective countries and this skill which will significantly strengthen the challenge to deliver results that can be used to cost-effectively improve service delivery.

International research experts Prof Bruno Vellas, Prof Sandrine Andrieu, Prof Matteo Cesari and Prof Yves Rolland from University of Toulouse Institute of Ageing and INSERM, will provide expertise on frailty and Alzheimer's in community-dwelling and nursing home older adults. International research experts on polypharmacy will also be involved in the Challenge. Professor David Le Couteur and Professor Sarah Hilmer from University of Sydney and Professor Darrell Abernethy, Associate Director of Drug Safety at the FDA will provide expertise in relation to the use of the Drug Burden Index as a predictor of poor health outcomes.

#### 1.4.4. Linkages to other NZ research

The issues of ageing societies and the issues of enabling older people to retain their social, economic and cultural contributions has been an important thread in both public good science research and research commissioned by other funders beyond the Challenges and the CoREs:

- Current MBIE funded research includes the Longitudinal Study of Ageing (Massey University) and Finding the Best Fit (CRESA). The Massey led-study into change in the regions also has a major component around the issue of ageing as does Dr Natalie Jackson's current Marsden Fund research into provincial population decline.
- Previous and important studies include Waikato University led MBIE funding research Enhancing Wellbeing in an Ageing Society and CRESA-led Good Homes: Older People and Repairs and Maintenance and Community Resilience: Doing Better in Bad Times which looks to enable older people's contribution to effective planning and response in the context of adverse natural events.
- There is a raft of Health Research Council funding of bio-medical and public health research such as LiLACS, work on bone density, neurology, cardiovascular research that focuses on older people and physiological and other determinants of well-being. Many of these provide the springboard for the Challenge to develop the innovative, mission-led approach to research and provide, along with the CoREs the bedrock of business as usual, but valuable and necessary research effort.
- Newly funded HRC projects on bone health (Professor Ian Reid), osteoarthritis (Associate Professor Haxby Abbott) and ageing drivers (Dr Rebecca Brookland), ageing and oral health (Dr Jonathan Broadbent) are all very pertinent to *Ageing Well*. The Director will shortly communicate with these PIs and seek ways in which the research can collaborate and/or share knowledge with the *Ageing Well* research activities.
- There is also research funded and/or carried out by other agencies including SuperU (previously the Families Commission), the Ministry of Social Development, the Commission for Financial Capability and operational and policy arms of MBIE. These include research into net benefits of dwelling investment, retirement incomes and asset use, paid and non-paid work, and the economic impact of older people.

The wide research networks of researchers involved in the *Ageing Well* Challenge will ensure that the above and other opportunities for mutual leveraging of research knowledge are optimised.

#### 1.4.5. Building the team

The Ageing Well research team has been developed over the last two years through engagement with relevant research institutions, groups, and individuals, through calls for research proposals, open meetings with the research community, ongoing e-mail communication and regular updates, and – where appropriate – iterative development of the research projects and research plan, led by the Science Leadership Team.

The current Challenge Science Leadership Team was established as an interim leadership group following MBIE acceptance of the Outline for the Challenge; this interim Science Leadership Team (Figure 3) involves senior researchers from across the research community in New Zealand and comprises a variety of expertise and experience in a range of research areas (Appendix 5). All members have been actively engaged in the development of the Challenge since mid-2013.

The core funded research projects include a number of NZ researchers, as well as international collaborators. These have been through a rigorous development and prioritisation process, which has engaged research groups from across the country.

Through the Commencement Phase we have continued communication with the wider *Ageing Well* research community in New Zealand (Appendix 11 Communications Plan), and we have maintained open and transparent engagement with researchers and stakeholders through open meetings and circulation of relevant documents as the Research Plan has developed.

In going forward, the Challenge will offer various opportunities and forums for development and refresh of our team and network, from research training opportunities for graduate students associated with our research projects, to leadership opportunities for mid-career researchers. We will also continue to engage with our various communities (including researchers and stakeholders, as well as the general community) through our communication strategy and our annual national *Ageing Well* Colloquium.

#### 1.4.6. Building on existing capability and developing new capability

The Challenge team includes a multidisciplinary mix of the leading researchers into ageing in New Zealand, spanning social, demographic, policy, health services, public health, clinical and biomedical research disciplines. For the first time, the Challenge provides the environment through which these teams can collaborate to achieve significant societal impacts.

Part of the Challenge’s acknowledged role is to foster the development of new capacity and capability in the area of ageing research. Opportunities to build knowledge, experience and qualifications and to enable succession planning, will be actively pursued across all themes and projects in this Challenge. Wherever possible, we will explore opportunities for capability building with the Centres of Research Excellence (CoREs) that have overlapping interests in *Ageing Well* research, *Rangahau Roro Aotearoa/Brain Research New Zealand* for Brain research.

The first tranche of funding will provide opportunities for new graduate researchers, through the inclusion of Master’s and PhD students in the research. Additionally, emerging researchers are incorporated into several teams, with the expectation that the long-term nature of Challenge funding will provide a very real opportunity for these researchers to establish their careers. Māori and Pacific researchers, both established and emerging, are well represented across teams.

We will undertake dedicated novice researcher sessions at national level, formal mentoring arrangements, which may include inter-institutional networks, and dedicated graduate researcher poster sessions at the annual Colloquium. The Health Challenge Directors’ Group (who discuss matters related to Health Challenges monthly) will consider formal mechanisms of inter-Challenge/inter-CoRE engagement.

Person who will be upskilled	Career Point	Ethnicity	Nature of Training
TBA	Undergraduate	Not specified	Training in transcranial magnetic stimulation technique (by Dr Shemmell) and research methodology and underpinning theory by Assoc Prof John Reynolds.
Dr Joyce Lim	Graduate	Pakeha	Postgraduate training and mentoring from Prof Dirk de Ridder in surgical skills and Assoc Prof John Reynolds in underpinning neuromodulation theory.
TBA	Graduate	Māori and not specified	2 PhD students to be funded through University scholarships for work related to social integration & engagement
TBA	Graduate	Māori or Pacific Peoples	One doctoral fellowship Victoria University in housing tenure research
TBA	Graduate	Asian	Supervision of Master’s student thesis University of Auckland on housing tenure
TBA	Postdoctoral Fellow	Māori	Fellowship in enhancing the role of older people in work; mentoring & support by Prof Alpass
E. Maxted	Early career	Māori (Ngā Puhī)	Mentoring by Teh and Wham
A. Rolleston	Early career	Māori (Ngāiterangi, Ngāti Ranginui)	Mentoring by Kerse in regard to assessment of programmes for reducing of falls and frailty

Roy Lay-Yee	Middle Career	Not specified	Applying and extending knowledge and experience, including mentoring for late career researcher Peter Davis
Rita Krishnamurthi	Middle career	Indo-Fijian	Development of capacity as lead investigator
R Bhattacharjee	Early career	Not specified	Development of data management skills
Priya Parmar Study manager	Early career	Not specified	Development of capacity as lead statistician
R. Teh	Mid career	Asian	Mentoring by Kerse in regard to research leadership
Claire Heppenstall	Mid career	Not specified	Mentoring by Connolly in regard to research leadership
Cameron Lacey	Early career	Māori (Te Atiawa)	Upskilling in polypharmacy and research leadership Upskilling in ability to analyse & interpret big data in relation to delivery of health outcomes
Hamish Jamieson	Early career	Not specified	Upskilling in ability to analyse & interpret big data in relation to delivery of health outcomes Mentoring by Dr Nigel Millar, Prof Martin Connolly, Dr Sally Keeling
Philip Schluter	Mid career	Not specified	Upskilling in analysis of big data in regard to health Mentoring by Dr Nigel Millar, Prof Martin Connolly
TBA	Early career – data analyst	Not specified	Upskilling in regard to analyzing Drug Burden Index and interRAI data and delivering results in a clinically relevant way
TBA	Early career – research nurse	Not specified	Upskilling in project admin, data interpretation and coordinating research
Jackie Robinson	PhD	Not specified	Mentoring by Professor Merryn Gott and Dr Michal Boyd
Dr Julia Slark	Postdoctoral	Not specified	Mentoring by Professor Merryn Gott and Dr Michal Boyd
Dr Deborah Balmer	Postdoctoral	Not specified	Mentoring by Professor Merryn Gott and Dr Michal Boyd

#### 1.4.7. Prioritisation and contestable funding

There will be two tranches of Challenge Funding.

##### Tranche 1

For the Challenge first tranche (to June 2019) the research funding mechanisms are (as detailed in Appendix 2):

- A. Core project funding: from October 2015 \$8.1M
- B. Contestable Round Funding: from April 2016 \$2.8M

Principles for prioritisation in assessing research plans in Tranche 1 have been:

- The research will advance at least one of the agreed research strands for *Ageing Well*;
- The research is considered to be of high value to the people and cultures within Aotearoa New Zealand;
- The research is highly ranked through independent, national, and international peer review;
- The research is highly ranked according to the principles of *Vision Mātauranga*; and,
- The research is of direct or indirect economic benefit to Aotearoa New Zealand.

It is likely that these principles will remain the same throughout the course of the Challenge but they will be reviewed annually.

A. *Core funding* has been proposed for an initial set of research activities described in the Research Plan (Section 2.1), which were prioritised from proposals submitted by the research community in New Zealand in 2014, taking into account feedback from the MBIE Science Board.

B. *Contestable Round Funding*. The Challenge has set aside funds of \$2.8M to provide an *Ageing Well* Contestable Funding Round. This round will be targeted towards gaps in the current research portfolio, and will prioritise projects which have the potential to be transformative and develop new multidisciplinary programmes of work in Years 6-10 of the Challenge. Applications for contestable funding will be invited prior to 31<sup>st</sup> December 2015, with a target of awarding funds to support research projects starting April 2016, subject to peer review. The Director has had initial discussions with the CEO of Health Research Council (Professor Kath McPherson) to explore the

potential of HRC running the contestable round on behalf of the Challenge, with the potential for co-funding of some projects. Alternatively, the Challenge will work with relevant MBIE staff to undertake the contestable round.

## **Tranche 2**

Tranche 2 funding will be initiated by a review at the end of 2019, which will be used to identify priority research areas for funding in Years 6-10. It is likely that in Tranche 2 we will again divide funding between Core and Contestable funds.

### **1.4.8. New approaches, higher risk research, dynamism & refresh**

The Challenge recognises that to meet its mission and the aspirational goals, new research approaches are required. Therefore the Challenge research strategy has deliberately stepped away from the more usual investigator-led approach, to incorporate productive interactions with stakeholders and knowledge users. Many members of the Challenge research team have links with end-user organisations in both the public and NGO sectors (as described in the research portfolio, Section 2.1) and these links have facilitated the development of a relevant research strategy through co-creation of research directions, the formation of a sound knowledge exchange platform, leading to research which will be easily and rapidly implemented by co-creators. As an example, a package of work looking at improving volunteer visiting to reduce social isolation and to promote engagement has been developed with, and will be acted on by, a major NGO organisation Age Concern New Zealand.

Within the overall mission-led approach, *Ageing Well* has included some high risk-high return work, recognising that the Challenge provides an opportunity for risk taking in research that does not readily exist through other funding mechanisms. As an example, the Challenge will support a safety and efficacy (phase 0-I) trial of an innovative implanted electrical stimulator that could improve recovery from stroke. While high-risk, in that many early phase clinical trials will not lead to commonly used interventions, the trial is cutting edge, exploits New Zealand's expertise and international connections and may deliver very significant benefits. In the area of stroke, this risky research complements other work to be undertaken in the Challenge which is more certain to deliver, including investigating the use of "health coaches" in stroke prevention, which builds from world-leading New Zealand epidemiological and mechanistic research funded through other processes.

While the Challenge has prioritised particular packages of work that it sees as most important at this time for the mission (see Section 2.1), there is a need to continually monitor research progress and provide opportunities for refresh of both research aims and research teams. Annual monitoring of research progress by the Director and Science Leadership Team, with input from stakeholders, the Kāhui group and the Engaged Knowledge User Group, will lead to recommendations to the Governance Group about shifts in direction or emphasis of funded research. The regular reviews of progress reports and feedback from colloquia and research meetings will be used to identify gaps or emerging opportunities, which will be addressed through reprioritisation and through contestable funding opportunities. The latter also provides the opportunity to bring in new expertise into the Challenge team.

During 2019, there will be a major opportunity for new funding and shifts in research emphasis, as the second tranche of Challenge funding is available for investment. It is likely that at this time the research programme will have developed much greater integration, as findings from initial work have produced clearer pathways for translation and implementation of research into impacts. An extended review of national and international ageing research will aid prioritisation. The International Science Advisory Panel and stakeholder group will provide significant input in shaping the second five years of work by the Challenge.

Dynamism and refresh will extend beyond the research plan. There will be refresh both in the Challenge Board and the Science Leadership Team. The Board will need to adapt its skill set over time to suit the needs of the Challenge, while maintaining sufficient continuity. Board appointment processes are detailed in the Collaboration Agreement.

Science Leadership Team members (SLT) will retire in a staggered manner. This will allow:

- SLT skills to be aligned with emerging research directions;
- A breadth of established and early career researchers to gain research management and research leadership skills;
- Senior scientists involved in the Challenge to maintain an active research practice, as well as contributing to leadership.

### **1.4.9. Co-funding**

The HRC and MBIE represent the only significant public good funders of research directly relevant to the *Ageing Well* Challenge mission. Both the Challenge and the HRC recognise the importance of aligning their research

investments, to maximise outcomes and deliver efficiency of investment process. Discussions have been commenced, and will continue, regarding how to best align Challenge and HRC research while preventing overlaps. In the case of MBIE, shifts of the funding framework towards the Challenge structure will ensure alignment of research and funding activities at a national level.

Other co-funders outside of the research community are contributing already to Challenge research projects, as indicated by project in Section 2. The Challenge will continue to seek and exploit opportunities to leverage funding as it progresses.

#### 1.4.10. Fit with sector and research strategies

Since the release of the *Positive Ageing Strategy* in 2001, central and local government, as well a range of community based organisations and services, have been actively using its goals as a framework for their developing focus on older people and creation of an age-friendly society in the context of structural ageing. The *Ageing Well Challenge* aligns closely to the ten goals set out in the Positive Ageing Strategy and the Strategy's commitment to "enabling a society where people can age positively throughout their lives, and where older people are highly valued and recognised as an integral part of families and communities."

The latest report on progress to date notes the important research that has already contributed to Positive Ageing Strategy outcomes. Many of those research teams are involved in this Research Plan. The Research Plan builds on the research platform which includes the public good science programmes *LiLaCs* (University of Auckland), *Good Homes Repairs and Maintenance* (CRESA), *NZ Longitudinal Study of Ageing* (Massey University), *Enhancing Wellbeing in an Ageing Society* (Waikato University), and *Finding the Best Fit* (CRESA).

The Strands of the *Ageing Well Challenge* directly address the *Positive Ageing Strategy* and the strategies and action plans of local government and government agencies which it has shaped including the:

- *NZ Health of Older People Strategy* which addresses the Positive Ageing Strategy Goal 2 looks to develop an integrated approach to health and disability support services responsive to older peoples' varied and changing needs which allows older people to access services in a timely manner, at the best place and with the right provider.
- *NZ Transport Strategy* which addresses Goal 4 of the *Positive Ageing Strategy* and seeks to enable more age-friendly public transport as well private transport options (related to Strand 5).
- *New Zealand Housing Strategy* area seven of which is directed to addressing older people's diverse housing needs both in relation to dwelling performance but also issues of affordability, tenure security and the ability to make housing choices that optimize older people's functionality and connectivity (related to *Ageing Well Strands 1 and 5*).
- *The Health Quality and Safety Commission's* (HQSC) foci over the last 5 years have emphasised prevention of injury from falls through partnership with the Ministry of Health and through a nationwide campaign (related to Strands 1 and 4). HQSC also prioritises reducing harm from unnecessary medication use through increased provider education. Prof Ngaire Kerse sits on the combined committee of ACC, HQSC and the Ministry of Health as National Advisor and Assoc Prof Waters sits on the HQSC, Southern Falls Alliance and HOPSLA as a member and research advisor.

The Challenge and its Research Plan also reflect the on-going research priorities expressed in the:

- *Age Concern Research Strategy* which highlights isolation (Strand 2), elder abuse, housing (Strand 5) and responsible lending among its key research priorities;
- *ACC Research Strategy* priority of fall prevention (related to Strands 1 and 4). This priority of fall prevention has led to partnering of ACC and Aged Concern to encourage SAYGO (strength and balance exercise) programmes through-out New Zealand. These activities combine neatly with Challenge research which will rigorously test the programme and establish the added benefit of nutrition advice in combination with SAYGO.
- *HRC Strategy – Health and Wellbeing* signals include research optimising function and quality of life in ageing (Strands 1, 4 and 5).
- *Health of Older People Strategy of 2002(123)* prioritised living at home, increased self management and optimisation of health services. *Ageing Well Strand 1* focuses on independence and autonomy, aligning with this strategy.

## 1.5. Outputs and Pathways to Outcomes

The outputs from the Programme will include:

- A. Research knowledge
- B. Policy knowledge
- C. Best practice and better services
- D. Practical knowledge for older people
- E. Technology to be commercialised

Pathways to outcomes will depend on the type of output:

**A. Research knowledge** will be conveyed through

- Teaching
- Student supervision
- Research publications
- Conference presentations
- Direct reporting of research findings to study participants, communities and end users
- Lectures and seminars to public and professional groups.

**B. Policy knowledge** will be conveyed through:

- Relationships and direct communications between researchers and central Government (Ministry of Social Development, Ministry of Health, Office for Senior Citizens, Te Puni Kokiri, Building & Housing Group, Housing NZ, Treasury, Commission for Financial Capability, ACC, MBIE, Ministry of Pacific Island Affairs)
- Relationships and direct communications between researchers and councils
- Relationships, direct communications between researchers and healthcare organisations including researchers being employees of such organisations: District Health Boards, Primary Healthcare Organisations, PROCARE, Stroke Foundation of NZ, Neurological Foundation of NZ

**C. Best practice and better services** will be achieved through:

- Relationships and communication between researchers and community service providers including direct communication to these groups: Age Concern, Rural Women NZ, NZ Council for Christian Social Services, Community Networks Aotearoa, U3A, Grey Power, Menz Sheds, retirement villages, residential care facilities
- Relationships and communication with rental property investors, tenancy agents and tenants' protection agencies direct communication to these groups: Community Housing Aotearoa, Marlborough Sustainable Housing Trust Dwell, Bay Trust, Community of Refuge Trust, Habitat for Humanity, Abbeyfield (in the case of housing best practice)
- Relationships and communication with healthcare professionals (nurses, general practitioners, clinicians), including researchers being healthcare professionals across New Zealand via professional meetings and publications
- Incorporation into relevant software e.g. incorporating the Drug Burden Index into decision-based software for clinicians
- Use of the national and international interRAI assessment framework

**D. Practical knowledge** for older people will be conveyed through:

- Direct participation in the research projects by older people
- Presentations to the older people participating in the research projects
- Presentations and community reports for local iwi and runanga
- Digital stories – first person narratives of lived experience shown at dissemination events
- Social media and Twitter announcements of new and interesting findings
- Website repository of information

**E. Technology** will be released and may be commercialised according to the appropriate pathway for the particular technology. An early example where such commercialisation has been considered is in regards to the implanted electrical stimulators to augment stroke recovery. In this case commercialisation will include:

- Trials of feasibility and safety
- Multicentre trials

- Protection of any IP generated by the researchers by the University of Otago as Challenge holder jointly with the company providing the electrical stimulators (St Jude Medical, Plano Texas)
- Manufacturing by St Jude Medical in the case of the implantable stroke generators
- Sales by St Jude Medical coordinated by the researchers and University of Otago to the Ministry of Health

## 1.6. Impact & Benefits

The work and influence of the Challenge, through its mission-led research, will drive changes to ensure that ageing is a more positive experience for older New Zealanders. This impact acknowledges that there are a variety of life trajectories for people in New Zealand and that more must be done to capture the longevity dividend, given increased life expectancy.

The Challenge seeks to create specific-to-New Zealand novel interventions and technologies and to influence policy and health and social service environments so that “active ageing” (as described by the World Health Organisation) becomes a reality. WHO define active ageing as the process of optimising opportunities for health, participation and security in order to enhance quality of life as people age. The latter element reflects access to appropriate housing, food, and health and social services.

To achieve this outcome of active ageing, the Challenge work and its close engagement with stakeholders and those organisations that will act on the new knowledge, will support the development of:

- Age friendly environments*, including a variety of housing tenure options, and living environments that are adapted to the specific needs and expectations of older individuals.
- Greater social integration and reduced isolation*, with the delivery of appropriate support services, recognition of the value, rather than the burden, of societal – including workforce - participation by older individuals.
- An appropriate range of health and well-being services and interventions, that will *reduce the onset of frailty, limit the impacts of illness and disability relevant to older individuals*, and particularly lessen inequity in health and well-being outcomes across New Zealand’s different ethnic and socio-economic groups.

The five research strands that will be supported by the Challenge will build the evidence base for the policies, technologies and interventions that are needed to achieve the state of active ageing. In the short term, the work that has been prioritised by the Challenge will deliver evidence in areas where significant gains can be made.

- Age friendly environments*. Research on housing tenure will contribute to policy and planning which drives the availability of affordable and good quality housing for older people. This will affect the numbers of people in residential care since if people’s houses are not suitable for them they are often pressured to move into care. Māori are particularly affected by housing tenure and quality because they are typically overrepresented in rental housing. Assessment of the affordability of retirement villages will contribute to discussion and policy regarding affordable housing and best approaches to ageing in place.
- Social integration and reduced isolation*. Research on understanding loneliness in different spatial and cultural contexts will lead to improved methods of engagement with older people, with volunteer visiting a particular focus. This work will lead to improved planning of visiting of those who may be at risk of loneliness, and reduced loneliness is linked to reduction of people in residential facilities as loneliness is strongly correlated with poor health, and thus inability to stay in one’s own home. Māori are more at risk of loneliness than in the past and new and improved mechanisms to reduce loneliness in older Māori will be a focus. Related to loneliness, is understanding of risk factors for reduced social engagement in older people. Once these risk factors can be used as predictors, they will be incorporated in policy and planning, resulting in improved health outcomes through social integration, which will reduce people in residential care facilities. New methods to increase participation of older people in the workforce, both paid and unpaid, will reduce numbers of people in residential care facilities as they remain more active, integrated and thus healthy through making satisfying contributions to society. A step towards achieving this will be delivery of policy and planning strategies which foster active participation in the workforce. The research will identify barriers to workforce participation, including understanding of different barriers for different cultural groups i.e. helping to meet the needs of Māori and Pacific Peoples.
- Limiting the impact of frailty, disability and illness*. Research on reducing frailty will lead to improved intervention programmes (exercise and nutrition). Associated policy and planning will ensure that the right groups get the right programmes. Reduction in frailty, falls and treatment will reduce the number of people

in residential care, since improved health will mean more people are able to stay in their homes. Reduction in the negative effects of health from polypharmacy, through use of the Drug Burden Index to improve prescribing for older people, will also reduce the number of New Zealanders of all cultures in residential care. Improved health outcomes, and thus reduced numbers in residential care, will also result from well-designed Health and Wellness Coaching, to reduce cardiovascular disease (CVD) and stroke. Māori and Pacific Peoples are disproportionately at risk of CVD and stroke, thus tailoring the coaching programme will reduce inequity in disease burden. A highly novel approach to stroke recovery will be tested; while the research is high risk as it is still at the safety and feasibility stage of testing, it holds the promise of a paradigm shift in management of stroke recovery.

Following the initial research activities, the Challenge work will move to a phase where evidence will be translated, at regional and national level, into policy recommendations and scalable interventions. The emphasis will be on real-world testing and implementation of approaches that reduce disability, impact of chronic disease and premature mortality, and support inclusion of age friendly environments into planning.

Specific performance indicator and targets are discussed in Section 3.10, but it is worth noting that the Challenge recognises that its funding alone cannot deliver on the desired outcomes. Therefore, the Challenge will work at building and sustaining mutually beneficial relationships with stakeholders and knowledge users, both to ensure that research directions and priorities are relevant, and that there is a seamless transfer from research to implementation. The importance of these components of a broader knowledge exchange and transfer framework are fundamental to achieving the Challenge mission.

# RESEARCH PLAN

## 2. RESEARCH PLAN

### 2.1. Project Portfolio Overview

A set of ten projects has been selected (Table 6) based on the prioritisation criteria (Section 1.4.7) and in the knowledge that the Challenge must select priority activities as its resources do not enable it to tackle the myriad of potential research challenges. These projects are described in the following sections, but a summary is provided here, together with a demonstration of the plethora of linkages between project and research strands that integrate the Challenge (Table 7). Priorities will be reviewed on an annual basis by the Science Leadership Team, and particularly for the second tranche of funding.

**Table 6 Project summary**

Project Full Title	Project Short Title	PIs	Organisations*	Challenge Funding** \$000
A. Enabling older people's independence, active lives & participation in the face of structural housing tenure changes	Independence & housing tenure	Saville-Smith, Cumming, Kearns, James, Ho, Cram	CRESA, Katoa, MU UoA, VU,	\$1,880
B. Transforming ways of living & reducing frailty	Reducing frailty	Teh	MU, UoA, UoO, NDHB	\$2,156
C. Social isolation & loneliness amongst older people in the multicultural NZ context	Social isolation	Gott	UoA, UoO VU, UoSUK Age Concern NZ	\$418
D. Enhancing the role of older people – enabling participation in paid & unpaid work	Older people in work	Alpass, Stephens, Lay-Yee	MU, UoA, UoO	\$701
E. Can neurodegenerative life care be improved with individualised interventions?	Neurodegeneration & individualised interventions	Boyd	UoA, UoO MoH, WDHB	\$255
F. Older people in retirement villages: unidentified need & intervention research	Retirement villages	Connolly	UoA, WDHB	\$704
G. Risk factors for reduced social engagement in older people	Risk factors in reduced social engagement	Jamieson, Keeling	Te Atiawa, UoC, UoO, BUU, UoQA, UoWC NZHITB, CDHB	\$226
H. Evaluation of the Drug Burden Index to predict adverse outcomes in older people	Drug Burden Index	Jamieson	Te Atiawa, UoO, UoC, UoA, FDA, JHUU, UoSA, CDHB, NZHITB,	\$161
I. Health & wellness coaching for primary stroke & CVD prevention	Stroke & CVD prevention	Feigin	AUT, TWAA, UoA	\$1,195
J. Implanted electrical stimulators to augment stroke recovery	Electrical stimulators for stroke recovery	Reynolds, de Ridder, Hale, Shemmell, Barber	UoO, UoA ADHB, CCHDHB	\$398

\* AUT = Auckland University of Technology, CRESA = Centre for Research Evaluation & Social Assessment, MU= Massey University, TWAA = Te Whare Wānanga o Awanuiārangi, UoA = University of Auckland, University of Canterbury, UoO = University of Otago, VU = Victoria University

BUU = Brown University – USA, FDA = Federal Drug Agency – USA, JHUU = Johns Hopkins University – USA, UoQA = University of Queensland – Australia, UoSA = University of Sydney – Australia, UoSUK = University of Sheffield – UK, UoWC = University of Waterloo – Canada

ADHB = Auckland District Health Board, CCHDHB = Capital & Coast Health DHB, CDB = Canterbury District Health Board, MoH = Ministry of Health, NDHB = Northland DHB, NZHITB = NZ Health IT Board, WDHB = Waitemata District Health Board

\*\*The funding amount listed here is the total awarded by the Challenge over the life of the project, from 1 to 5 years.

**Table 7 Project relationships to Research Strands**

	1 Maintain wellness, independence & autonomy	2 Promote social integration & engagement	3 Value older people in all settings	4 Reduce disability and the impact of disability	5 Enhance age friendly environments
A. Independence & housing tenure	Yellow	Yellow	Grey	Grey	Dark Red
B. Reducing frailty	Dark Red	Grey	Grey	Grey	Grey
C. Social isolation	Yellow	Dark Red	Grey	Grey	Grey
D. Older people in work	Yellow	Dark Red	Yellow	Grey	Grey
E. Neurodegeneration & individualised interventions	Grey	Grey	Dark Red	Grey	Yellow
F. Retirement villages	Dark Red	Grey	Grey	Yellow	Grey
G. Risk factors in reduced social engagement	Grey	Dark Red	Grey	Grey	Grey
H. Drug Burden Index	Yellow	Grey	Grey	Dark Red	Grey
I. Stroke & CVD prevention	Yellow	Grey	Grey	Dark Red	Grey
J. Electrical stimulators for stroke recovery	Yellow	Grey	Grey	Dark Red	Grey

A summary of research to be undertaken in the different Strands is:

**Strand 1: Maintain wellness, independence and autonomy**

- A. *Independence & housing tenure* will forestall maintain independence and autonomy through assisting older people to remain in safe and comfortable environments even when they are renting their home.
- B. *Reducing frailty* will assist older people to remain independent by slowing the development of frailty which often leads to people developing disability, moving into care and losing autonomy as they can undertake fewer activities on their own and for themselves.
- C. *Social isolation* is closely associated with declining health and reducing it will assist people to remain well and independent.
- D. *Older people in work* will assist with maintaining wellness through connection with others and financial independence.
- F *Retirement villages* and the healthcare system in general lack data on residents for the purposes of accurately identifying their level of need in order to increase their wellness. The level of physical and mental health and social need in retirement villages is unknown as is the trajectory of health and function over time.
- H The *Drug Burden Index* offers a potential means to identify risks and consequently reduce impacts of polypharmacy on wellness.
- I *Stroke & CVD prevention* will undertake health and wellness coaching in stroke free and heart attack free individuals who are at a moderate to high risk of stroke and cardiovascular disease in order to improve their health outcomes and thus maintain wellness and autonomy.
- J *Electrical stimulators for stroke recovery* will reduce direct disability resulting from stroke damage and thus assist people to maintain independence and autonomy.

**Strand 2: Promote social integration & engagement**

- A. *Independence & housing tenure* will enhance age friendly environments that enable older people's integration and engagement within their communities by generating tenure and housing frameworks which are suited to older people.
- C. *Social isolation* will assist people to remain socially integrated through identifying the causes of isolation, particularly investigating the efficacy of volunteer visiting services.
- D. *Older people in work* will assist older people to integrate with the paid and unpaid workforces.
- G. *Risk factors for social engagement* is focused on ensuring a meaningful life through social integration and engagement.

### Strand 3: Value older people in all settings

- D. *Older people in work* will increase the perceived value of older people as they will be seen contributing to wider society as a result of being more likely to be in paid/unpaid employment.
- E. *Neurodegeneration & individualised interventions* acknowledges that the Aged Residential Care Service is the place of dying for many older people and therefore understanding and improving end of life care for this population is an important component of valuing older people.

### Strand 4: Reduce disability & the impact of disability

- F *Retirement villages* aims to reduce disability through understanding mental health and medical dependence trajectories of retirement village residents.
- H. *Drug Burden Index* Side effects of polypharmacy include impaired cognition, falls, early admission to rest homes, and lethargy. This project will use an emerging technology to reduce polypharmacy and by doing so it will reduce the resultant disability and increase autonomy.
- I *Stroke & CVD prevention* will undertake health and wellness coaching in stroke free and heart attack free individuals who are at a moderate to high risk of stroke and cardiovascular disease in order to improve their health outcomes and thus reduce potential disability resulting from stroke.
- J. *Electrical Stimulators for Stroke Recovery* will reduce direct disability resulting from stroke damage and thus also reduce the impact of functional decline on processes leading to dementia.

### Strand 5: Enhance age friendly environments

- A. *Independence & housing tenure* will enhance age friendly environments through developing better rental market and housing frameworks which are suited to older people.
- E. *Neurodegeneration & individualised interventions* Understanding the unique care needs of older people with neurodegenerative conditions is key to providing the evidence needed to enable age friendly environments that accommodate all disabilities and promotes the best quality of life possible.

## 2.2. Prioritisation

A call for proposals was made by the Challenge. Following initial shortlisting by the Interim Science Leadership Team, 18 proposals (from an initial pool of 31) were identified and the relevant research teams invited to resubmit on standardised application templates. A total of 15 proposals were resubmitted, which were then independently assessed by our International Science Advisory Panel for research quality and relevance to *Ageing Well*, and by a sub-group of the Interim Science Leadership Team who were not conflicted as Principal Investigators in resubmitted projects. In parallel with this, our Wise Heads group independently provided feedback and comments on the resubmitted projects.

Recommendations for prioritisation (i.e. for core funding) were initially developed by the sub-group, and taken to a full meeting of the Interim Science Leadership Team for endorsement, prior to seeking final approval by the Governance Group. A total of 10 proposals have had funding approved, with the remaining 5 being treated as reserves (i.e. these are considered fundable, but fall outside the current funding envelope). The full set of proposals is listed in Table 8. The status of these proposals will be kept under review over the first year of the Challenge, and teams will be encouraged to pursue contestable funding where appropriate.

**Table 8 Proposals submitted for consideration**

	Project	PI(s)	Project cost
Funding envelope	A. Independence & housing tenure	Saville-Smith, Cumming, Kearns, James, Ho, Cram	\$1,880
	B. Reducing frailty	Teh	\$2,156
	C. Social isolation	Gott	\$418
	D. Older people in work	Alpass, Stephens, Lay-Yee	\$701
	E. Neurodegeneration & individualised interventions	Boyd	\$255
	F. Retirement villages	Connolly	\$704
	G. Risk factors in reduced social engagement	Jamieson, Keeling	\$226

	H. Drug Burden Index	Jamieson	\$161
	I. Stroke & CVD prevention	Feigin	\$1,195
	J. Electrical stimulators for stroke recovery	Reynolds, de Ridder, Hale, Shemmell, Barber	\$398
Reserve projects	Brain proteins for reducing stroke-induced disability	Abraham, Dalrymple-Alford, Clarkson	\$561
	Maintaining independence in early Parkinson's disease	Dalrymple-Alford	\$359
	Modelling the challenges and opportunities for unpaid care of older people: New measures, new approaches	Koopman-Boyden	\$1,309
	Sensory processing, language and cognitive reserve	McAuliffe, Thorne	\$688
	Development of a blood biomarker test diagnostic of mild cognitive impairment and risk for Alzheimer's disease	Williams, Poulton	\$473

### 2.3. Project Portfolio

#### Strand 1: Maintain wellness, independence & autonomy

B. Transforming ways of living & reducing frailty				
Cost \$000	\$2,156	Co-funding		Ringa Atawhai Trust, Whangarei Anglican Care Trust, Age Concern Whangarei, Age Concern County Manakau: time and meeting rooms provided ACC part funding for delivery of SAYGO in Tauranga & Invercargill Age Concern Otago: trial facilitation, meeting rooms, ongoing liaison
Start Date	1 October 2015	End Date		30 September 2020
	Name	Organisation	FTE	Skills
PIs	R. Teh	University of Auckland	0.4	Randomised controlled trials (RCT), nutrition, physical activity, frailty
AIs	N. Kerse	University of Auckland	0.02	RCT, falls, physical activity, frailty
	D. Waters	University of Otago	0.025	Physical activity, frailty
	L. Hale	University of Otago	0.025	Physical activity
	E. Maxted	Northland District Health Board	Advisor	Māori dietetics
	A. Rolleston	Te Kupenga Hauora Māori	Advisor	Māori culture advisor, physical activity
	R. Edlin	Health Systems	Advisor	Health economist
	Biostatistician	Statistics NZ, University of Auckland	0.3	Biostatistics
	Carol Wham	Massey University	Advisor	Dietetics
	Claire Heppenstall	University of Otago	Advisor	Geriatrician
	Martin Connolly	University of Auckland	Advisor	Geriatrician

This research leverages existing interventions targeting physical frailty to investigate the effectiveness of programmes focusing on physical activity and nutrition, enhanced by cultural and social support. The relative benefits for pre-frail adults of the SAYGO (strength and balance exercises) and Senior Chef (nutrition and cooking) programmes will be compared with and a social group including equal numbers of Māori and non-Māori.

#### Impacts

- By 2016 a newsletter on study recruitment, engagement in physical and nutrition activity and overall update will be communicated to local stakeholders.

- By Q1 2018 the SAYGO programme will be self-sustaining with peer leaders in all sites.
- By mid-2018 a methodology paper will be submitted on the process of creating and sustaining peer-led classes of SAYGO and Senior Chef to assist in the roll-out of these programmes nationally.

## Context and Opportunity

By 2050, demographic changes will lead to a marked increase in both the numbers and proportion of older people in New Zealand. Physical frailty and falls are significant health issues for older people. Frailty and falls are likely to be intimately linked with physical activity and nutrition.

*Frailty:* Physical frailty is a precursor to functional loss and results in considerable risk for health care needs (124). In four large cohort studies (Cardiovascular Health Study, Canadian Study of Health and Ageing, Women's Health and Ageing Study and Study of Osteoporotic Fractures), pre-frailty and frailty were associated with increased risk of falls, worsening disability, hospitalisation, residential care admissions and mortality (125). Age-associated frailty is a significant cause of disability and dependency: 25% of healthy men and 35% of women aged 85+ in the US have difficulty climbing stairs, and 70% of men and 80% of women cannot do heavy housework. These studies, conducted in European descent populations, showed frailty is prevalent. Up to 51% of community-dwelling older people were pre-frail (125), and over 60% in LiLACS NZ (126). With the increasing ageing population, acceptable, sustainable and economically viable ways to prevent and manage frailty at a population level are needed.

*Falls:* At least a third of those aged 65+ and half of those aged 80+ will fall in any one year (127). Many older people fall, sometimes with serious personal and societal consequences. Falls result in fear of falling and in 75% of fallers with subsequent loss of physical activity and function (128). Falls predict fractures, mobility/functional decline, residential care admissions, hospitalisations and death (125). Analysis of the Dunedin falls prevention studies and the Auckland Hip Fracture database have shown that almost a third of all hospital costs for women aged 80+ resulted from a fall. This equates to an annual total direct cost of osteoporotic hip fracture with hospitalisation, recovery and residential care of \$NZ331 million (129) and the New Zealand Accident Compensation Corporation states the costs for falls are predominantly spent on older people (Personal Communication ACC). Falls-related costs will increase as the proportion of the older population living longer increases thus increasing the risk exposure to falls. The most effective community intervention for falls is strength and balance exercise (127).

*Physical Activity:* Epidemiological evidence that habitual activity benefits longevity, cardiovascular health and well-being for older people is well established (130). Physical activity and exercise have proven successful in improving functional status, health status and life satisfaction for older people (131, 132) and is effective in treatment and prevention of cardiovascular disease, diabetes mellitus and falls (131). Physical activity interventions also improve participation in 'life' (133) and may reduce the risk of frailty (134). Physical activity trials have had some success in changing lifestyle (135-138) but there is no widespread implementation of programmes for older people in New Zealand, with Māori neglected almost completely. Steady As You Go (SAYGO) is a programme grown from the Otago Exercise Programme (one of the most successful falls prevention programmes (139-141) which also improves executive function (142), which has been successfully piloted in the general community of older people in group format, but not tested formally.

*Nutrition:* Food is the natural partner for physical activity as food provides the energy source needed for physical activity and activity stimulates appetite (143). Older people are vulnerable to poor nutritional status and have an increased risk of developing health problems as a result of inadequate food intake (144-147). Older adults at risk of malnutrition will have less energy for physical activity as the maintenance of vital organ functions consumes proportionally more energy. Supplements have been proven to increase weight, particularly in those with malnutrition (149), but impact on frailty is uncertain and wider implementation of supplements may be costly.

*Social Aspects:* Social interventions are hard to test (150) but there is a great need to better understand how and for whom social and cultural aspects of life can be improved. Longitudinal research emphasises the combination of factors related to positive outcome and social enhancement of both physical activity and nutrition improves adherence. It is hypothesised that the synergistic effect on the combination of physical activity, nutrition and social support intervention will improve function and QOL in older people (151). Senior Chef is a nutritional education programme which has been developed to improve nutrition particularly for older people who live alone.

The opportunity is to rigorously test two studies underway, SAYGO and Senior Chef (outlined above), in order to identify their effectiveness in pre-frail older adults and for Māori. The limited research on SAYGO and Senior Chef appears to show that these programmes are effective (152-154). The effectiveness of the complex intervention and its delivery in New Zealand in a sustainable and acceptable way to impact on physical function and reduce falls risk

needs to be established by a fully powered randomised controlled trial as proposed in this application. Most intervention studies employ a single strategy, with few combining strategies in community interventions (155-158). The SAYGO and Senior Chef programmes are unique in that they empower people to engage with maintaining their health from both a physical and a nutritional perspective.

### Research question & research outline

**Research question:** Are the programmes SAYGO (physical activity) and/or Senior Chef (nutrition and cooking class) effective and cost in reducing falls and frailty in pre-frail older people?

**Study design:** Randomised controlled trial using a 2x2 factorial design.

- **Primary Outcome:** falls; *Secondary outcomes:* frailty, physical function. *Process outcomes:* food intake and reduced sedentary time.
- **Participants/recruitment:** Māori aged 60+ and non-Māori aged 75+ from Whangarei, Howick, Tauranga, and Invercargill will be approached through general practices and Māori providers. Age-eligible adults will be pre-screened using the FRAIL scale (159, 160) and those identified as pre-frail will be invited to participate.
- **Eligibility criteria–Inclusions:** Living in the community; age-eligible; Fried score pre-frail (1 or 2 criteria)(161).
- **Exclusions:** Significant communication barriers; advanced dementia from GP records; terminally ill as judged by the general practitioner or Māori health provider. Assessments will be completed by research assessors.
- **Randomisation, blinding:** Enrolled participants will be randomised to one of four groups:
  - 1) Exercise (SAYGO)
  - 2) Nutrition (Senior Chef)
  - 3) SAYGO plus Senior Chef
  - 4) Social group activity. Randomisation is by computer generated randomisation after a baseline assessment, communicated to the study coordinator by phone from a researcher not involved in recruitment. Outcome research assessors will be blinded to group allocation of participants.

#### Intervention:

- 1) SAYGO: 10 weeks facilitator-led strength and balance exercise classes based on the Otago Exercise Programme followed by ongoing peer-led class. Peer-leaders will be identified between week 8 and 9 of the facilitator-led class. Findings from the feasibility study suggest that the peer-led class needs to be supported by the facilitator as the group of pre-frail older adults have less confidence in taking the class after 10 weeks. Support will be provided by the facilitator in the form of phone calls and monthly visits in the first 6 months and bi-monthly visit in the subsequent 6 months.
- 2) Senior Chef: 8 weeks facilitator-led nutrition and cooking programme developed by Canterbury District Health Board. The group meetings will reinforce messages delivered during the 8-week programme and discussion on topical food and nutrition topics.
- 3) SAYGO plus Senior Chef, and 4) social groups (control group) run by locally organised groups (eg Communicare, Grey Power). RT will continue working closely with Margaret Dundo (SAYGO, Age Concern Otago) for peer-led SAYGO classes; Sally Watson and the Nutrition Foundation to explore 'peer-led' Senior Chef (younger healthier older people). Oversight and support will be provided by Age Concern, Anglican Care and other NGOs depending on the locality of the classes. Kaupapa Māori research methodology and local community knowledge will adapt the intervention for Māori.

#### Measures:

- Sociodemographics, living arrangement, medical history (chronic conditions, hearing and visual impairment, falls) and medications will be ascertained at baseline.
- Chronic conditions will be ascertained from self-report, review of GP records (by the practice nurse or research trained assessor) and NHI matched hospital records.
- Hearing and visual impairment and falls will be ascertained from face-to-face interview using standardised questionnaire. Falls incidence will be assessed by monthly fridge calendars, filled in daily, and mailed in monthly.
- Medications use will be established by direct observation of the medications (prescribed and non-prescribed) at the participants' residences or brought in by the participants to the local medical/health centre.
- The Short Physical Performance Battery (SPPB) will be used to measure physical performance.

- Falls Efficacy Scale-International (FES-I) will be used to measure the level of concern about falling during social and physical activities inside and outside the home whether or not the person actually does the activity(162).
- Functional status will be assessed using the Nottingham Extended Activities of Daily Living Scale (NEADL) (163).
- Physical activity–CHAMPS: Community Healthy Activities Model Program for Seniors is reliable, valid and sensitive questionnaire to evaluate the effectiveness of a programme at increasing physical activity levels in older people (164).
- Nutrition–24 hour Multiple Pass food Recalls (MPR) on two separate days to record detailed dietary information. The MPR is suitable for the general (165) and oldest old population (166). Quality of life will be assessed using the SF-12.
- Cognition (3MS (167)) will be assessed to enable subgroup analyses.
- Depression, a risk factor for falls, will be assessed using the Geriatric Depression Scale. A score of 5 or more will be considered having significant depressive symptomatology (168). Physical assessment (height, weight, grip strength, bio-impedance (by Tanita scale), blood pressure, and waist and hip circumference) will also be measured.

Time post intervention				0	6m	12m	36m	60m	
	Eligi.	Base (T0)	10 weeks formal intervention	T1	T2	T3	T4	T5	
Frail scale	√								
Fried tool	√					√	√	√	
All measures*		√		√	√	√	√	√	√

\* FES-I, SPPB, CHAMPS, MPR, SF-12, NEADL, GDS and physical assessment. No 3MS at T1. No CHAMPS and MPR at T4,

**Cost-effectiveness analysis** will consider whether the intervention is cost effective relative to social contact (no intervention) and will (initially) report from a within-trial perspective. Resources counted include intervention costs, residential care/hospitalisation costs (from NHI matched hospital records), and will be valued according to the type of hospital admission (e.g. diagnosis/ specialty) and length of stay. Quality of life at baseline and 15, 39 and 63 months will be used to estimate quality-adjusted life years (QALYs) as an area under the curve, with the value for money of the intervention assessed using incremental cost-effectiveness ratios.

**Sample size:** The sample size and power calculations are based on the primary outcome of falls. A sample of 504 ( $\geq 126$  in each of 4 groups) will provide 80% power at a 5% significance (2-sided) to detect a 30% reduction in the rate of falls (2x2 factorial design [reduction of 30% (169) in falls (from 58% to 41% (170))]. With an attrition rate of 10% we will need to approach 560 eligible older people.

**Analysis:** The primary approach for analysis of primary and secondary outcomes will be on an intention-to-treat basis for all participants who have at least one baseline measurement. We will use negative binomial regression to estimate difference in fall rates between groups. Potential confounders will be adjusted for in regression models. Interactions between falls and frailty (overall and separately for gender and ethnicity) will be examined.

### Giving effect to VM

Little is known about older Māori in regards to falls, frailty and their impact in this population. LiLACS NZ which recruited more than 400 Māori (aged 80-90) and over 500 non-Māori (aged 85), identified nutrition, physical activity, social and cultural activity as being related to function and QOL (171-173). LiLACS NZ also found that 42% of their participants were living alone. Living alone was a significant factor associated with nutrition risk. Falls were reported by up to 40 % of LiLACS NZ participants and one in five fallers were hospitalised.

This project has Māori leadership and direct participation of Māori from the community and academics. This will help unlock Māori potential in preventing falls and frailty. Eruera Maxted, a Māori dietitian, has advised us about adapting the Senior Chef programme to Māori communities. The programme will be delivered on the marae in Whangarei to enable older Māori to easily participate. Our study will also recruit in Invercargill. Murikihu/Southland has the largest Māori population of district health boards in the South Island. Of the population in the DHB area, , 15% are non-Māori over 65 and 4% are Māori over 65.

## Linkages with other Challenge Projects

Project Title	Link
B. Health and Wellbeing Coaching	Exercise and nutrition may act synergistically to reduce cardiovascular risk. The Health and wellbeing coach will also work on lifestyle change. The groups will share knowledge and strategies for engagement and behavior change.
D. Older people in work	Our trial will also ask about work participation, a focus of Project D.
F. Retirement villages	The health enquiry of the RV project will assess mental and physical health and examine life style patterns. the two project overlap in examining impact of an intervention on health status. The groups will be similar except Project D will specify pre-frail status.
G. Risk factors in reduced social engagement	Social participation will also be tracked in Project D.

Title	F. Older people in retirement villages: unidentified need & intervention research			
Cost \$000	\$704	Co-funding	\$590 in-kind for clinical aspects of project salaries for Connolly, Boyd, Bloomfield and WDHB gerontology nurse practitioner Bish from Waitemata DHB \$25k in negotiation with Retirement Villages Association	
Start Date	1 October 2015	End Date	30 September 2019	
	Name	Organisation	FTE	Skills
PIs	Prof Martin Connolly	University of Auckland & Waitemata DHB	0.2	Study design including randomised controlled trials. Gerontology research and clinical expertise. Research presentation. Team leadership
AIs	Dr Michal Boyd	University of Auckland & Waitemata DHB	0.1	Study design including randomised controlled trials. Gerontology research and clinical nursing expertise. Research presentation. Team leadership. Sector engagement
	Dr Dale Bramley	Waitemata DHB	Advisor	Rapid research translation. CEO of Waitemata DHB.
	Ms Joanna Broad	University of Auckland	0.15Yr 1 0.1Yrs 2-4	Study design including randomised controlled trials. Gerontology research expertise. Statistical and epidemiological expertise. Research presentation.
	Dr Kathy Peri	University of Auckland	0.03Yrs 1-2	Gerontology research and clinical nursing expertise. Sector engagement
	Prof Julia Kennedy	University of Auckland	0.05	Pharmacy clinical and research experience including STOPP/START role in polypharmacy
	Prof Merryn Gott	University of Auckland	0.05	End of life care
	Dr Katherine Bloomfield	University of Auckland & Waitemata DHB	0.03	Gerontology research and clinical expertise
	Mr Xian Zhang	University of Auckland	0.2Yrs 1&4 0.1Yrs 2&3	Statistical expertise
	Ms Tanya Bish	Waitemata DHB	0.8	Randomised controlled trail execution. Sector engagement. Clinical gerontology nurse expertise.

This research will investigate the needs and levels of healthcare use of retirement village residents. The study will assess whether targeted intervention can decrease entry to residential aged care (RAC) beds and acute

hospitalisation. This is a growing issue; retirement village residency is rapidly increasing, village residents are more likely to move to RAC or hospitalisation, but the per capita number of RAC beds is declining.

### Impacts

- By late 2016 the first large and detailed survey of demographics, social engagement, health and functional items in retirement village (RV) residents in NZ will be completed, describing the social, health and functional needs of residents.
- By October 2019, one-year and two-year follow-ups of all residents by late 2017 and late 2018 will be analysed and formally reported.

### Context and opportunity

From 1988 to 2008, the population aged over 65 years increased by 43% in Auckland; the over 85 population more than doubled (174). This increase was not mirrored by residential aged care 'beds' (RAC: rest home/private hospital): provision of which *decreased* from 95 to 67 per thousand (174). There is current focus on "ageing in place" - ageing in one's own home for as long as possible (175, 176). Compared to the late 1980s, RAC residents today are more physically dependent, and more frail when entering RAC (177, 178).

During this period, the retirement village (RV) sector saw enormous growth. Resident numbers rose from almost none (1988) to 27,000 in 2010 in NZ, of which 35% are in Auckland; more than the 7600 elders in RAC facilities there (174) and 25,854 in NZ (179). In 2004, an estimated 5% of the 'over 65s' in NZ were living in RVs.(180) Latest estimates indicate that NZ has 330 registered RVs housing 30,000 people (181). RV dwelling numbers increased from 10,000 (1998) to 17,250 (2010) and are projected to rise by c1000pa (9). In Australia 3.7% of 'over 65s' live in RVs (182).

RVs fill a gap for those unable or not wishing to maintain their home but not needing 24-hour RAC care. The focus of RVs is on quality of life/independence for older people within a business model (180, 183). Many RVs do provide a continuum of accommodation/care options: '3 levels of care', independent units, serviced apartment and rest home/dementia/hospital care (184). RV support services range from alarms in units to homecare services (185).

Data from our own feasibility work and from the work of others indicates that NZ's RV residents are older, more educated, have more financial resources *but* significantly greater dependency than those in private dwellings (186-188). This is not a universal finding, in the UK RV residents report higher levels of general/mental health vs. community dwellers (187). Much of the (limited) research in the RV sector comes from outside NZ and little is known about the social/health/dependency characteristics and needs of NZ's RV residents. Further, given their greater dependency vs. those living in private dwellings) they represent a potentially more vulnerable group in terms of transition to RAC and acute hospitalisation/mortality. We thus need to understand the medical acuity and medical/ dependency 'trajectories' (actuality and time scale of move to RAC, hospitalisation, mortality) and primary care provision of residents. This will inform health planning to improve quality of life (QoL), facilitate independence and reduce service demand. Currently these data are absent in NZ and elsewhere.

In addition, our own work in the RAC sector (the only RCT in this field in the literature) indicates that targeting of vulnerable older people with co-morbidity and offering multi-disciplinary, gerontology nurse specialist/ practitioner (GNS/GNP)-led, complex intervention reduces unnecessary hospitalisations for several important conditions by over 20% (189-191). It is feasible that similar targeted interventions will benefit the (larger) RV community *but we have been able to find no previous literature in this area, and thus believe this approach to be novel and to bridge an important gap in the evidence for this vulnerable population.* RVs are not unique to NZ and our findings will provide important information to aid policy planning and provision both in NZ and internationally.

Our work aligns with NZ InterRAI data and adds to this, as our methodologies have been consistent since 1988, thus providing trends data that is directly comparable (which InterRAI is unable to do). Our previous (189-191) and current work (HRC Health Delivery Partnership Grant 12/884) provides the only RCT evidence of effectiveness of interventions within RAC designed to reduce avoidable acute hospitalisation/Emergency Department presentation. Our current proposal and its planned extensions (currently non-Challenge funded and Y5-10) will help to target resources more effectively (e.g. residents with particular risk factors and, from our preliminary RAC data, medical diagnoses). Again this will be of value in NZ and internationally.

## Research question & research outline

**Hypothesis:** We hypothesise that RV residents have multiple unmet need and high healthcare use, and targeted intervention will decrease RAC entry and acute hospitalisation.

### Aims:

- 1) Describe demographic, clinical and functional characteristics, healthcare use, self-rated health and QoL of RV residents.
- 2) Examine residents' 'cohort trajectory' (3 years, including the effect of inappropriate medications).
- 3) Assess (cRCT- Cluster-randomised controlled trial) effect on trajectories of multidisciplinary integrated care package led by gerontology nurse practitioner (GNP) for 'high risk' residents with multiple co-morbidity over 3 years (including the effect of application of STOPP/START criteria on medicines prescribed).
- 4) Health economic analysis (subject to further funding and in conjunction with Prof Toni Ashton - Health Economist, UoA).
- 5) Extend follow up of 2) and 3) to six years (subject to further funding).

**Population:** Random selection of RVs (30 of the 60 complexes in Auckland/Waitemata DHBs) will be selected-stratified by DHB. A random selection of residents aged 65+ will be asked to participate. *Exclusions:* Refusal of consent; ACER (validated cognitive score) < 70 or person GNP/SW/GP feels lacks capacity –in such cases relative/NOK will be approached to complete a questionnaire about the resident. *Ethics:* HDEC approval/ written informed consent/assent.

**Phase 1:** Residents' self-completed questionnaire including demographic, social engagement, decision making paradigms (e.g. re. move to RV and any putative move from RV to RAC), views on the RV environment, health and functional items - informed by our feasibility study (188). The primary purpose is to describe social, health and functional needs of residents. We will approach 2250 units (assuming mean number of units per village is at least 75: Retire Village Association, pers. comm.) and anticipate that 1500 residents will agree to participate and supply NHIs. Baseline questionnaires will be completed by 12 months from start, representing 125 surveys per month (with random cross validation of 5% at interview by a clinical PI/AI).

**Phase 2:** Social engagement and healthcare trajectories for all participants will be followed for at least 3 years from survey date using MOH routinely collected service utilisation data (RAC admission, hospitalisation) and mortality. Abbreviated survey interviews will be repeated at 12, 24 and 36 months. *Primary Outcome (Phase 2):* to describe trajectories of healthcare utilisation and identify resident clusters by baseline characteristics and trajectories. Further follow-up: 6 years - subject to separate grant application. *Power (Phase 2):* Assuming 1500 residents (inc. 300 in the intervention group of Phase 3 [below] with intervention as a co-variate) and a design effect of 1.5: If the risk of  $\geq 1$  acute hospitalisation is 15% p.a. we will have 94% power to show a 4% difference in the proportion in any categorisation (12 months) – assuming 50:50 ratio. If the risk of RAC entry or death is 15% p.a. then we will have 92% power to show a 3% difference in the proportion (12 months) as above.

**Phase 3:** Based on validated criteria (189-193) we will select a sub-sample of residents 'at high risk' of health and functional decline from Phase 1's sample. A multidisciplinary team (MDT) led by GNP will complete a comprehensive geriatric assessment (InterRAI) and develop/ implement an RCT- validated intervention plan (189, 190) in collaboration with the older person and their nominated support person(s), geriatrician, village staff, physiotherapist, occupational therapist and clinical pharmacist (STOPP/START criteria). Treatment goals will be developed, and the GNP and MDT will record interventions. GNP will meet regularly with MDT: General Practitioners (GPs) will be invited to attend - if unable the GNP will liaise in writing and in-person (though in current studies we have had almost 100% GP attendance at MDTs ((189) HRC 12/884)). Intervention duration (not <5 months) will be person-specific and followed by open-ended clinical GNP support (DHB funded). The intervention will be tested by cluster-RCT of usual care vs. intervention. The 'high risk' intervention and control groups will have assessments repeated at the end of first and third years. Healthcare use (MoH databases) will be evaluated 1 year pre- and 1 and 3 years post-intervention (and at 6 years depending on separate funding). 1o outcome (Phase 3) : acute hospitalisation assessed by time to event analysis (i.e. continuous time endpoints) 2o outcomes Phase 3): RAC admission or death, functional ability, QoL, assessed by time to event analysis. Power (Phase 3): Assuming 600 people are assessed high risk and randomised: if the risk of  $>1$  acute hospitalisation is 26% p.a. (194-196) and risk of RAC entry or death is 15% p.a. (197) and allowing for design effect of 1.5 (190) this yields for example 93% power for 20% difference in hospitalisation (3yrs) and for example 80% power for 30% difference in RAC admission or death (3yrs). Further follow-up: 6 years - subject to separate grant application.

## Giving effect to VM

This project contributes to *Vision Mātauranga's* research theme of Hauora/Oranga: Improving Health and Social Wellbeing. A very small national survey of 173 RV residents by the Retirement Commission (198) suggested that no more than 2% identified as Māori and almost all identified as European, consistent with our own 2012 pilot data (n=110) from Auckland. In contrast, our data for residential care (rest home + private hospital) residents shows that those identifying as non-European (including both Māori and Pacific Peoples) has risen from about 4% in 1988 to about 10% in 2008 (178). The large size (n=1500) of the proposed study will allow to identify methods to produce gains in health and social wellbeing for those Māori living in retirement villages.

## Linkages with other Challenge Projects

Project Title	Link
A. Independence & housing tenure	Closely related projects. Opportunities for data sharing and for joint data collection. Other collaborations are being actively discussed between the two teams.
B. Reducing frailty	Both relate to strategies to reduce frailty/disability. Extensive history of cooperation between the two research groups. Connolly is co-investigator.
C. Social isolation	Links in methodology and outcomes. Extensive history of cooperation between the two research groups. Scope to explore engagement amongst retirement village residents with befriending services. Gott is co-investigator.
D. Older people in work	Gott is co-investigator. No direct links between projects planned at this stage.
E. Neurodegeneration & individualised interventions	Connolly, Boyd, Gott and Bramley are so-investigators. Extensive history of cooperation between the two research groups. No direct links between projects planned at this stage.
G. Risk factors in reduced social engagement	Some similar endpoints. Opportunities for data sharing. Connolly, Boyd and Gott are co-investigators.
H. Drug Burden Index	Some similar endpoints. Opportunities for data sharing. Connolly is co-investigator.

## Strand 2: Promote social integration and engagement

Title	C. Social isolation & loneliness amongst older people in the multicultural NZ context			
Cost \$000	\$418	Co-funding	Age Concern will pay for the time of L. Rees – AVS coordinator	
Start Date	1 October 2015	End Date	30 September 2017	
	Name	Organisation	FTE	Skills
PIs	Prof Merryn Gott	University of Auckland	0.5	Gerontology, Palliative Care, Qualitative research, Mixed methods research, Bi-cultural research, Participatory research
AIs	Ms Louise Rees	Age Concern New Zealand	0.1	Not-for-profit service delivery and coordination, nursing, rehabilitation
	A/Prof Judith Davey	Victoria University	0.1	Policy analysis – implications of population ageing. Social science research on older people – housing, income, intergenerational relationships, general wellbeing.
	Dr Tess Moeke Maxwell	University of Auckland	0.2	Kaupapa Māori and Māori-centred research, palliative care research, bereavement research, research with older people/whānau, qualitative and participatory methods
	Dr Janine Wiles	University of Auckland	0.05	Gerontology, Qualitative Research, Geography, Participative Research.
	Dr Richard Edlin	University of Auckland	0.05	Health economics
	A/Prof Robyn Dixon	University of Auckland	0.01	Survey design, mixed methods, health literacy
	Dr Gabriella	University of	0.4	Data management, qualitative interviewing, narrative

	Trussardi	Auckland		methodologies, critical feminist theory, project management
	Dr Ofa Dewes	University of Auckland	0.2	Pacific ethnic-specific, cross-cultural/interdisciplinary research in NCDs, Research and communication methodologies for Pacific, Community/ systems-based participatory research, Mixed methods research
	Dr Hong-Jae Park	University of Auckland	0.1	Gerontological social work, Mixed methods research, Filial piety and elder abuse, Diaspora and migrant communities, Working with older people in a foreign land (Asian elders)
	Dr Lisa Williams	University of Auckland	0.05	Digital storytelling, bi-cultural research, qualitative methods, feminist research
	Dr Hamish Jamieson	University of Otago	0.02	Gerontology, Palliative Care, Qualitative research, Mixed methods research, Bi-cultural research, Participatory research
	Dr Clare Gardiner	University of Sheffield	0.05	Not-for-profit service delivery and coordination, nursing, rehabilitation

This research will interact with *G. Risk factors in reduced social engagement* to assess the efficacy of visitor services in reducing social isolation. In addition, it will investigate the experience of social isolation and loneliness as understood in different ethnicities – Māori, Pacific Peoples, NZ European and Asian older people.

### Impacts

- By 2018 service development plans will have been created which: 1) inform the provision of the existing Age Concern volunteer visiting service in the short, medium and long term; 2) guide the establishment of new service models to meet the needs of socially isolated and lonely older people, with a particular focus on the service needs of Māori, Pacific and Asian elders

### Context & Opportunity

It has been estimated that approximately 10% of people over the age of 65 are lonely all or most of the time, with rates rising to 50% amongst those over 80 (199). Loneliness has a marked negative impact on the health of older people; a recent meta-analysis estimated that individuals with weak social ties are one third more likely to die prematurely than those with strong social ties (200). A significant body of international literature regarding social isolation and loneliness amongst older people has emerged over the last few decades (201). However, key knowledge gaps exist which need addressing not only to further the theoretical development of the field, but also to ensure the effectiveness and sustainability of services developed to address this significant and growing need. Within the New Zealand context, two issues in particular require urgent research attention.

Firstly, both nationally and internationally, little research attention has been paid to exploring how loneliness and social isolation are understood and experienced by indigenous and minority cultural groups and the implications of these understandings and experiences for service provision (202). Within the New Zealand context, our HRC-funded research has found that older Māori are at increasing risk of social isolation due to smaller whānau and that whānau are increasingly living away from their papakainga (203). Given the need to ensure equitable service provision for Māori older people, in line with the Treaty of Waitangi, research in this area is urgently needed. Over the next two decades demographic projections predict marked increases in the oldest age groups amongst the diverse Pacific population groups in NZ (204). Diversity amongst Pacific older people (due to cultural variations and multiple ethnicities) means that services for Pacific Peoples need to be adaptable and innovative in order to be culturally-centred and responsive to their varied needs and preferences (205). Similarly, older Asian people who have moved to New Zealand are likely to experience an ‘invisible’ type of social isolation and exclusion in later life. Differences in language and culture often lead to significant constraints in their social activities and networks (206, 207).

Secondly, whilst a range of volunteer visiting and befriending services have been developed internationally to address social isolation and loneliness amongst older people, there is little robust research evidence regarding their effectiveness. A particular concern is the lack of comprehensive analysis of the economic costs and benefits of visiting services, although there is limited evidence that they are likely to be cost-effective. For example, effects of such services have been reported to include increased physical and mental health resulting in reduced use of hospital services and delayed entry into aged residential care (208). Within a context of increasingly constrained health and

social care budgets, establishing the positive downstream economic effects of visiting services will be crucial to their long-term viability. Indeed, if proven to be cost effective overall, there is a strong argument for them to be integrated into DHB and council service provision at a community level. Moreover, there is evidence from other areas, including dementia care (209) and the prevention of domestic abuse (210) that community level interventions of this nature can have a very significant economic impact.

Age Concern NZ has recognised the diverse nature of New Zealand's population and the need to tackle the growing problem of social isolation and loneliness amongst older people nationally. One means for addressing these issues has been their development of an Accredited Visiting Service (AVS), a volunteer delivered service aimed at providing companionship and reducing loneliness amongst socially isolated older people. Age Concern has collated evidence from client satisfaction surveys, which indicate high levels of satisfaction with AVS, including reports of reduced social isolation and loneliness (211). However, in order to further develop the service or devise additional ones to meet the needs of NZ's multi-cultural population of older people, they are keen to partner with academic colleagues to develop the evidence base needed to underpin future service development. Working with an established service provider enables the research conducted not only to make an important scientific contribution at an international level, but will also ensure it has immediate impact upon the lives of older New Zealanders. This proposal was developed as a result of the research team meeting with Age Concern NZ CEO Robyn Scott and LR (lead for AVS) to identify their research related priorities.

### Research question & research outline

**Question:** How are social isolation and loneliness understood and experienced by Māori, Pacific Peoples, NZ European and Asian older people, how might their social isolation and loneliness be ameliorated, and to what extent can a volunteer visiting service address this problem?

**Methods:** In order to address this question the study will use mixed methods to:

- i. Examine how social isolation and loneliness are conceptualised by Māori, Pacific Peoples, NZ European and Asian older people
- ii. Elucidate their experience of social isolation and loneliness, the social and cultural context influencing these experiences, and explore effects upon overall physical and psychological wellbeing
- iii. Identify factors which contribute to, and protect against, social isolation and loneliness
- iv. Examine the reasons why older people engage with a volunteer visiting service, as well as the barriers to engagement
- v. Identify factors associated with the effective delivery of culturally-appropriate volunteer visiting services
- vi. Examine the effect of a volunteer visiting service on the wellbeing of older clients
- vii. Establish the cost effectiveness of the volunteer visiting service
- viii. Capture the experience of volunteer visitors delivering the service, identify their motivation for involvement and examine their views of the programme
- ix. Explore stakeholder views of the role and purpose of volunteer visiting services, how they could be optimised to meet the needs of New Zealand's increasingly culturally diverse population of older people, and identify their views regarding levers for increased integration, and funding, of such services
- x. Use this information to support Age Concern to develop a service delivery plan for their AVS volunteer visiting service in the short and medium term
- xi. Identify implications for other service providers and policy makers
- xii. Ensure findings are disseminated to all stakeholders in an accessible and engaging format.

*1) Qualitative data collection with older people, volunteers and key stakeholders and analysis (months 1-18; addressing objectives 1-6 & 8, 9).*

Forty in-depth qualitative interviews will be conducted in three localities: Auckland North Shore, Auckland Counties Manukau and Gisborne, areas chosen for diversity (socio-demographic, economic and rural/urban split) and because they all have established AVS services. Five interviews will be conducted with AVS users and five with older people recruited via GPs who meet criteria for AVS, but who are not current AVS clients for the following ethnic groups: Māori, Pacific Peoples, Asian and NZ European. Interviews guides will be developed to address objectives 1-6 above. Cultural protocols developed in our previous work will inform the approach taken with the 30 interviews conducted with Māori, Pacific Peoples, and Asian older people: e.g. interviewers matched by ethnicity/language and preferred cultural protocols followed (e.g. offering of koha or kai/food in Māori and Pacific Peoples interviews) and a 'filial piety' protocol for Asian elders. Nine focus groups (three in each area) will also be conducted with volunteer visitors and stakeholder groups with questions particularly addressing objectives 8 and 9 above. Interviews and focus groups will be audio recorded with permission and transcribed in full. Narrative (212), thematic (213) and Kaupapa Māori (214) analyses will be conducted within a critical gerontology framework (215)

with the aid of NVivo. Accepted techniques of data rigour will be adopted, e.g. double coding (216). Findings will determine the final selection of outcome measures for Study 2 and add context to the quantitative data to be gathered. The findings will also be used to identify ways in which Age Concern and other providers might develop new services to address loneliness and isolation within a multicultural context.

### *2) Phase 1: Service user and comparison group survey (months 7-20; addressing objectives 2, 3, 5-7)*

The impact of AVS will be determined using a before-after repeat measure of national AVS clients and a comparison group of older people matched on key socio-demographic variables. Formal sample size calculations are not possible due to the lack of prior data on effect sizes, however a sample of n=c.150 in each group is large enough to reflect important variations in the population, but small enough to allow for intensive study method (217). The comparison group will be recruited from areas where there is no volunteer visiting service for older people and which are broadly comparable in terms of rural/urban split and socio-economic profile. AVS clients will be recruited at random prior to their first volunteer visit and invited to provide data on a range of validated psycho-social, health and economic outcomes using standardised tools where available and including: the UCLA Loneliness Scale (218); SF36 Physical & Mental Health Scale (219); EQ-5D (220); Quality of Life Profile – Seniors Version (221, 222); and a service use questionnaire (which includes items on family/whānau care provision) (223) (exact selection informed by Study 1 findings). Open-ended questions will also be added to enable elucidation of unexpected outcomes. The comparison group will be recruited via GPs and DHBs and matched on key socio-demographic and health related variables. All participants will be administered the same measures by telephone at baseline and 9-10 months later. Previous evidence suggests that this duration will be sufficient to demonstrate effect (224). Participant NHI numbers will also be requested in order to collect data on number of hospital admissions and length of stay, emergency department visits, and outpatient visits. Culturally appropriate research techniques will be used to ensure inclusion of Māori, Pacific Peoples and Asian participants. Appropriate descriptive and multivariate analyses will be conducted to address the research objectives under the guidance of Dr Avinesh Pillai, an experienced University of Auckland-based biostatistician. This phase will also address the feasibility of conducting a full RCT of the AVS service; if feasibility is established, follow on funding will be sought.

### *3) Phase 2: Economic analysis (months 7-20; addressing objective 7)*

The economic analysis will compare the cost-effectiveness of provision of AVS against no provision over the 9-10 months of the intervention using a societal perspective. We will use the data collected earlier in the research, including hospitalisation costs per patient (via NHI-linked data), before-after quality of life for older people (EQ-5D, assessed using QALYs). Carer impacts (total carer costs/benefits, QALYs) will be based on needs/carer characteristics and results from current analysis on LiLACS NZ Longitudinal Study of Ageing (225). Any other costs (and any potential benefits) to AVS volunteers per visit will be assessed using a short questionnaire to 40 volunteers (226, 227). Together these data allow calculation of both costs and QALY outcomes amongst the study and comparison (standard care) groups, with multiple imputation used to account for missingness. The analysis will attempt to consider the QALY impacts to patients and carers against overall cost (hospitalisation, carers, AVS and volunteers), and will represent these as a cost-per-QALY figure for AVS vs. standard care, with uncertainty assessed using a cost-effectiveness acceptability curves/frontiers, as is standard. The potential national implications of volunteer services can then be extrapolated from trial data by first relating costs and outcomes to demographic information, before adjusting for the demographic mix amongst older people.

## Giving effect to VM

Driven by Māori health priorities, the study responds to the needs of socially isolated and lonely kaumātua by identifying strategies to increase their hauora (health) and oranga (wellbeing) guaranteed to them under Article Two of The Treaty of Waitangi. The indigenous knowledge and tikanga of kaumātua who experience being mokemoke (lonely/isolated) will be explored to produce critical knowledge about ageing and the socio-cultural context associated with this. This information will help Age Concern and the wider sector to develop new services, resources and activities to reduce loneliness and prevent social isolation among kaumātua.

The subject is relevant to Māori as whānau demographics have changed in the last 20-30 years; there may be too few whānau members to visit and care for older Māori which may increase the likelihood of conditions contributing to social isolation/loneliness. Gains will be made through the research producing culturally rich information about loneliness and social isolation, as well as identifying meaningful cultural solutions.

All research involving Māori directed by Professor Gott, Te (Te Ārai, Research Director) is overseen by the Te Ārai Kaumātua Advisory Group led by senior kaumātua Rawiri Wharemate and Whio Hansen. Dr Tess Moeke-Maxwell (Ngai Tai ki Tamaki Makaurau), an experienced Māori Te Ārai researcher, will provide advice to the study on all aspects of research involving Māori. Interviews with Māori clients/stakeholders will be conducted by a Māori

researcher, in line with the Te Ārai kaupapa Māori research framework. One of the study sites has been selected on the basis of a relatively high proportion of Māori clients and volunteers; this ensures the views of kaumātua are appropriately represented within the project.

### Linkages to other Challenge Projects

Project Title	Link
A. Independence & housing tenure	A high proportion of older people live alone and this is encouraged by ageing in place policies. Most older people live in “mainstream” housing but many are in need of support to maintain their independence. Social contact and community participation is influenced positively or negatively by housing circumstances.
E. Neurodegeneration & individualised interventions	Prof Gott is co-investigator on both projects although no specific content overlap is currently proposed at the moment.
F. Retirement villages	Prof Gott is co-investigator. There is scope within this project to explore engagement amongst retirement village residents with befriending services.
G. Risk factors in reduced social engagement	Prof Gott is co-investigator. InterRAI data will be used to add context to findings (InterRAI assessment is one means by which older people are referred to befriending services).

Title		D. Enhancing the role of older people. Enabling participation in paid and unpaid work.		
Cost \$000	\$701	Co-funding	HWR study data (MBIE funded) will be utilised COST: European Cooperation on “Gender & health impacts of policies extending working life in western countries” will fund international networking & knowledge transfer	
Start Date	1 October 2015	End Date	30 September 2021	
	Name	Organisation	FTE	Skills
PIs	Prof Fiona Alpass	Massey University	0.05	Survey methodology. Longitudinal data analysis. Academic writing.
	Prof Christine Stephens	Massey University	0.05	Survey methodology. Longitudinal data analysis. Academic writing.
	Mr Roy Lay-Yee	University of Auckland	0.05	Survey methodology. Longitudinal data analysis. Kaupapa Māori advisory.
AIs	Mr Brendan Stevenson	Massey University	0.05	Survey methodology. Gerontological expertise.
	Dr Sally Keeling	Otago University	Advisor	Quantitative methods in social science. Aspects of health policy (particularly quality of and access to services), and social policy (social inequality, programme evaluation). Evaluating public policy. Simulation modelling and statistical analysis. Survey practice.
	Prof Peter Davis	University of Auckland	0.3	Experienced health and social researcher, including in the area of ageing. Skilled in quantitative data management, analysis, and modelling.
	Prof Ngaire Kerse	University of Auckland	Advisor	Survey methodology. Older people’s health expertise.
	Postdoctoral Fellow TBA	Massey University	1.0	Longitudinal data analysis. Academic writing.

This research will draw on existing cohort studies of older people in the work place, leveraging existing and big data as well as bringing the cohort studies into closer collaboration. It will involve older people in the research, in ‘Living Labs’, creating new methods of engagement, which will enhance both the nature of knowledge developed as well as its uptake. Its goal is to identify best methods to encourage participation of older New Zealanders in both paid and unpaid workplaces.

## Impacts

- By 2018 policy makers in the Ministry of Health will be using the models developed in the research to understand the drivers and determinants of participation and wellbeing among older people.
- By 2018 researchers in New Zealand, and internationally, will be using the standardised module of survey items across cohort studies of older people. The combined power of a common set of instruments will enable ongoing enquiry into relationships between social participation and wellbeing among diverse groups of older adults in New Zealand.

## Context & Opportunity

Participation, including contribution to family/whānau, community and society by working and volunteering, contributing to marae activities and governance, or caregiving in the home, is an important aspect of health for older people (228). International evidence consistently demonstrates significant positive effects of social connections on older peoples' physical and mental health (229, 230). Poor social connections and social disengagement in over-65s predict cognitive decline (39, 231) and social isolation predicts morbidity and mortality (232). Among older New Zealanders, wider social networks are related to better health and lower premature mortality (228, 233, 234). Results of a recent meta-analysis of the social relations and health of older people (235) estimated that individuals with strong social ties have a 50 per cent greater likelihood of survival than those with poor social relationships and networks over an average follow up period of 7.5 years. This effect was compared to that of smoking 15 cigarettes a day and is greater than other well-established risk factors for mortality such as physical inactivity and obesity. The authors concluded that social relationships influence the health outcomes of adults and we should take social relationships as seriously as other risk factors that affect premature mortality.

However, interventions to enhance social support have had disappointing results (236, 237). We need broader concepts regarding the support of wellbeing through social connections. These include the wider social environment and different aspects of people's everyday lives. The meta-analysis (235) findings suggested that social integration was more important than social support alone. Such findings lead to a focus on the ways in which the social and physical environment supports older people's ability to participate in society; therefore this project focuses on participation through work and volunteering.

Workforce participation is an important aspect of social participation for many citizens. To prolong the workforce participation of the baby boom generation, increasing research attention is being paid to the match between older workers' resources and the demands of the job (238-240). The psychosocial characteristics of the work place (241) are also key aspects of job satisfaction for employees. The proposed study will investigate the physical and social demands of the workplace and their relationship with ability to participate as important targets for change. Unpaid work is also an important aspect of participation. Older volunteers are likely to have better physical and mental health, and report higher self-esteem and satisfaction in life (242-244). Volunteering may be formal service to community, or informal and private, such as care-giving for a family member (245). Informal volunteering, especially caring for a relative or friend, although valued by those who provide care, can also be burdensome and have negative impacts on health and wellbeing when appropriate support is not available (33, 246).

Barriers to contributing to family, community, and society through work or volunteering, may include lack of resources such as income, transport, and time, inflexible workplace practices, ageist attitudes and poor health or disability (247, 248). Such factors prevent contributions, cause discomfort and distress and exclude some older people (27, 249). People who are unable to contribute experience isolation and alienation from communities and the wider society (249, 250). Accordingly, the proposed study will inquire into the physical and social environmental barriers to paid work or formal and informal volunteering by older people in New Zealand.

The research builds on an environmental perspective, which is the basis of a current MBIE-funded research project (MAUX1403 "Enabling Participation by all Older People") and a proposal to HRC to study housing arrangements as an important facilitator of social connections. We developed this focus by including other important aspects of the social environment: the ability of older people to participate in paid and unpaid work and contribute as active members of society. We will leverage existing research capacity by combining resources with other longitudinal studies and databases in New Zealand, and develop new capacity in ageing research, particularly among Māori, to develop innovative perspectives on promoting social participation. These perspectives, located within the everyday lives of older people will provide the basis for a second phase of data collection, leading directly to participatory interventions.

## Research question & research outline

The programme has seven interrelated research aims:

- i. Establish the relationships between participation in paid and unpaid work and loneliness, isolation, and health.
- ii. Identify barriers and facilitators to working, including the impact of age discrimination, the logistics of travel, non-flexible work, caring commitments and volunteering requirements.
- iii. Identify the different needs and avenues for participation of different ethnic groups including Māori, Pacific Peoples, NZ European, and Asian peoples. Include the specific issues for immigrants.
- iv. Identify the specific issues for caregivers of older and younger people.
- v. Develop, implement and evaluate design models for an inclusive workplace which optimises health, wellbeing, safety, productivity and workability of workers across the life course.
- vi. Develop and evaluate plans for community, iwi, and agency use to support older people who wish to volunteer their services or care for family members at home.
- vii. Adopt continuous and active engagement with agencies, iwi, employers and older people to guide the research process and deliver effective and wide ranging dissemination of the findings and outputs.

The research will be carried out across three Phases:

### *Phase 1 Aims i. to iv. Years 1-2*

Phase 1 brings together researchers and data sets across New Zealand to join skills, knowledge and technological expertise in order to use a wealth of existing data:

- We will use existing data from cohort studies and public datasets (including Statistics NZ and Ministry of Health data) to identify important predictors, investigate the effects of aspects of participation on social isolation and health for different groups of older people, and statistically model the outcomes of projected policy applications.
- We will collaborate with the Health, Work and Retirement (HWR) and Life and Living in Advanced Age (LiLACS NZ) cohort studies, using joint data from these studies of different age groups (55 to 95 years), to establish relationships between network types, social support, social capital, participation, caregiving, and physical and psychological wellbeing over time in older Māori and non-Māori.

### *Phase 2 Aims 1-4, Years 2-3*

Phase 2 will develop a new collaboration between New Zealand cohort studies and use their population samples and in-depth background knowledge of the participants' lives to answer new questions about the needs for participation, desired avenues of participation, and the health outcomes of participation of older people, which are raised in Phase 1. A standardised module of questionnaire items will be developed in collaboration with all groups, that can be utilised across existing cohort studies (HWR, LiLACS NZ, DMHDS, CHALICE) to examine relationships between participation and health and quality of life outcomes.

### *Phase 3 Aims 5-6, Years 4-6 (funding yet to be established)*

Phase 3 will apply the knowledge generated from Phases 1 and 2 through a novel approach to intervention development. 'Living Labs' will be used to develop interventions with stakeholders (e.g. Iwi representatives, Volunteer NZ, Employer groups, Unions) and older people themselves. Living Labs are user-focused and draw on principles of participatory design and the co-production of interventions based on evidence. Participative methods will be used to identify the unmet needs related to the participation in paid and unpaid work of older New Zealanders as they age in place. Unmet needs are then prioritised and actions initiated to address these needs through the development of pilot projects, in partnership with community stakeholders and end users.

Using a structured set of intervention goals based on Phase 1 and 2 evidence we will engage community members of one representative and diverse locality in New Zealand to design and develop a set of relevant interventions for application and systematic evaluation. These interventions will include:

- work design models for an inclusive workplace which optimises health, wellbeing, safety, productivity and workability of workers across the life course;
- plans for community, iwi and agency use to support older people who wish to volunteer their services or care for family members at home.

The co-design and production stages involve the creation of a range of group activities and meeting opportunities for direct stake holders, as well as opportunities for broader input from all community members.

## Giving effect to VM

This project directly addresses Theme 3 of Vision Mātauranga – Hauora/Oranga: Improving Health and Social Wellbeing. The HWR and LiLACS studies oversampled Māori in order to contribute to an evidence base that provides a better understanding of the health and wellbeing of older Māori and the factors and issues that impact on their health and use of health care services. Understanding the circumstances of older Māori (as unique experiences and as compared to non-Māori) throughout the late life course, transitioning to retirement, and during retired life, is an essential first step to designing more effective interventions and policy for this growing proportion of the population. LiLACS applies a Kaupapa Māori approach to research. Te Rōpu Kaitiaki Tikanga Māori (Protectors of principles of conduct in Māori research), a group of pan tribal kaumātua, aged 60+ to 85+ ensures that Te Reo Māori me ngā tikanga is protected from damage.

HWR has an established Māori Advisory Reference Group to ensure that design and research protocols are appropriate for Māori. This group is coordinated by Mr Brendan Stevenson (Ngā Puhi, Ngāti Porou), a named investigator on the proposed project. Māori PhD and Masters students will have the opportunity to utilise the study for postgraduate research projects and theses. Stipends to support the research development of Māori students will be sought through additional funding applications.

## Linkages to other Challenge Projects

Project Title	Link
A. Independence & housing tenure	The HWR population level survey data provides prospective information from 7 waves of data collection about older people's housing tenure change, participation and social engagement and wellbeing.
B. Reducing frailty	The HWR population level survey data provides background information from 7 waves of data collection about older people's physical activity levels and health risks.
C. Social isolation	HWR population level survey data provides prospective information from 7 waves of data collection about older people's social isolation and loneliness.
F. Retirement villages	The HWR population level survey data provides background information from 7 waves of data collection about older people's perceptions of retirement villages and subsequent movement into retirement villages or other forms of housing.
G. Risk factors in reduced social engagement	The HWR population level survey data provides prospective information from 7 waves of data collection about risk factors for reduced social engagement in older people as they move from work into retirement in New Zealand.
H. Drug Burden Index	The HWR population level survey data provides information from Face-to-face interviews in 2010 (N=903) on common medication use. Data-linkage with MoH pharmacy database for 7 waves of data collection is currently underway.

Title	G. Risk factors for reduced social engagement in older people			
Cost \$000	\$226	Co-funding		The project will leverage off significant investment to date by MoH and the NHB in the national database InterRAI
Start Date	1 Oct 2015	End Date		1 year
	Name	Organisation	FTE	Skills
PIs	Dr Hamish Jamieson	University of Otago & Canterbury DHB	0.2	Geriatrician working in assessment, treatment and rehabilitation of older people. Extensive research experience in ageing and older persons health.
	Dr Sally Keeling	University of Otago, Christchurch	Advisor	Social scientist with research experience in health services policy and development. Led evaluation of assessment methodologies for MoH and NZ Guidelines Group, involved since in evaluation and implementation of interRAI.
AIs	Prof Philip Schluter	University of Canterbury	0.05	New Zealand's inaugural Professor of Biostatistics; specialist in quantitative and epidemiological study designs and analyses – particularly observational and longitudinal.

Dr Nigel Millar	Canterbury DHB	Advisor	Geriatrician, Chief Medical Officer of CDHB, interRAI Fellow. Involved in implementing numerous national Health IT projects.
Prof Martin Connolly	University of Auckland	Advisor	Senior geriatrician, leading collaborator in multi-disciplinary research in ageing; will link with Project F.
Dr Cameron Lacey	Te Atiawa & University of Otago	0.02	Māori Psychiatrist with clinical experience working with older Māori. Will provide cultural advice & translate findings into clinical care.
Dr Michal Boyd	University of Auckland	Advisor	Senior Lecturer and Nurse Practitioner for Older Adults at Waitemata DHB. Specialist in population changes and evaluation of innovative care models for care of older adults, chronic conditions management, palliative care for older people and development of advanced nursing practice.
Prof Merryn Gott	University of Auckland	0.2FTE	Will link with project C on social isolation.
Prof Simon Kingham	University of Canterbury	Advisor	Geographer who brings techniques of spatial analysis to the project.
A/Prof Ruth Hubbard	University of Queensland, Australia	0.05FTE	Academic geriatrician with expertise in frailty in older people, in depth knowledge of interRAI tools.
Prof Len Gray	University of Queensland, Australia	Advisor	20 years experience with interRAI systems in hospitals, home care and long term care; international interRAI Board Member. Extensive experience in telemedicine.
Prof John Hirdes	University of Waterloo, Canada	Advisor	Advisor to on implementation and development of NZ interRAI. Extensive understanding of the interRAI database development for Canadian Institutes of Health Information, advocate for research utilisation of interRAI data for service improvement.
Prof Vince Mor	Brown University, USA	0.02	Prof Mor has assembled linked RAI data on all nursing home and home health care recipients and merged those with Medicare insurance records.

This research is linked with Project H., the Drug Burden Index, and both will leverage off the interRAI data and methodology to determine risk factors that will underpin the development of appropriate interventions to enhance social engagement for New Zealanders of different ethnicities.

### Impacts

- By 2018 the project will generate world-leading information on social engagement and social support by ethnicity/gender/age/region which will allow regional comparisons in outcome, guide other studies by identifying those at high risk of health decline or living in an unsupportive environment and assist service planning in public, private and community sectors to better target those at high risk of social isolation or poor outcomes.
- By building New Zealand's own evidence base within the interRAI methodology, this project will enable the findings to be applied directly into computer-generated treatment and care plans after interRAI assessments. This will allow improved use of health resources and improved targeting of interventions aimed at improving social engagement for the 46,000 New Zealanders who have an interRAI assessment each year.

### Context & Opportunity

Reduced social engagement of older people is an international challenge (251-253). There is a strong relationship between social engagement and health, and measures of poor social engagement are a consistent predictor of poor health outcomes for older people in New Zealand (254, 255). This project explores the large and unique New Zealand interRAI database in relation to social isolation, loneliness and reduced social engagement, and the sustainability of social support. To our knowledge researching social engagement with such a large and complex data set, with regional comparisons, has not been performed anywhere in the world. After an evidence-based review the Ministry of Health chose the InterRAI (international residential assessment instrument) as the 'best practice' process for comprehensive geriatric assessment throughout New Zealand (256). The interRAI has been used by a

multidisciplinary collaborative network of academics and clinicians in over thirty countries (257-261). The 1.5 hour interRAI homecare assessment is usually completed in the person's home and records responses to 236 standardised questions – 22 of which are directly related social engagement.

Past work based on the effects of social engagement on health outcomes using interRAI assessments involved residents in nursing homes. The interRAI social engagement scale was developed in USA nursing homes in the mid-1990s (262) and validated within a few years in Denmark, Iceland, Italy, Japan, and USA (263). Two further studies applied different aspects of the social engagement scale to staff training and development, and found benefits of engagement to residents' health outcomes (264, 265). One study found that undertaking the assessment process itself improved social engagement (265).

New Zealand is the first country in the world to implement a universal standardised comprehensive geriatric assessment for all older people who are being considered for access to publicly-funded community services or residential care. This has created a researchable dataset that is almost unparalleled in the world. To date, 80,000 homecare assessments have been completed and it is anticipated that another 46,000 will be completed annually, which equates to approximately 8% of the population over 65. There has been extensive consultation with Māori during its development, and the assessment has been adapted for use in Māori (266). Additionally, the data has a unique identifier (known as National Health Identifier or NHI) attached which allows tracking of medium term outcomes such as admission into residential care and mortality.

The interRAI offers the opportunity of a large dataset which can be interrogated to explore the complex risk factors for social isolation and reduced social engagement in, and sustainable support for, older people. The large data size allows for stratified analyses of different ethnic groups including Māori (>5,000 assessments completed for Māori), Pacific Peoples and Asians. In addition interRAI data includes domicile coding, allowing consideration of socioeconomic status, access to green spaces and other environmental factors, and access to social and recreational services (267, 268). To our knowledge researching social engagement with such a large and complex data set, with regional comparisons, has not been performed anywhere in the world. Results can be directly applied to improve the care of the 46,000 New Zealanders who have an interRAI assessment every year.

### Research question & research outline

Using the 'big data' available from the national interRAI database and linkage to other national databases our project has four research aims to address two linked key questions:

1) What are the relative risk factors for reduced social engagement alongside the other 214 individual questions in the interRAI assessment?

2) In what ways are medium and long term outcomes for older people mediated by varying interRAI measures of social engagement and environment (such as living situation) and sustainability of social support?

Both of these questions will take into account the roles of reduced cognition, the risk of falls and reduced mobility, and the other factors assessed in the interRAI including pain, depression, anxiety, continence and fatigue, and limitations in activities of daily living.

The following data will be extracted from the 81,236 existing New Zealand interRAI 9.1 homecare assessments. Permission to use the data has been obtained from the New Zealand InterRAI Board. National ethics approval has been obtained from the Health and Disability Ethics Committee for this research.

A) Demographic data including age, sex, date of assessment, ethnicity (from 20 categories), NHI number and domicile code

B) The 236 individual questions in an interRAI assessment

C) CAP scores, outcome scales and 23 Resource Utilisation Groups (RUGs) produced after the interRAI assessment.

Medium-term outcomes (at six months, one year and two years) of recurrent hospital admissions, requirements/referrals for residential care and mortality will be sourced using the NHI-linkage of the data using the National Minimum dataset, and births, deaths and marriages data.

The datasets will be linked by an analyst as data manager. Current, best practice data management techniques will be employed covering broad domains: information; infrastructure; and informatics. All data will be anonymised to maintain patient confidentiality.

**Aim 1:** *Determine the prevalence of varying measures of social engagement in older people in New Zealand and the medium term outcomes associated with them.*

The interRAI homecare 9.1 assessment contains 22 questions on social relations including specific questions on: social relationships, recent change in social activities, loneliness, length of time alone, recent stressors, living situation and environment, communication, hearing and vision; and social supports. Data will be evaluated to identify the relative risk factors of the 22 individual questions on social engagement for producing poor medium term outcomes (such as the need for residential care or mortality).

**Aim 2:** *Identify risk factors for reduced social engagement of older people from different demographic groups.* Multiple sub-analyses will be undertaken for different demographic groups. Firstly results will be compared in different ethnic groups including Māori. Gender and regional comparisons will be made and the reasons for any disparities identified.

**Aim 3:** *Use other interRAI-related data to determine the effect of potential confounding factors (such as continence, mobility and depression) on reduced social engagement.*

All remaining interRAI data will be assessed to determine the extent (if any) they are influencing social engagement. These include physical factors such as the presence and degree of urinary and faecal incontinence; mobility as assessed by a timed four meter walk test; falls screen (six questions); and ability to perform activities of daily living and instrumental activities of daily living. The database also includes psychological factors such as depression, anxiety and cognitive impairment. Data will be evaluated to determine the relative risk that each of these factors contributes towards reduced engagement in society.

**Aim 4:** *Use data from other national datasets to determine the effect of geospatial factors on social engagement.* InterRAI assessments record domicile code which allows the client’s location to be identified to the area of a quarter of a postcode. Information will be combined with census data and Geographic Information Systems (GIS). Euclidean buffer analysis will be used to explore the effect of location, socioeconomic status and the proximity to green space and social and recreational services on social engagement and outcomes (267, 268).

Contemporary epidemiological and bio-statistical methods will be employed in the analysis and interpretation of the data to derive estimated effect sizes and confidence intervals while mitigating, where possible, the impacts of any associated biases. Residual diagnostics and influence statistics will be undertaken so that the robustness of all statistical models can be explicitly asserted and demonstrated. Apposite generalised linear models, such as logistic and linear regression models, will be employed and extended to multi-level models to account for clustering where possible. Analysis will follow the Strengthening the Reporting of Observational studies in Epidemiology (STROBE) guidelines (269). The statistical evaluation will be supported by Professor Philip Schluter who was the first professorial appointment in biostatistics in New Zealand.

### Giving effect to VM

This project has been developed with a strong focus on embedding the principles of *Vision Mātauranga* and has had close liaison with Māori at all stages of its development and implementation. The interRAI governance board has had a Māori member for the last four years and, prior to that, Health of Older Persons (HOPS) and NZGG engaged with Māori throughout a decade of progressive implementation of interRAI in NZ. In the development of the interRAI in New Zealand, Māori consultation was led by the interRAI Māori strategy work stream of the National DHB interRAI implementation project. A Meihana model was developed for an overarching clinical assessment framework for Māori in interRAI. This was to guide the 1800 nationwide interRAI assessors on working with Māori

Dr Cameron Lacey (Te Atiawa) will advise on the cultural interpretation of the research and will assist with ongoing consultation with Māori in the implementation of results. Recommendations for Māori assessment include: facilitating the use of karakia and other aspects of Tikanga and Kawa if they are important to the person, identifying where the person comes from, and building trust and respect with the person and their whānau. In accordance with section 2.3 of the “Hauora/Oranga: Improving Health and Social Wellbeing” theme from the “*Vision Mātauranga*” document, the project will identify successful approaches to Māori health and social needs, issues and priorities. All results will be fed back to the interRAI Māori Strategy work stream. Key findings will also be presented at Hauora Māori research hui including Te Ora Hui a Tau and the Pacific Region Indigenous Doctors Conference.

### Linkages to other Challenge Projects

Project Title	Link
A. Independence & housing	Living situation and housing circumstances are key components of older people’s engagement and participation. We will investigate this in Project G using comparable

<b>tenure</b>	measures and identifying particular populations at risk of poorer outcomes.
<b>B. Reducing frailty</b>	Study G will contribute useful analyses to projects such as B, by showing how social and other clinical factors identified at baseline may assist in interventions (such as Senior Chef, and Steady As You Go) being targeted for effective benefit.
<b>C. Social isolation</b>	Study G has named the PI of Study C (Prof Gott) as an AI; this reflects our intention to work collaboratively between the two projects, particularly in understanding how particular services and communities might make a difference to social isolation and loneliness.
<b>D. Older people in work</b>	Study D draws on two major longitudinal cohort studies of ageing in NZ (LILACS and HWR), both with longstanding collaborative links with Dr Keeling, co-PI. Understanding the particular social and health circumstances of each cohort, alongside the Project G cohort of “those assessed with interRAI prior to service access” is critical to systematic analysis of the features of “Ageing Well in NZ.”
<b>E. Neurodegeneration &amp; individualised interventions</b>	As study G will contribute social correlates of an extensive range of clinical variables, effectively providing baseline patterns, intervention studies such as E could benefit by sharing both design and development, as well as understanding results of local interventions alongside a broader national study.
<b>F. Retirement villages</b>	Professor M. Connolly and Dr Boyd (PIs) are AIs on Project G, which is a relationship designed to enhance potential linkages. As with Project A, the social circumstances of those living in retirement villages are likely to be highly relevant to identification of needs and to interventions..
<b>H. Drug Burden Index</b>	While project H. focuses on medication use there will be extensive sharing of the methodological steps in conducting the various analyses.
<b>I. Stroke &amp; CVD prevention</b>	As a preventative intervention aimed at older people in community settings, this project will be well served by Project G, as social factors are necessarily part of effectiveness.

### Strand 3: Value older people in all settings

<b>E. Can neurodegenerative end of life care be improved with individualised attention</b>				
<b>Cost \$000</b>	\$255k	<b>Co-funding \$000</b>	\$207 from the Perpetual Guardian Ted & Molly Carr Trust \$9k in kind personnel time Waitemata DHB	
<b>Start Date</b>	1 October 2015	<b>End Date</b>	3 years	
	<b>Name</b>	<b>Organisation</b>	<b>FTE</b>	<b>Skills</b>
<b>PIs</b>	Dr Michal Boyd	University of Auckland	0.2	Previous PI for large cross-sectional and intervention aged residential care studies. Clinical expertise in gerontology, dementia and palliative care.
<b>AIs</b>	Prof Merryn Gott	University of Auckland	0.03	Professor and international research leader of ageing and end-of-life-care practice and policy.
	Prof Martin Connolly	University of Auckland	0.03	Professor, geriatrician, international expert and research leader of ageing, long term conditions and residential aged care interventions.
	Dr Rosemary Frey	University of Auckland	0.1	Expertise in survey-based research and statistical analysis
	Dr Julia Slark	University of Auckland	0.05	Clinical and research expertise in the care of people with stroke.
	Ms Jackie Robinson	University of Auckland & Auckland DHB	0.05	Clinical and research expertise in palliative care.
	Ms Susan Foster	University of Auckland	0.4	Previous project manager for large cross-sectional and intervention studies in residential aged care.

	Dr Tess Moeke-Maxwell	University of Auckland	Advisor	Dr Tess Moeke-Maxwell provides Māori bicultural leadership of the Te Arai Palliative Care Research group and Kaumatua ropu.
	Dr Dale Bramley	Waitemata DHB	Advisor	Public health physician and expertise in healthcare policy.
	Prof Heather McLeod	Ministry of Health & University of Otago	Advisor	Palliative care epidemiology expertise.

This research is focused on quality of dying, particularly for those with neurodegenerative diseases. The challenge of giving best quality of life to people with severe disability and in the face of impending death is an issue growing with our older population. We know little about end of life experiences so this research will collate information that will be comparable to international data, leveraging on international knowledge, and will be directly useful to developing interventions.

### Impacts

- Phase 1: will deliver data on the quality of life and care for people with neurodegenerative disease in aged residential care (ARC) in New Zealand that can be directly compared to other international data, thus providing critical evidence for MoH/Hospice New Zealand ARC integration models of care.
- Phase 2: will provide valuable evidence of family perceptions of quality of care for their family member in ARC, and allow for comparison with staff perception of care.
- Phase 3: Palliative ‘Care Guides’ will be developed based on the research results, and other international evidence, for distribution throughout New Zealand. This model of research translation has been very successful in the past for several key projects through projects led by Dr Boyd such as the Residential Aged Care Integration Programme and the Ministry of Health.

### Context & Opportunity

The vast majority of people die in their later years, hence ageing well includes dying well. Approximately 45% of people in NZ over 65 years live in an aged residential care (ARC) facility at the time of their death, the highest rate of death in ARC facilities of any published worldwide (270). 66% of Auckland ARC residents have some form of cognitive impairment (271, 272) similar to internationally reported rates (273). Over 68% of all deaths for those 65+ years result from neurological conditions (including dementia and stroke) with most requiring ARC 24-hr care before death (274). Supporting the best quality of life (QoL), even in the face of severe disability and impending death, is critical to older people’s wellness. This will become more important as deaths for those 85+ years quadruple in the next 40 years and with a large proportion likely to occur in ARC (275). It has been estimated that just under half of ARC deaths would benefit from specialist palliative care input (275), yet under 3% of people 85+ years die in a hospice (cf. almost 20% of those under 65 years). It has been suggested that ARC facilities serve as a ‘de facto’ hospice for older people due to the extensive palliative care they provide (58). Māori have higher rates of risk factors for dementia such as cardiovascular risk, depression, head trauma and substance use issues and very little is known about their end of life experience in ARC (59, 276).

There are many barriers to high-quality neurodegenerative palliative care. For example, unlike death from cancer, it is very difficult to predict impending death (277). End of life issues are often more complex, particularly for people with dementia where cognitive ability is obviously compromised (278). People who die with dementia often have quite severe symptoms and clinical complications and have difficulty communicating their needs/preferences, increasing the risk of suffering at end of life (279). They also have high rates of pneumonia, other infections, incontinence, pressure sores, cachexia and dehydration. The most commonly reported symptoms for people with dementia in the last month of life are pain, fear, and anxiety, issues common to many requiring palliative care irrespective of their diagnosis (280-282). It is well established that high quality palliative care for people with cancer improves QoL (283) and reduces suffering. However, best practice end of life care for those with dementia has not been established (284, 285) and there are few large-scale empirical studies about end of life experiences in ARC for those with dementia (286, 287).

Our group recently conducted a census of palliative care need at Auckland City Hospital. We found the sole predictor of avoidable hospitalisation was ARC facility residence (288). This led us to explore the palliative care education needs of ARC staff [n=431]. We found that a quarter reported spending over 50% of their time working with those in the last year of life, yet 53% said that they had no palliative care education (289). A strong predictor of willingness to engage in such education was previous experience in end of life care (290). We have also found that staff burnout decreases likelihood of engaging in palliative care education and staff members with limited education

often struggle with trying to meet the needs of dying residents (291). Health care assistants who perceived education as “always available” had lower exhaustion scores (292). Organisational environment has been identified as a factor influencing changes to care (278, 291, 293). Previous research has also highlighted communication as a key component in providing effective palliative care (294, 295). This indicates that increased availability of palliative care education is a necessary but not sufficient step to improve the quality of care delivery. ARC staff palliative care support needs have been recognised nationally. For example Hospice NZ, in part informed by our own research above, is currently implementing an ARC palliative care education programme across NZ. However, the clinical impact of this program for ARC residents has not been established (296).

Overall, relatively little is known in NZ or internationally about the end of life care experience of people with neurodegenerative conditions such as dementia and stroke who live in ARC facilities (275, 287, 297). The Ministry of Health (MOH) has called for more systematic research into the palliative care needs of ARC residents (298). The New Zealand Palliative Care Strategy has identified “scanty provision of palliative care in institutional settings for care of older people and those with degenerative conditions” and The Palliative Care Council identified palliative care in ARC as an area requiring further research in order to identify how palliative care might be improved in that setting (298). It was in response to these calls and related gaps in knowledge at a national and international level that the current research was formulated (285, 298).

End of life care guides are needed for neurodegenerative conditions in ARC and this will provide a solid evidence base for future guidelines for individualised interventions that can improve QoL and reduce suffering for people with end-stage neurodegenerative conditions in ARC. Our consortium, the Te Arai Palliative and End of Life Care Research Group is the only group with a palliative care focus in NZ (288, 289, 299). The Freemasons’ Department of Geriatric Medicine has produced some of the largest ARC research studies in New Zealand over the last 30 years (300, 301). The collaboration between these two groups provides the expertise to successfully complete ARC palliative care research.

## Research question & research outline

Research Questions:

**Phase 1:** From the perspective of ARC staff, what is the perceived health status, quality of dying and advanced care planning prior to death of ARC residents with neurodegenerative diseases (dementia and stroke)? Validated questionnaires will be used for this investigation.

**Phase 2:** What is the dementia/stroke dying experience from the family/whānau perspective and to what extent does it correlate with ARC staff experience using the same validated questionnaires?

**Phase 3:** Based on the results of the above research, what is needed to translate the evidence into palliative care guides to improve ARC care of those dying of neurodegenerative conditions?

**Phase 4:** Do individualised ‘best practice’ interventions for those with neurodegenerative diseases in ARC improve end of life care? We propose a RCT intervention trial for this phase. Funding for phase 4 will be sought upon completion of the phases 1, 2 and 3.

**Phase 1:** The aim is to determine quality of death from the perspective of ARC care staff. The design is a retrospective cross-sectional study, based on a similar Belgian study, and fulfilling an identified need for international comparison studies (282, 285).

*Population:* A random cluster sampling of 60 representative facilities (average size 44 beds, approximately 2,640 representative ARC beds). It has been estimated that there is approximately 1 death per month in the average size facility, resulting in n=180 total deaths from neurodegenerative diseases over 3 months (274, 276, 282). Facilities will be randomly selected and stratified by: region (Auckland/Wellington/Christchurch); size (< 70 beds/ ≥70 beds); for profit/ not for profit status; location (rural/ urban facilities). If facilities decline to participate, another facility will be recruited until each stratified category has an adequate number of facilities.

Data:

*Deaths:* All resident deaths (whether occurring in the facility or elsewhere) during a specified 3-month period will be recorded by facility administration and cross-checked with MoH databases. Information obtained will include:

*From Aged Care Facility Administrator:* Place of residence before ARC admission, secure/ non-secure unit, last cognitive assessment charted (MMSE, MoCA, other).

*From GP or Nurse Practitioner providing care within a month of death:* Resident’s health status, cause of dementia or other neurodegenerative condition, co-morbidities.

*From Registered Nurse (RN) involved in the subjects care within a month of death:* Presence of family carer at time of death, resident health status, stage of dementia. Enduring power of Attorney (EPOA) (Health & Welfare), EPOA

- 1 month before death - the RN will be asked to base their response on clinical notes as much as possible: Functional and cognitive status, Bedford Alzheimer Nursing Severity Scale (BANS-S); Global Deterioration Scale (GDS – classifying dementia into 7 stages based on deficits in cognition and function); Cognitive Performance Scale (CPS) (validated measure assigning residents to cognitive performance categories); Sentinel events (pneumonia, febrile episodes (other than pneumonia), problems with eating/drinking, hip fracture, stroke, gastrointestinal bleeding, cancer, other); Quality of dying; Presence of distressing symptoms in last month of life measured by the Symptom Management End-of-Life in Dementia (SM-EOLD) .
- 1 week before death - the RN will be asked to base response on clinical notes as much as possible: Quality of dying Comfort Assessment in Dying End of Life in Dementia (CAD-EOLD) and Quality of Life in Late-Stage Dementia (QUALID); Functional status; decubitus ulcers, incontinence, and restraints.

*Statistical Analysis:* Differences in distribution between very severe/advanced dementia, severe dementia, and moderate/mild dementia calculated using Fisher Exact Tests. Medians and averages tested using Kruskal-Wallis and analysis of variance with post hoc least significant difference (significance level  $P \leq .05$ ) Phase 1 protocol and statistical analysis is based on Vandervoort et al. 2013 (282).

**Phase 2:** The aim is to determine quality of death from families' perspectives.

We will use mixed methods with interviews exploring family members' perspectives of end of life care (3 months to 6 months post-bereavement) conducted using standardised surveys (SM-EOLD) and qualitative semi-structured interviews. The family/whānau member most closely involved in medical decision-making and most knowledgeable about the circumstances of the resident's death will be recruited from Phase 1 participating facilities. A sub-group of Māori and Pacific Island families/whānau will be specifically targeted for interviews. Results of the SM-EOLD survey will be compared to staff SM-EOLD survey for the same resident. Qualitative interviews will be recorded and transcribed verbatim and subjected to thematic analysis (213). Accepted techniques to ensure data rigour will be adopted.

**Phase 3:** Following the above, a palliative care guide for neurodegenerative conditions will be developed using the similar methods used for the 'RN Care Guides' and 'Medication Care Guides' to translate evidence into practice.

**Phase 4:** Further funding will be sought to conduct a randomised controlled trial (RCT) in ARC. This RCT will draw on the evidence from Phases 1-3 and also on the results of a PBRF funded pilot project we are currently conducting (302). The goal will be to assess the impact of the intervention on end-of-life quality of care in ARC.

### Giving effect to VM

Māori have higher rates of risk factors for dementia such as cardiovascular risk, depression, head trauma and substance use issues (59). As the population ages the prevalence of dementia also increases for all New Zealanders, including Māori (276). Older people hold a highly respected position for Māori because of their mātauranga (knowledge of te ao (Māori world) and whakapapa (genealogy), te reo (Māori language) and tikanga (cultural customs). Kaumatua (older men and women) contribute significantly to the overall well-being of the whānau. The study aligns with Māori health philosophy by building whakawhanaungatanga (trusting relationships) and by ensuring whānau safety through processes of manaakitanga (caring for participants) and kotahitanga (establishing consensus through collaboration/partnership). A holistic approach to death (due to neurodegenerative conditions in ARC) will ensure the needs of whānau are met.

Our palliative care research group operates under a bi-cultural framework (Te Arai) under the advice of our colleague Dr Tess Moeke-Maxwell. Te Arai has been developed by Te Arai's advisory group, led by Kaumatua Rawiri Wharemate and Whio Wharemate (Ngati Whatua). The framework provides us with a cultural protocol to work safely with Māori who are seriously ill or dying, and their whānau.

This project falls within Vision Mātauranga's research theme of Hauora/Oranga: Improving Health and Social Wellbeing. The project will increase quality of life for Māori, as it will for all New Zealanders. We have included funding for consultation from our existing Te Arai Kaumatua ropu and for Dr Tess Moeke-Maxwell who provides facilitation for Te Arai Palliative Care Research group and Kaumatua ropu. In addition, all projects submitted from the Faculty of Medicine and Health Sciences, University of Auckland, are reviewed by the Tumuaki, Associate Professor Papaarangi Reid, within the Faculty of Medical and Health Sciences.

## Linkages with other Challenge Projects

Project Title	Link
A. Independence & housing tenure	Residential aged care is the place of death for almost 60% of woman and 50% of men aged 85 years and older. This research seeks to better understand and provide individualised intervention to enhance the end of life experience and therefore there is opportunity to link this research with our research
B. Reducing frailty	Increasing frailty is integral to end of life for older people and this research seeks to investigate and promote the best palliative care possible even with severe frailty.
C. Social isolation	Very little is known about the experience of people dying in aged care in New Zealand and this research will provide the evidence needed to enhance social connectedness at the end of life. We have a robust Kaumatua and Kuia ropu who will guide our identification of end of life experience for Māori elders and their whānau.
D. Older people in work	There is currently very little research about the quality of life and quality of dying for older people in New Zealand. This research will focus attention on how quality of life can be enhanced even in the face of death.
F. Retirement villages	Many older people live in retirement villages prior to the physical decline that precedes death when 24 hour care in aged care facilities is required. Collaboration between these two projects will provide evidence about the continuum of care as people age.
G. Risk factors in reduced social engagement	Little is known about the social engagement for older people in aged care at the end of life. Our project will provide evidence about quality of life, including social engagement as death approaches in residential aged care.
H. Drug Burden Index	There is opportunity to evaluate the drug burden for those at the end of life in collaboration with this research, and therefore to collaborate with this research team regarding drug burden changes at the end of life.
I. Stroke & CVD prevention	Our research seeks to better understand the palliative experience of those with neurodegenerative diseases, including stroke. Our research complements Project I by expanding understanding of healthcare needs for those with stroke at the end of life.

## Strand 4: Reduce disability and the impact of disability

Title	H. Evaluation of the Drug Burden Index to predict adverse outcomes in older people			
Cost \$000	\$161	Co-funding	None	
Start Date	1 October 2015	End Date	1 year	
	Name	Organisation	FTE	Skills
PIs	Dr Hamish Jamieson	University of Otago & Canterbury DHB	0.2	Older Persons Health Specialist in dual clinical and academic role.
AIs	Dr Prasad Nishtala	University of Otago	0.02	Geriatric pharmacoepidemiologist
	Dr Nigel Millar	Canterbury DHB & NZ Health IT Board	Advisor	Geriatrician, Chief Medical Officer of CDHB, interRAI Fellow. Involved in implementing numerous national Health IT projects.
	Prof Philip Schluter	University of Canterbury	Advisor	New Zealand's inaugural Professor of Biostatistics; specialist in quantitative and epidemiological study designs and analyses – particularly observational & longitudinal.
	Dr Cameron Lacey	Te Atiawa & University of Otago	Advisor	Māori Psychiatrist with clinical experience working with older Māori. Will provide cultural advice & translate findings into clinical care.
	Matthew Doogue	University of	0.02	Clinical Pharmacologist with expertise in

	Otago, Christchurch		Medchart (the NZ electronic prescribing system).
R. Kirk	University of Canterbury	Advisor	Health Services Researcher with expertise in Health Technology Assessment, Health Informatics and Evidence Based Medicine.
C. Heppenstall	University of Otago & Canterbury DHB	0.02	Polypharmacy and inappropriate prescribing in frail older people.
T. David	University of Canterbury	Advisor	Managing large datasets
C. Hanger	Canterbury DHB	Advisor	Geriatrician with strong clinical interests in frailty and community care
M. Connolly	University of Auckland	Advisor	Geriatrician who will link the findings of this study with Project F
S. Hilmer	University of Sydney, Australia	Advisor	Pharmacoepidemiologist researcher and in clinical practice. Developed the Drug Burden Index (DBI).
D. Abernethy	FDA & Johns Hopkins University, USA	Advisor	World expert on polypharmacy, currently Associate Director of Drug Safety for the US Food and Drug Administration (FDA).
D. Le Couteur	University of Sydney, Australia	Advisor	Geriatric pharmacology and pharmacoepidemiology, including clinical trials of large cohorts.

This research offers the opportunity for rapid wins from Challenge activities, through leveraging existing knowledge integrated in the Drug Burden Index and as related to the big data available in the InterRAI, to predict adverse medium terms outcomes from polypharmacy.

### Impacts

- By 2016 we will determine if an increased Drug Burden Index (DBI) score is predictive of poor medium-term health outcomes (including fractures, falls and hospital admissions) that are independent of confounding factors. Confounding factors include gait speed, Changes in Health, End-stage disease and Signs and Symptoms (CHESS) score, medical conditions and social engagement.
- By 2017, if we find the DBI is predictive, we will start trials to test the effectiveness of incorporating DBI into decision support systems for e-prescribing. If this works, then the DBI can be used as a novel and cost-effective way of improving patient care with the emerging technology of electronic prescribing in hospitals.

### Context & Opportunity

Inappropriate prescribing leads to adverse outcomes in older people (71, 303-305). We have an opportunity to examine this through use of the big data available in New Zealand's world leading interRAI database on older people. The key advantage of using the interRAI data is that potential confounding factors such as gait speed, medical conditions, social engagement and a scale that identifies individuals at serious risk of decline can be assessed as potential confounding factors (257, 261, 306, 307). Exclusion of this data has been a major deficiency of previous polypharmacy research (70, 308). As well as medications, interRAI data contains important data relating to an older persons life expectancy. This includes information on gait speed and validated scales on the ability to perform activities of daily living. It also has a CHESS scale which is designed to identify individuals at risk of serious decline (309).

The Drug Burden Index (DBI) produces a scale that estimates the anticholinergic and sedative side effects from over 400 medications (310). The advantage of the DBI is that it is not medication or therapeutic class specific, but allows summation of side effects over multiple classes of medications (311). Cross-sectional studies in the American, Australian, Finish and UK populations and longitudinal studies in the United States have demonstrated that high DBI scores are associated with functional impairment in older people (310, 312, 313). An increased DBI has also been shown to predict falls, frailty, hospitalisation, General Practitioner visits and mortality (314). However, the fact that people on more medications have a worse outcome may reflect the fact that these people simply have more advanced diseases (315). The NZ interRAI data will allow these factors to be assessed as potential cofounding components.

The findings of the project will build on evidence to help better align DBI with principles and practice of geriatric care. To improve prescribing and service delivery, New Zealand is currently implementing electronic prescribing (known as Medchart) for inpatients in all publicly funded hospitals. Electronic prescribing systems in New Zealand hospitals will be safer if they incorporate a decision support system that alerts physicians to the problem of polypharmacy. If the DBI identifies inappropriate or harmful prescribing in the New Zealand context, it could be combined with Medchart to help prevent inappropriate or harmful combinations of medications being prescribed to patients.

### Research question & research outline

Questions:

- Will an increased Drug Burden Index (DBI) score predict poor medium-term health outcomes (e.g. falls, residential care admissions, and mortality) for New Zealand elderly people?
- Is the DBI independent of other potential confounding factors (such as gait speed)?
- What poor medium-term outcomes will the DBI predict for New Zealand Māori and other minority ethnic groups in New Zealand?
- Could the DBI be added to New Zealand hospitals' new electronic prescribing system as a decision support aid?

InterRAI assessments that have been developed by international consensus using the best available evidence. Multiple studies have confirmed that the data obtained is reliable and valid (121, 122). This study will use data gathered from NZ interRAI assessments. Data from people who consented to have their data used for research will be used in the study; consent rates are approximately 93%. Permission to perform this study has been obtained from the NZ InterRAI Board. Ethics permission has also been obtained.

- i. Data will be extracted from 30,000 interRAI New Zealand home care assessments between 2008-2014. Data will be on medications at the time of assessment, age, sex, timed four meter walk, medical conditions, ability to perform activities of daily living, functional status and social engagement. Validated scales will also be obtained from interRAI data on CHES scale, cognitive performance scale, depression and activities of daily living scale.
- ii. Medium-term outcomes of fractures, falls-related hospital admission, recurrent hospital admissions, requirements/referrals for residential care, and mortality will be sourced from the Ministry of Health using the NHI-linkage to the National minimum dataset.
- iii. The DBI for each aged person will be determined using published methods.
- iv. The ability of the DBI to predict medium-term outcomes will be determined after correcting for potential confounding factors. Contemporary epidemiological and bio-statistical methods would be employed in the analysis and interpretation of the data to derive estimated effect sizes and confidence intervals while mitigating, where possible, the impacts of any associated biases. Residual diagnostics and influence statistics would be undertaken so that the robustness of all statistical models can be explicitly asserted and demonstrated. Apposite generalised linear models, such as logistic and linear regression models, will be employed and extended to multi-level models to account for clustering where possible.
- v. A separate analysis will be made for ethnicity, including Māori.

### Giving effect to VM

This project has been developed with a strong focus on embedding the principles of *Vision Mātauranga* and has had close liaison with Māori at all stages. In collecting interRAI data, Māori consultation was led by the interRAI Māori strategy work-stream of the National DHB interRAI implementation project. A Meihana model was developed for an overarching clinical assessment framework for Māori in interRAI. The data will be analysed by ethnicity. Dr Cameron Lacey (Te Atiawa) will advise on the cultural interpretation of the research and assist with ongoing consultation with Māori when the results are implemented.

### Linkages to other Challenge projects

Project Title	Link
A. Independence & housing tenure	There are significant linkages between our project and project A as living situation and housing circumstances may be influenced by the side effects of inappropriate prescribing and polypharmacy (such as impaired cognition, falls and fatigue). We will enhance linkages by doing a separate analysis in our study to determine the effect of housing type, location and socioeconomic status on DBI-related outcomes.

<b>B. Reducing frailty</b>	The proposed DBI project fits well with project B objectives because both projects share the aim of finding early interventions that will help prevent the complications of frailty in older adults.
<b>C. Social isolation</b>	People with high DBIs are at higher risk of frailty, impaired cognition, and consequently social isolation. If our study finds significant association between high DBI levels and frailty (independent of confounding factors), then applying the DBI to manage medications could be an additional intervention to improve outcomes for socially isolated older people.
<b>D. Older people in work</b>	Applying the DBI to reduce the adverse effects of polypharmacy may help prolong an older person's independence, social engagement, and ability to work.
<b>E. Neurodegeneration &amp; individualised interventions</b>	Prof Connolly is an AI on both studies. The effect of high levels of medication (as assessed by the DBI) in the last three months of life will be assessed to determine how this influences the experience of those dying and may guide appropriate medications to support those who are dying.
<b>F. Retirement villages</b>	Project F. proposes to identify unmet needs of people in retirement villages - one of these is potentially polypharmacy and Prof Connolly is named on both projects.
<b>G. Risk factors in reduced social engagement</b>	The adverse effects of polypharmacy and reduced social engagement are likely very closely related and Dr Jamieson is involved in both projects, which will ensure standardised methodology and use of the same datasets.

<b>Title</b>				
<b>I. Health and wellness coaching for primary stroke and CVD prevention</b>				
<b>Cost \$000</b>	\$1,195	<b>Co-funding</b>		None
<b>Start Date</b>	1 October 2015	<b>End Date</b>		1 April 2019
	<b>Name</b>	<b>Organisation</b>	<b>FTE</b>	<b>Skills</b>
<b>PIs</b>	Prof Valery Feigin	Auckland University of Technology	0.2	Neurologist and certified clinical epidemiologist. Principal Investigator (PI) of the HRC funded ARCOS IV Programme (2011-2015), named investigator (NI) of HRC funded ARCOS III (2002-03), PI of the ARCOS III-based 5-year functional and neuropsychological outcomes study (ASTRO; 2006-09), PI of the HRC-funded 4-year follow-up study (2013-2015), and NI Stroke Attention Rehabilitation Trial (START; 2006-09).
<b>AIs</b>	Prof Alan Barber	University of Auckland	0.05	Neurologist of Māori descent, was NI of ARCOS III, ARCOS IV Programme, and the PRIMING and TRIO studies. He is the PI of the Auckland TIA study.
	Elaine Rush	Auckland University of Technology	0.05	Nutrition and healthy life-style interventions, was: NI in the 2004 Te Wai o Rona Diabetes Prevention Strategy with 5000 Māori; PI of the Project Energise (2004-2006), NI of the study to reduce health risk in older Indian people in Auckland (2007), Pacific Peoples Families study (on going) and NI in the Metformin in Gestational Diabetes follow up trials (2008, 2012)
	Rita Krishnamurthi	Auckland University of Technology	0.2	A neuroscientist of Indo-Fijian ethnicity was Co-Director and Coordinator of the ARCOS IV Programme, PI of the pilot primary stroke prevention trial for this Programme, PI of the Outcomes of Subarachnoid Haemorrhage in the Community Study, and NI of the pilot international Stroke Recovery Self-Management Trial (SMART)
	Prof Bruce Arroll	University of Auckland	0.05	Expert in general practice and studies on lifestyle issues and cardiovascular disease in NZ, was NI of the ARCOS IV Programme, Auckland BP control trial, DeLLITE-depression prevention in elderly
	A/Prof Suzanne	University of	0.05	Clinical neuropsychologist, was Co-Director of the ARCOS IV Programme, PI of the START trial, NI of

	Barker-Collo	Auckland		ASTRO, BIONIC, and TBI goal setting studies
	Alain Vandal	Auckland University of Technology	0.05	A senior biostatistician involved in ARCOS IV and BIONIC studies, and other cardiovascular disease trials.
	Priya Parmer	Auckland University of Technology	0.2	A senior biostatistician involved in ARCOS IV and GBD studies, and other cardiovascular disease trials
	Hinemoa Elder	Te Whāre Wananga o Awanuiārangi	0.05	Child and adolescent psychiatrist of Māori descent, with strong Māori community links. Particular interest in the neuropsychiatry of insults to the brain and in primary prevention.
	Alice Theadom	Auckland University of Technology	0.05	Registered psychologist with expertise in qualitative research and health behavior change, NI of the pilot international Stroke Recovery Self-Management Trial (SMART), NI of the HRC-funded population-based traumatic brain injury (TBI) incidence and outcomes study (BIONIC; 2009-12) and 4-year follow-up study (2013-2015)
	Paul Brown	Auckland University of Technology	0.05	Senior health economist and health services researcher Co-applicant with a focus on exploring health economic aspects of the HRC funded ARCOS III, ASTRO and BIONIC studies.

This research will assess whether Health and Wellness Coaching (HWC) is effective in reducing risk of primary stroke and coronary vascular disease (CVD), in Māori, Pacific Peoples, Asians and NZ Europeans. 80% of strokes are considered preventable and Māori and Pacific Peoples are more likely to experience stroke and CVD as a result of significant ethnic disparities in the risk factors.

### Impacts

- By the end of 2018 the trial will deliver robust evidence on the effectiveness of HWC for primary stroke and CVD prevention in terms of reduction of absolute CVD risk and changes in specific lifestyle related outcomes such as improved adherence to prescribed medications, improved diet and increased physical activity.
- By the end of 2018 we will inform ways of improving the implementation of the HWC intervention to increase uptake and effectiveness in clinical practice through identifying evidence of barriers and facilitators of the uptake of the HWC intervention in different ethnicities.

### Context & Opportunity

Strokes are the main cause of disease burden in older adults, yet evidence suggests more than 80% of strokes are preventable, with adequate control of modifiable risk factors (316). This proposal to test the effectiveness of Health and Wellness Coaching (HWC) for primary prevention of stroke builds from our HRC funded project, The Auckland Regional Community Stroke Study (ARCOS IV, 2011-2012) (317) and our recently completed pilot randomised controlled trial (RCT) on HWC and is particularly relevant to the ageing population (318), where most strokes occur.

The ARCOS IV studies are the most recent of a longitudinal series of population-based studies on the incidence and outcomes of stroke that provide accurate estimates of stroke burden in adults in New Zealand (NZ) across all ethnic groups (317). This has highlighted a need to enhance primary prevention initiatives in NZ (318). ARCOS showed that the incidence of stroke in NZ is still relatively high (119 per 100,000) compared to other developed countries like France and the UK (87 per 100,000) and, in particular, the incidence of stroke in Māori and Pacific Peoples is much higher relative to the NZ European population (155 and 197 per 100,000 compared to 122 per 100,000 in NZ Europeans, Feigin et al. Lancet Neurology 2015 [in press]). A further component of the ARCOS study included an RCT of motivational interviewing as a strategy for secondary stroke prevention (319). Motivational Interviewing may be difficult to implement for less motivated people without stroke/TIA and the study does not look at primary stroke prevention, which will be crucial to reduce the burden of stroke in New Zealand and to improve the wellness of our ageing population. No RCT has been conducted in NZ or internationally to test the effectiveness of HWC for primary prevention of stroke. This intervention ties in with the current primary CVD prevention strategies already in use in NZ primary care (e.g. PREDICT). However, PREDICT does not include on-going support to adhere to lifestyle recommendations and this is where the HWC intervention fills the gap.

**Current international and national research:** While management strategies for primary stroke prevention in high CVD risk individuals are well established (320, 321), they are under-utilised (320-323) and existing methods of primary stroke prevention are not sufficiently effective (324-326). The healthcare system has been largely unsuccessful in providing relevant meaningful information to assist people in adhering to recommended lifestyle changes and medications (320, 321, 324, 325, 327-329). Uptake of this information is particularly low in people with moderately increased risk of stroke who would benefit from lifestyle modifications (324, 329, 330). Inadequate CVD risk factor management (324, 325) and lack of effective communication between health professionals and stroke patients/family (324, 331-333) are implicated in underutilisation of evidence-based primary stroke prevention strategies in those with moderately increased risk of stroke (331). Behavioural interventions are emerging as highly promising strategies to improve CVD risk factor management (334-341). Clinical approaches to help people change behaviour include use of cognitive behaviour therapy, Motivational Interviewing, stages of change approach, counseling/coaching and education (334).

Evidence from previous NZ research such as a community-developed and led diabetes prevention program (342) shows that behaviour changes in Māori can result from preventative efforts directed at behaviour change. There is also evidence that behavioural changes are feasible in other high-risk populations (335, 343) where behavioural counseling by practice nurses led to improvements in healthy behaviour in participants with increased risk of coronary heart disease. Behavioural change in different socio-economic groups at a community level, for example, in a disadvantaged community, has been demonstrated (344). A risk-weighted behavioural and pharmacological primary CVD prevention intervention utilising absolute CVD risk approach is currently underway in Canada (324), but the study involves a prospective pre-post intervention design and a non-randomised comparison group.

HWC is an innovative, structured, patient-focused (345-352) and cost-effective (353-355) multi-dimensional psychological intervention designed to motivate participants to adhere to recommended medication and lifestyle changes (349) and has been shown to improve health and enhance wellbeing (356-359). HWC is being increasingly used in primary care (355, 360-363), in various areas of medicine (364-368), including CHD (357), BP management (369), diabetes (370-372), weight control (373, 374), healthy lifestyle (351, 355, 375, 376) and mental health (377) with positive results. HWC has the capacity to deliver effective interventions more cheaply (e.g., over the phone) (364, 370) than other behaviour change methods (353-355). HWC is of particular relevance to primary stroke and CVD prevention as it has the potential to address multiple risk factors. A health coach can help a person and their family/whānau /supporters identify individual strengths, empowering them to focus on lifestyle-related behaviours that the individual wants to, and can change (378).

Individuals who receive HWC are shown to have increased perceived health status, medication adherence, and physical activity, with decreases in stress levels (357, 372, 379). Telephone-delivered HWC has also been shown to significantly improve health outcomes for myocardial infarction patients (380, 381). Additional major advantages of HWC over other behavioural interventions are that HWC is goal oriented, can enroll non-English speakers and may cost less. Benefits of HWC for participants with diabetes and other chronic conditions were recently demonstrated in randomised controlled trials (RCTs) (360, 372), including weight control (373), diabetes (371) and blood pressure control (382). HWC has been identified as a high research priority for the field (348-350, 352-354, 361, 376, 383, 384).

In Auckland, approximately half of the population aged 35-74 (about 300,000 people) (385) have now been assessed for CVD risk using the Framingham-based cardiovascular risk web-based PREDICT system (322, 386). According to the “*NZ Guidelines for The Assessment and Management of Cardiovascular Risk*” (387), it is recommended that assessment of absolute CVD risk should be the starting point for all discussions with people who have CVD risk factors measured with the goal of preventing CVD by reducing absolute CVD score. This absolute CVD risk approach is also recognised internationally (330, 388-392). The NZ Ministry of Health has set a primary health care goal of using PREDICT for assessment and management of CVD risk in 90% of eligible participants by mid-2014 (393). CVD prevention is under-utilised in NZ (322) mainly because of poor compliance of the participants.

A recent review of the literature on health behaviour change for chronic care published in the NZ Guidelines group found that disease-specific information is an essential component of health behaviour change interventions. HWC is exactly such an intervention, where health information is an integral part of the coaching processes. The review also suggests that those at higher risk are more likely to benefit from behaviour change interventions and should be given higher priority (394). Thus, testing a new, practicable and potentially widely applicable approach to improve adherence to evidence-based guidelines for primary stroke/CVD prevention in people with moderate to high risk of CVD development utilising the existing PREDICT system fits with current primary health care practice and guidelines in NZ.

## Research question & research outline

**Question:** *Is HWC effective for primary stroke and CVD prevention in Māori, Pacific Peoples, Asians and NZ Europeans?* The primary outcome sought is a substantial relative risk reduction (RRR) of CVD in the next 5 years 9 months post-randomisation. This is defined as a 10% RRR amongst those at moderate 5-year CVD risk (10-15%) (395, 396) and a 25% RRR amongst those at high risk (>15%) (395, 397). Additional outcomes will be to evaluate the effectiveness of HWC on (a) self-reported adherence (self-reported use of anti-platelet, statin and BP lowering therapy as prescribed), (b) self-reported changes in adherence to medication and changes in readiness of change, (c) cardiovascular events (new stroke or coronary heart disease, both fatal or non-fatal), (d) lifestyle changes (e.g., change in physical activity, smoking status, diet pattern etc); (e) health related quality of life, (f) change in participants' expectations of treatment benefits; (g) screening for depression, (h) participant satisfaction, and (j) healthcare resource consumption and cost-effectiveness at 6, 9 and 12 months follow-up:

**Study design:** A phase III, prospective, randomised, open-treatment, blinded end-point trial. *Aim:* to determine the effectiveness of HWC for primary stroke prevention in Māori, Pacific Peoples, Asians and NZ Europeans.

**Inclusion/exclusion criteria:** Participants will include 320 adults (>35 years old for Māori and Pacific Peoples due to earlier age of stroke in these ethnic groups; >45 years old for other ethnic groups) (398) with absolute 5-year CVD risk  $\geq 10\%$  (80 Māori, 80 Pacific Peoples, 80 Asians and 80 NZ Europeans). The participants will be identified through GP practices that use PREDICT or a similar tool for CVD risk calculation (387, 398-400). Individuals will be excluded if they: (a) had previous stroke or heart attack; (b) have significant impairments or medical conditions precluding participation; (b) cannot give informed consent; (c) deemed inappropriate for the intervention by the participant's GP; (d) receiving treatment that can contaminate the study intervention; or (e) are likely to move out of the study area during the year.

**Recruitment & randomisation:** Eligible residents from Auckland who consent to participate will be randomised to HWC or usual care (UC). Participants will be stratified into 4 equal strata by ethnicity: Māori, Pacific Peoples, Asians and NZ Europeans. Stratified minimisation randomisation will be used to balance possible prognostic factors; age, sex, and CVD risk.

**Intervention:** The HWC group will have 9 sessions with HWC coaches, of which 7 will be carried out within the first 3 months of the intervention and the remaining two sessions will be done three months apart (at 6 and 9 months after the intervention to facilitate longer term behaviour change). The initial session will be in-person in the participant's place of residence. Remaining coaching sessions will be done via telephone or in-person, if required. Group sessions will also be offered and carried out, if needed, depending on participants' preferences. Coaching sessions will take up to 1 hour and, will be tailored to have a whānau/family focus as recommendations for lifestyle/medication change/adherence often fail without support from significant others (401). Thus, family support members will be invited to attend the initial session, but this will not be required (family member attendance will be recorded). Specific cultural competency training will be provided for study HWC providers/nurses. Follow-up assessment will take place at Baseline, 3, 6, 9 and 12 months. Participants in the UC group will receive standard care, which does not include HWC. Participation in HWC sessions will be identified and recorded at follow-up assessments.

**Statistical considerations and power calculations:** Intention-to-treat analysis will be employed. Assuming 20% non-compliance and loss to follow-up (402), 320 participants (80 Māori, 80 Pacific Peoples, 80 Asians and 80 NZ Europeans) are required to provide 90% power at two sided  $\alpha=0.05$  to detect a clinically significant (324, 327) 10% and 25% relative risk reduction (330, 403-405) ethnic specific difference in the absolute 5-year CVD risk in moderate (10-15%) and high (>15%) CVD risk participants respectively between HWC and UC groups in each ethnic group at nine months after randomisation.

## Giving effect to VM

This research brings together the unique Māori knowledge in Māori communities and this research team. The research design is innovative, using mixed methods, including Rangahau Kaupapa Māori, to better understand the experiences of Māori with stroke; the Māori community is significantly more at risk of stroke. This project will create new knowledge that can improve Hauora/Oranga for Māori. In particular, it has the potential extend the life and wellbeing of those Māori at risk, improve health service delivery through the provision of interventions, like HWC, that are more likely to work in Māori communities to reduce the morbidity and mortality associated with stroke.

All aspects of the research, from the protocol development to dissemination of findings are informed by Vision Mātauranga. Dr Hinemoa Elder is an associate investigator on the trial and will assist in ensuring the study is responsive to meeting the needs of Māori.

### Linkages with other Projects

Project Title	Link
<b>A. Independence &amp; housing tenure</b>	Stroke is a major contributor to reducing independence, active life and participation in older people. Therefore, informing strategies to prevent stroke will facilitate enabling older people's independence, active life and participation.
<b>B. Reducing frailty</b>	Health and Wellness Coaching intervention to be tested in the randomised controlled trial for primary stroke and CVD prevention represents one of the strategies for transforming ways of living towards healthier life, therefore our project is indirectly linked with this project.
<b>D. Older people in work</b>	Health and Wellness Coaching intervention to be tested in the randomised controlled trial for primary stroke and CVD prevention may represent one of the strategies for preventing disabilities related to stroke and therefore enhancing participation in older people in paid and unpaid work, therefore our project is indirectly linked with this project.
<b>E. Neurodegeneration &amp; individualised interventions?</b>	Health and Wellness Coaching intervention to be tested in the randomised controlled trial for primary stroke and CVD prevention represents one of the individualised interventions that may have relevance not only for primary stroke prevention but also for the reduction of impact of neurodegenerative disorders. In this respect, our project is indirectly linked with this project.
<b>F. Retirement villages</b>	Health and Wellness Coaching intervention to be tested in the randomised controlled trial for primary stroke and CVD prevention may be used in retirement villages. In this respect, our project is indirectly linked with this project.
<b>G. Risk factors in reduced social engagement</b>	Health and Wellness Coaching intervention to be tested in the randomised controlled trial for primary stroke and CVD prevention is about the management of risk factors in older people. Stroke and CVD leads to reduced social engagement. In this respect, our project is indirectly linked with this project.

Title		J. Implanted electrical stimulators to augment stroke recovery		
<b>Cost \$000</b>	\$398	<b>Co-funding \$000</b>	\$180 for implantable pulse generators and leads by St Jude Medical, Plano, Texas \$11 from a Charitable Trust for implantation into a patient	
<b>Start Date</b>	1 October 2015	<b>End Date</b>	2 years	
	<b>Name</b>	<b>Organisation</b>	<b>FTE</b>	<b>Skills</b>
<b>PIs</b>	A/Prof John Reynolds	University of Otago	0.08	Cellular neuroscience; translational neuroscience; mechanisms of neuromodulation and synaptic plasticity
	Prof Dirk de Ridder	University of Otago	0.05	Academic neurosurgery; Neuromodulation using transcranial magnetic stimulation, transcranial direct current stimulation and intracranial electrical stimulation; EEG analysis
	Prof Leigh Hale	University of Otago	0.05	Academic physiotherapy; Rehabilitation paradigms in stroke
	Dr Jon Shemmell	University of Otago	0.05	Neuromodulation using transcranial magnetic stimulation; Human neurophysiology; Brain plasticity in stroke
	Prof Alan Barber	University of Auckland & Auckland DHB	0.02	Stroke epidemiology; Brain plasticity in stroke recovery; Advanced brain imaging in stroke
<b>AIs</b>	Mr Agadha Wickremesekera	Capital & Coast Health DHB	0.02	Neurosurgery

This research is cutting edge, creating a new technology for improving recovery from stroke through brain stimulation. The research will specifically look at whether upper limb functional recovery can be augmented via implanted electrical stimulation.

### Impacts

- By 2018 the use of implanted electrical stimulators and burst stimulation application has been proven safe and feasible for a range of types of stroke.
- By 2018 a multicentre clinical trial is underway, determining the efficacy of implantable pulse generators to improve upper limb function and general wellbeing after cortical or subcortical stroke.

### Context & Opportunity

Each year in New Zealand approximately 8,000 people experience a stroke. Stroke is the third most common cause of death here and disproportionately affects Māori and Pacific Peoples. 85% of patients never regain upper limb function (406), which accounts for much of the poor subjective well-being after stroke (407).

Recovery through rehabilitation is limited in part by excessive inhibition imposed by surviving brain circuits. This in turn reduces the excitability of surviving cells and impairs plasticity (ie. the ability to remodel function) of neural circuits surrounding the affected motor cortex (408). The excessive inhibition is in part mediated by imbalanced interhemispheric inhibition (IHI), by which the cortex in the intact hemisphere exerts exaggerated inhibition onto the surviving cortex surrounding the stroke affected area, restricting motor performance and recovery (409). In the proposed human feasibility and safety study, grounded in solid translational neuroscience in rat models (410), we will investigate a novel approach to modulating IHI using implanted electrical stimulation.

Individualised neurostimulation may improve function after stroke, when gains achieved by standard rehabilitation have plateaued. Non-invasive neurostimulation techniques, such as repetitive transcranial magnetic stimulation (rTMS), have been extensively trialled to determine their effectiveness at augmenting motor recovery after stroke. Although some individual gains have been reported (411), there is no convincing evidence of benefit over and above the ceiling that is reached after approximately 6 months of usual rehabilitation (412-414). Similarly, transcranial direct current stimulation, where electrical stimulation is applied through electrodes on the scalp, has shown inconsistent results with larger clinical trials reporting no overall functional benefit (415, 416). It is clear that new approaches are required to elevate the ceiling of recovery and reduce the burden of stroke on the individual and their family/whānau.

Neurostimulation therapy trials have usually tried to rebalance the relative excitability of the cerebral hemispheres, either by enhancing the excitability of the stroke affected hemisphere and/or reducing the excitability of the opposite, less affected hemisphere. However, motor recovery following stroke might be better enhanced using a therapy that targets specific functional circuitry (417), rather than attempting to rebalance hemispheric excitability. Physiological ‘priming’ of specific motor circuits, rather than unfocussed priming using rTMS, has been shown to enhance the rate at which patients reach their peak motor recovery post stroke, although the ceiling of maximum recovery achievable through rehabilitation is not exceeded (418). The extent of improvement correlated with reductions in IHI of the peri-lesional area and occurred on a background of persisting gross asymmetry in hemispheric excitability (418). This evidence suggests that motor recovery involves plasticity within transcallosal circuits driving IHI. Therapies specifically modulating IHI may therefore provide a brief therapeutic window in which rapid rehabilitation gains can be achieved.

The success of non-invasive neurostimulation has been impeded by a lack of understanding of the effects of these therapies at the cellular level. Our approach is unique in being based on published (410) and ongoing discoveries made in single neurons of the motor cortex of the synaptic mechanisms contributing to IHI and its modulation through targeted electrical stimulation. We used theta-burst stimulation (TBS) protocols, previously shown using rTMS to modulate the excitability of motor cortical circuits in some participants (419, 420). We found that particular TBS parameters applied to the hemisphere *opposite a stroke lesion*, specifically targeted and blocked IHI, and enhanced motor recovery after stroke by 42% compared to sham stimulation (410). The application of stimulation to the non-lesioned hemisphere is different to conventional wisdom, but we emphasise that our stimulating electrode placement and ability to measure the cellular effects of our stimulation have allowed us to design parameters that *specifically target neural circuits underlying IHI*.

Electrical stimulation applied continuously at high frequency via implanted stimulators to augment recovery after stroke has been attempted previously. The approach showed promise in Phase II trials (421), but benefits were not confirmed in the EVEREST Phase III trial (422), largely due to poor stimulator localisation and parameter testing. Based on our preclinical research, we hypothesise that our approach will be effective in improving post-stroke function since (i) it is applied to a brain area where viable pathways exist, (ii) discontinuous stimulation is used to ensure that improvement is not ‘undone’ through excessive stimulation that enhances inhibition and (iii) the patient carries the stimulator around so does not need to attend a specialist rTMS session. We aim here to determine the feasibility and safety of this approach in humans and to provide compelling preclinical evidence to support a subsequent trial of chronic targeted electrical stimulation for stroke. Our vision is to provide another tool for clinicians to offer people with chronic stroke to improve their ability to move.

To our knowledge, this work or work similar to it is not being undertaken elsewhere in NZ. HRC is funding a number of trials on non-invasive neurostimulation, Marsden a pharmacological investigation and computer-based cognitive trial for stroke recovery, and MBIE have funded projects on human assistive devices.

Our preclinical work has determined that the ability to modulate interhemispheric inhibition and improve the functional return following stroke requires a particular pattern of burst stimulation. Conventionally, deep brain stimulation therapy utilises implantable pulse generators (IPGs) that are only capable of providing continuous stimulation. Through a relationship established between Prof Dirk de Ridder and St Jude Medical (SJM, Plano, Texas, USA) we will be supplied IPGs capable of providing the required burst stimulation free of charge for this project. For these reasons, we believe we are the only centre internationally able to undertake a feasibility trial using these IPGs. One of our team (de Ridder) has been actively involved in clinical translation of electrical stimulation paradigms for a number of years, but not around augmented stroke recovery. This project represents a marriage of clinical neurosurgery (de Ridder and Wickremesekera), clinical stroke rehabilitation (Hale and Barber) and translation of basic neuroscience (Reynolds and Shemmell) and is definitely beyond business as usual for the team. There is some urgency to undertake this work, since there is a time window of two years for these IPGs to be made available to us exclusively for this purpose.

Please note that details of the research protocols designed by the principal investigators and disclosed within are limited, but are given with the permission of SJM who hold the intellectual property for the use of these IPGs in this manner for this application.

### Research question & research outline

We will determine if upper limb functional recovery can be augmented using implanted electrical stimulators fitted over the contralesional motor/sensory cortex, following the application of discontinuous theta burst stimulation at specific individualised parameters.

**Design and methods:** This is a two year feasibility study to determine safety and measures of upper limb function, using a TBS protocol applied via implanted pulse generators (IPGs) to epidural electrodes over the contralesional motor cortex. We aim to undertake a Phase 0/I trial, with a minimum of 6 participants receiving IPGs and 6 non-implanted controls. Any additional funding we receive to defray implantation theatre costs will be used to add additional pairs of participants at no additional cost to the NSC, to a maximum of 10 IPGs.

Participants will be 18+ years old with cortical or subcortical ischaemic stroke resulting in upper limb weakness at least 6 months earlier (Upper Extremity Fugl-Meyer Scale [UEFM] between 20 and 50) and without history of seizure disorder. All operated participants will undergo pre-operative MRI diffusion tractography to determine viability of descending and interhemispheric connections, and a postoperative CT to determine placement of the IPG. Assessment of motor potentials in hemiparetic limb will be made using TMS applied to the ipsilesional hemisphere, in conjunction with single electrical stimuli, to determine if the stimulation is altering interhemispheric inhibition.

Group 1 Stim (n=3) will receive 12 weeks of structured upper limb (UL) rehabilitation in conjunction with TBS (three sessions per week preceding rehabilitation). Group 2 Delayed Stim (n=3) will receive 6 weeks of UL rehabilitation only with the stimulator switched off, followed by 6 weeks of stimulation plus rehabilitation, and Group 3 non-implanted controls (n=6) will receive 12 weeks of standard stroke UL rehabilitation. An implanted but never stimulated control group is too high an ethical cost, therefore we include the Delayed Stim group (Group 2) who will not have stimulation switched on through the period of rehabilitation but have the opportunity to obtain additional functional gains when the stimulator is switched on at week 7. All groups will be matched as closely as possible for size, location and time from stroke and degree of upper limb weakness. Groups with stimulation will be

randomised to immediate or delay switch on, and will be blind to the status of the stimulation On or Off. Upper limb functional assessments will be undertaken at 0, 6 weeks, 12 weeks and 26 weeks.

**Outcome measures and significance:** The primary outcome is feasibility and safety. Secondary outcomes are measures of variability in upper limb functional improvement (determined by UEFM, ARAT, Wolf Motor Function, SULCS), depending on final approved rehabilitation protocol) to incorporate into the design of a Phase II/III multicentre RCT in subsequent years, investigating gains in motor function and associated gains in cognition (423). St Jude Medical has reviewed the preclinical data and approved the proposed sample size. This will be the first study internationally to investigate the effect of TBS via IPGs after stroke, and may lead to significant gains in function for those who have maximised improvement through usual rehabilitation.

### Giving effect to VM

Stroke is an important health condition for Māori. NZ has made inroads in reducing stroke incidence in non-Māori, and yet for unknown reasons we have an increasing disparity in incidence and outcomes from stroke for Māori and Pacific Peoples (17). Due to higher rates of risk factors for stroke such as hypertension, Type II diabetes and smoking, Māori are at 2 to 3 times greater risk for all types of stroke. Māori people are, on average, 10 years younger at the time of first stroke, meaning that there may be additional burdens placed on whānau through lost earnings due to disability. Māori have an outcome following stroke that is 30% worse than non-Māori. Māori and Pacific Peoples report being more dependent, disabled and dissatisfied with their quality of life than other ethnic groups. Overall, stroke carries the 7th highest disability adjusted life years burden for both Māori men and women (424).

Our research effort is directed towards improving rehabilitation following stroke, with reducing ethnic inequalities a primary focus. Although our study will not be powered to determine ethnicity effects, it is hoped that we may recruit Māori from the community, and will ensure that ethnicity data is collected at recruitment. We have consulted with the Ngāi Tahu Research Consultation Committee regarding electrical and magnetic stimulation being applied to humans to enhance stroke recovery. A number of considerations will be made in the design and implementation of treatment strategies, to take into account particular areas of concern for Māori. The head is acknowledged as the most sacred part of the body in Māori culture. A full explanation will be given of the procedures that will be performed, which will include a description of the surgery, and that for the magnetic stimulation component we will need to touch the head before bringing the stimulation coil in contact with the hair. The participant and their whānau will be given time to consider this fully and ask questions before consent is obtained. At the end of the study, we will disseminate the study outcomes to Māori groups (e.g. attend/present findings at the HRC’s Hui Whakapiripiri), and will consult again with the Ngāi Tahu Research Consultation Committee and similar committees in other centres before design of a further trial. Prof. Alan Barber (Ngāti Porou, Whakatōhea), is a named researcher on the project, and an expert on the effects of the management of stroke in NZ populations.

### Linkages to other Challenge Projects

Project Title	Link
A. Independence & housing tenure	Project A sets out to explore the impact and dynamics of the shift from home ownership to rental accommodation on wellbeing and independence; there is a reciprocal relationship between physical and cognitive disability and ability to live independently and well – the proposed project aims to increase the physical and cognitive functioning of people living with stroke, allowing them to live well independently for longer and to remain and maintain their ability to stay in their homes whether rented or owned.
B. Reducing frailty	Project B pilots an intervention to determine if increasing physical activity and engagement will reduce frailty. Since the proposed project is designed to improve functional activity through a combination of intense rehabilitation and neurostimulation, the proposed project will be informed by outcomes from Project B as to the rationale for undertaking widespread neuromodulation approaches to reduce frailty in older people.
I. Stroke & CVD prevention	Project I undertakes a trial that attempts to reduce the impact of risk factors on the occurrence of stroke in those at risk. The proposed project is aligned in terms of the need to reduce disability from stroke and prevent cognitive decline in ageing.

## Strand 5: Enhance age friendly environments

Title	A. Enabling older people's independence, active lives & participation in the face of structural housing tenure changes & reliance on rental housing			
Cost \$000	\$1880	Co-funding \$000	\$80 Māori, public & private sectors contributing time to the National Reference Group and engagement with stakeholders	
Start Date	1 October 2015	End Date	30 June 2019	
	Name	Organisation	FTE	Skills
PIs	Ms Kay Saville-Smith	Centre for Research, Evaluation & Social Assessment	0.23	Sociologist – housing; built environment; social and cultural aspects of ageing and intergenerational relationships; research design and management; survey design; integration of quantitative and qualitative data; evidence-based tools development; action research.
	Prof Jacqueline Cumming	Victoria University	0.2	Health economist – health services research; health policy and planning; economics of health and ageing.
	Dr Robin Kearns	University of Auckland	0.2	Geographer – social and cultural geography; health geography; geography of place; ageing in place.
	Dr Beverley James	Public Policy & Research	0.23	Sociologist - social and cultural aspects of ageing; housing; community development; qualitative research design; action research; evidence-based tools development.
	A/Prof Elsie Ho	University of Auckland	0.2	Psychologist – Asian and ethnic minority health and mental health; immigration and settlement; transnational ageing and care; culturally responsive services.
	Dr Fiona Cram	Katoa	0.21	Psychologist – kaupapa Māori research methodology; Māori and whānau health and wellbeing; Iwi development; culturally responsive services; evaluation.
AIs	Prof Natalie Jackson	Natalie Jackson Demographics Ltd & Massey University	0.15	Demographer – demographic analysis; population projections; population ageing; sub-national population analysis, cohort analysis.

This Project is about the future of older people in an increasingly diverse New Zealand (NZ) experiencing not only structural population ageing but what is effectively a housing tenure revolution. NZ's previously very high rate of owner occupation is falling rapidly and is accompanied by a rising dependence on the (mainly private) rental market (101-103, 425). This combination of tenure shock and structural ageing, likely to be highly differentiated regionally and ethnically, is not addressed in NZ research, policy, or services.

### Impacts

- By 2018 local and central government, housing providers and District Health Boards will have a planning platform for housing, health and service response within a robust demographic picture of the interaction between structural ageing and tenure change by region and by ethnic populations.
- By 2018 health, social support, housing and financial service providers will have tools to assess the extent to which current services, practices, and procedures meet the needs and circumstances of older renters.

### Context & Opportunity

NZ research, including some housing research, recognises that there will be many more older people in the future. But NZ's research and policies are largely geared to treating older people as a 'special needs' population, albeit a growing one. Little attention is given to the deep structural, market and socio-cultural institutional changes associated with structural ageing. This is only slowly beginning to change. For example, Dr Jackson and her Marsden funded team are researching structural ageing as a sub-national phenomenon driving depopulation though they do not include tenure change or consider the implications of declining owner occupation. No serious attention is

given, either in policy or in research, to the particular combination of structural ageing and falling home ownership, although the potential risks to NZ's health, social services, and income policies, have been highlighted by some commentators (104, 114, 426-431).

Current NZ research around housing and older people focuses on older owner-occupiers. It includes research on the extent to which owner occupation sustains older people's living standards and reduces their housing expenditure, opportunities for equity release and downsizing, and interventions to maintain the resilience, repairs, maintenance, and functionality of older owner occupiers' dwellings (76, 96, 104, 108, 109, 111-113, 429, 432-440). Building research, including the *Building Better Homes, Towns and Cities* National Science Challenge, typically excludes the implications of changing tenure in NZ. There is, consequently, a significant gap in the NZ research platform and its ability to provide a robust evidence base for promoting ageing well and ageing in place in a rental reliant future.

Overseas research shows that older renters, whether in public or private rentals, are more vulnerable to housing stress, dwellings in poor condition, and social isolation. Housing stress results from unaffordable housing related costs and tenure insecurity. Unaffordable housing-related costs can be from rents that are excessive as a proportion of income, high house operating costs arising from poor dwelling performance and amenities, and costs associated with transport arising from the poor connectivity of rental housing to services (95, 105-107, 441-445). These patterns are consistent with research on living standards in NZ as well as data on the physical condition of the NZ housing stock in owner occupation and rented. There is also evidence that tenure security in NZ's private rental market is low. All those conditions are likely to affect older renters, although it is not clear whether the experiences of older renters differ from other renters (101, 427, 430, 431, 446).

Ground-breaking research in Australia has identified tenure as a key determinant of older people's ability to optimise their independence and maintain their engagement and contribution to their communities and their families. Tenure is an independent variable in relation to admission to residential care; the probability of admission increases among those living in rental housing. The research also found the cost of home-based care (whether formal, mixed formal/informal, or informal) is higher among individuals living in rental accommodation (89, 90, 92, 447) although, as a population, renters may be poorly covered by home care services. The precise dynamics of those associations require further exploration, but highlight the importance of tenure for both older people's personal independence and engagement, as well as being a driver of care demand which may have considerable fiscal and other spill-over effects and externalities. The Australian research has tested analytic methods which can be used to illuminate the impacts of tenure change in NZ, although the construction of the dataset on which those methods can be applied is significantly different from Australia due to differences in NZ's: (a) funding models for in-home and residential care; (b) housing sector differences; (c) administrative data; and (d) access to data through NZ longitudinal studies, census, and the official health and disability surveys.

Overseas there is an emerging body of policy-oriented research on housing, intergenerational solidarity and inequality (86, 87, 97, 448). In NZ, by comparison, there is an acute research lacuna, despite tensions around the investment and support provided to today's older people when they were young compared with those offered to today's young people. Home ownership was a primary driver of narrowing of inequalities and set the platform for intergenerational reciprocities in the post-War period. The significant fall in home ownership that has emerged in recent years has been accompanied by increased income inequalities which are widening faster than in most OECD countries. Current generations of young people are confronted with restricted entry to home ownership, significant housing stress and some of the lowest labour force participation rates in the OECD. Conversely, older people in NZ have high labour force participation rates compared to most OECD countries (110, 113, 449). With NZ about to have more older people than children for the first time in its history and a falling rate of home ownership, the future looks very different from the past with potentially significant impacts on the three pillars of intergenerational solidarity: (a) The ability and willingness of older people to provide care and support to their partners, families, and friends; (b) The capacity and taste of younger and middle aged people to provide informal care and support to older people; and, (c) The societal sense of intergenerational commitment and valuing of people of all generations (74, 75).

The unusual combination of structural ageing and tenure shocks in NZ makes overseas research on intergenerational solidarity and housing, difficult to apply to NZ. Apart from its previously very high rates of owner occupation, NZ has an extremely lightly regulated rental market with poorly evaluated accommodation subsidies. Renters rely heavily on the private rental sector. There is little public rental stock for older renters and virtually no sheltered housing for older renters.

By 2045, rental is likely to be the dominant tenure for people entering the older cohort and there are projected to be 1.3 million people 65+ years, almost one-quarter of the population. Even by 2035 all population growth in 75% of NZ's local authorities will be among those aged 65+ years. Very high levels of mortgage-free home ownership among

older people in the past have generated policies, private and public services, and practices in health, housing and services mal-adapted to delivering ageing well and ageing in place under new tenure conditions and the heavy reliance on the rental market.

In the housing environment there is a common but mistaken view that falling home ownership rates will impact primarily on younger people at least in the short to medium terms. But older people are already affected. In 2001, 80.2% of older people owned their dwelling compared to 77.3% in 2013. Even this cross-sectional analysis mutes the shock for older ages of the tenure revolution. Cohort analysis is likely to reveal more pronounced and immediate tenure change for older people. Current housing market and policy shifts are misaligned to those trends. They include abolition of older people's tenure security in public rentals; under-supply of smaller homes; and, disposal of council pensioner housing stock. Community housing providers (CHPs) struggle to service older tenants. Retirement villages (RVs) have few rentals. RVs depend on asset-rich older people to buy licenses to occupy and with incomes high enough to allow them to pay service fees. The very few RV renters must pay both rent and service fees.

The lack of recognition of widespread tenure change to rental as an issue for older people, or, indeed, the needs of older people currently in rental housing, is evident in the inadequacies of needs assessment tools. The interRAI Home Care Assessment Form that is currently used to assess older people's needs for in-home or residential care, has 14 categories for residential/living status but it fails to distinguish between owner occupation and tenancy. Yet tenure has profound effects on an individual's length of stay and security, housing affordability and living standards, whether a dwelling has accessible and functional design, whether modifications can be made to a dwelling, and whether in-home treatment is viable. In rental housing those conditions may also vary between dwellings in the private rental market and the much smaller stocks of public, council and CHP housing.

The income support and the disability and health sectors are poorly equipped to deal with the tenure revolution. Income support settings assume older people have low housing costs due to mortgage-free owner occupation. Subsidised residential care funding (which the vast majority of older people in residential care access eventually) assumes costs of care can be offset by liquidating assets (usually the family home). Health and social services assume older people have stable extended family able to support them in the community despite 30% of the population living at a residential address for one year or less; renters typically move frequently. High levels of renting among younger family members may present a barrier to the informal support that is seen under high owner occupation.

In short, the combination of tenure shock and structural ageing present NZ with a future for older people which is far from business as usual. However, research on older people remains focused on greater numbers but with the assumption that other conditions will remain unchanged. It does not confront the deep structural, market and socio-cultural institutional changes associated with the shock of the tenure revolution and how those will drive intergenerational dynamics and shape whether people age well. This research will establish the extent to which current policy, market, service and socio-cultural institutions are aligned or misaligned to the new rental future, consider the impacts of the combined effects of structural ageing and falling owner occupation, and find adaptive strategies across housing, health and services.

### Research question & research outline

The research asks what are the future implications of falling home ownership and growing dependence on the rental market for:

- Different cohorts as they age? What will be the socio-economic and cultural characteristics of older people most reliant on rentals? What will be the regional patterns of older people's reliance on rentals?
- Older people's provision of care and support to others, intergenerational relations, their contribution to community and civic life, and their access to day to day services such as retail and banking?
- Provision of informal care and support to older people by their families, kin and friends?
- Older people's demand for, and access to, in-home care, in-home treatment, higher dependency living, particularly rest home care?
- Outcomes for older people in non-dominant populations – Māori, Pacific Peoples, Chinese new settlers?
- Current policy, funding, and social and health service practices and potential for adaptation to an ageing, diverse society experiencing rapid tenure change?

This is multi-method research structured around five components.

*Component 1: Housing tenure transitions*

Cohort analysis (rather than the usual cross-sectional analysis) will be applied to census data time series to demonstrate the cumulative experience of housing tenure change as age increases. This will be annotated to: (a) the timing of key policy changes in housing, health services and access, and retirement incomes policy; (b) economic or other shocks such as the Canterbury earthquakes. Intra-cohort analysis will be undertaken using ethnicity, place of origin, place of residence and other socio-economic variables to identify housing transitions within same-age cohorts. Analysis will be undertaken nationally and sub-nationally using both council and district health board boundaries.

#### *Component 2: Tenure, in-home and residential care transitions*

This research will test whether: (a) older renters are more likely to move (and/or move earlier) into residential care than older people in owner occupation or license to occupy dwellings; (b) older renters are less likely to access in-home care; and (c) older renters are less likely to access home modifications. The cohort analysis (component 1) and other longitudinal datasets will be used to triangulate transition probabilities. The primary analysis will be undertaken using: (i) the Health Survey time series of cross-sectional data, and (ii) anonymised, matched data from the InterRai for assessed need, Health Benefits and Home Modifications Funding data for service delivery, and Residential Care Subsidy Application Form data which provides tenure data for those seeking residential care. Two data cubes will be generated from (i) and (ii) above to develop a housing-care interface model. A Chi-square Automatic Interaction Detection technique, which is more efficient than traditional regression or ANOVA for the analysis of multiple categorical data, will be used to identify dependent and independent variables through risk estimation. To establish the most important predictors of entry to residential care, Cox regression (survival analysis) will be applied with 'hazard ratios' reported (90, 450-456).

#### *Component 3: A National Perspective on Older Renters in Policy, Planning and Services*

This research will establish whether current public policy and planning, and private, public and community service development and delivery to older people can respond to the material conditions associated with renting. Those conditions include: increased residential mobility and less stable addresses, limitations on home modifications, and higher housing costs. Taking a national perspective, this component involves:

*Cross-sectoral Reviews:* One review will focus on central government policy, funding, and services in the health and disability sector (including residential care and home modifications), income support, social services, and housing. The second review will focus on councils. Both reviews will comprise documentary analysis of strategies, statutes, service frameworks and practices, and provisions to increase older people's financial independence (e.g. through rates relief and deferral, warm homes subsidies, pensioner housing programmes). The cross-sectoral reviews will: (a) establish the extent to which access to services and subsidies assume, are attached to, or triggered by, owner occupation; and (b) the extent to which access to services or subsidies may be diminished by changes in tenure status.

#### *National Landlord Survey:*

The way older people are prioritised by landlords varies. Private landlords have expressed a preference for older tenants in the past. Older people are prioritised in NZ's small council rental stock, but not by CHPs. Older people are such low priority that they are virtually excluded from access to government owned rental stock as new tenants. Those existing tenants who have aged in place have now lost tenure security. They will have tenancies reviewed regularly in the future. This survey will explore the extent to which landlords across these segments: (a) recognise and plan to meet increased demand among older people; (b) have a 'taste' for older tenants and are able/willing to set affordable rents for them; (c) deliver stock with designs, locations and amenities suitable for older people.

*Component 4: Case Studies* will be used to provide a rich understanding of the diversity of ways in which older people, middle aged people, and younger people relate, and the array of services, market provisions, place-based amenities, cultural and social attachments that constitute the local social systems in which older people and renters operate. By providing an "...intense focus on a single phenomenon in its real-life context" case studies uncover transferability (457-459). They allow us to compare, under different and specific conditions: (a) the meanings that people bring to 'being an older renter' and the meanings people bring when relating to older renters; and, (b) continuities and contrasts in specific service delivery and practices around older renters. Case studies allow us to explore how factors associated with cultural identity and practice, place, and household circumstances, shape the experiences of older renters and their outcomes.

This enriched data contributes to: (a) an understanding of the transferability of findings to other older people; and (b) an analysis of the opportunities, practices and tools that will support ageing well under conditions of rental market reliance.

The six case studies are: (a) 2 place-based studies of Marlborough (the region with the highest old age dependency ratio); and Waiheke Island, part of Auckland but isolated from services and limited housing choice for its ageing

population; (b) a case study of older tenants in council housing; (c) 3 case studies around shared cultural and positional experiences. The Māori case study covers rental experiences in both urban and rural areas. The Pacific Peoples case study will be undertaken in the Wellington region. A new settler’s case study focuses on Chinese who have low rates of ownership and high rates of residential movement (428, 460-472). This mix of case studies will enable us to explore key groups in NZ’s diverse society. Using engaged theory and inquiry, the case studies will involve targeted surveys and qualitative methods such as talking circles, focus groups and scenario-building activities with older renters and non-renters, family and friends, as well as service providers across housing, health, social, retail, legal, financial, recreational and spiritual services. Local social systems and access mapping will be undertaken in each case study.

#### *Component 5: Learning to Adapt*

This component brings key stakeholders, including older people themselves, together using foresight research techniques and charrettes (445, 473-479). These techniques allow researchers and stakeholders to reflect on emerging findings from Components 1-4 and (a) explore alternative development paths and their probabilities; (b) generate consensus about the practices and services needed to optimise older people’s societal engagement, personal, familial and intergenerational wellbeing in the context of both structural ageing and declining home ownership, and (c) develop tools, models and best practice that allow services to assess and adapt current services, practices, and procedures to meet the needs and circumstances of older renters, their families and communities.

### Giving effect to VM

Vision Mātauranga and mātauranga Māori are crucial to this research. Māori cultural commitments to Manaaki Tangata are strongly articulated, particularly around older people. However, there is considerable evidence that Māori older people are under-serviced by health, social, and housing services in the public and private sectors. This partly reflects geographical distributions, with Māori populations over-represented in rural areas. It may also reflect low levels of owner occupation. Indeed, in some respects the experience of Māori is a forerunner of the emerging tenure revolution being confronted by the country as a whole. Māori owner occupation rose into the 1970s. In 1966, 46% of Māori adults owned the houses in which they lived but by 2013 only 28.2% did so (467-472). The implications for today’s older Māori as well as the older Māori of the future, their cultural and social participation, their wellbeing and their intergenerational roles and status, has yet to be systematically explored. What is clear is that Māori communities have significant experience in providing and living in rental housing, the provision of informal and formal care, and a willingness to be innovative in this context (480-484). The Māori case study has a central place in this programme and will explore the extent to, and conditions under, which those approaches and innovations are transferrable to other communities both Māori and non-Māori. In addition, careful attention will be given in this research to the Māori experience in the quantitative analysis and the futures forecasting for older Māori. The research involves Māori, has Māori-centred research, and has Kaupapa Māori research (485-488). This team has a leading Māori researcher, other members with longstanding relations with Māori communities and support of Māori stakeholders.

### Linkages to other Challenge Projects

Project Title	Link
<b>B. Reducing frailty</b>	Potential interface around the differential impacts of tenure on outcomes measured by this project, coverage of the evaluated service. Contribution of this project to the housing tenure change project is dependent on the participant profile and capture of key housing tenure and other socio-economic status data from the participants. The housing tenure change project will identify the impact of renting in the context of older people’s communities and the case studies will provide a rich set of data around the perceptions of frailty and their active (or otherwise engagement) with frailty prevention among older renters in a diversity of cultural, place-based and material settings.
<b>C. Social isolation</b>	Potential interface around the differential impacts of tenure on outcomes measured by this project, coverage of the evaluated service. Contribution of this project to the housing tenure change project is dependent on the case frame and participant selection within the project itself and the scoping of those defined as ‘key stakeholders’. The housing tenure change project will identify the impact of renting in the context of older people’s communities and the case studies will provide a rich set of data around interaction, engagement, loneliness and service access among older renters.
<b>D. Older people in work</b>	The housing tenure change project will provide data on the impacts of tenure and tenure security on older people’s interactions with others, provision of care and support to others and contributions to their communities, families and whānau
<b>E. Neurodegeneration &amp; individualised</b>	The housing tenure project will indicate the probability and timing of older people in different tenures entering residential care. There may be some ability to assist Phase 2 of this project to

<b>interventions</b>	expand the discussion of end of life care through the housing tenure case studies.
<b>F. Retirement villages</b>	The potential contribution of this project to the housing tenure project is limited by the very small numbers of tenants within retirement villages, its focus on the Auckland and Waitemata DHBs and the very low numbers of people moving into retirement villages from the private rental market. There is some opportunity for comparative analysis of data generated in the housing tenure project with the data generated by this project.
<b>G. Risk factors in reduced social engagement</b>	The INTERAI has no tenure data capture. There may be some opportunity for the housing tenure project to contextualise the outputs of the risk factors project outputs to make useful for forecasting purposes by end users. The housing transitions demographic analysis component and component 2 of the housing tenure project which will establish transitions from rental to care. This may be illuminated by and illuminate the data from the risk factors project.
<b>H. Drug Burden Index</b>	The INTERAI has no tenure data capture. There may be some opportunity for the housing tenure project to contextualise the outputs of the risk factors project outputs to make useful for forecasting purposes by end users. The housing transitions demographic analysis component and component 2 of the housing tenure project which will establish transitions from rental to care. This may be illuminated by and illuminate the data from the drug burden index project. There may be opportunity to use the DBI in the case studies.
<b>I. Stroke &amp; CVD prevention</b>	Potential interface around the differential impacts of tenure on outcomes measured by this project, coverage of the evaluated service. Contribution of this project to the housing tenure change project is dependent on the participant profile and capture of key housing tenure and other socio-economic status data from the participants. The housing tenure change project will identify the impact of renting in the context of older people's communities and the case studies will provide a rich set of data around the perceptions of stroke, wellness, prevention and coaching and their active (or otherwise engagement) with prevention among older renters in a diversity of cultural, place-based and material settings.
<b>J. Electrical stimulators for stroke recovery</b>	The power of this research lies in its potential to assist recovery and functionality among stroke victims. Tenants, because of their material and social circumstances, may be particularly vulnerable to poor stroke recovery. The housing tenure project will identify transitions into higher dependency care and this may contribute to developing research-based strategies for targeting, net benefits of the use of these stimulators, and support strategies if the stimulators are found to be efficacious.

### 2.3.1. Quality

All research funded in the first tranche has undergone extensive peer review, by the international Science Advisory Panel and by the senior management team, and has also been considered by stakeholders, the Kāhui Māori and the Wise Heads group. Part of the review has included the proposed methodology and the experience of the research teams. Proposals have been developed through several rounds of feedback, ensuring they are of high quality and are fit for purpose.

## 2.4. Research team

### 2.4.1. Research Organisations

This consortium has been formed by the major research groups and leading clinicians who are addressing challenges associated with ageing well. The following are the formal members of the Challenge who have agreed to be party to the Collaboration Agreement and are actively participating in the research activities:

- Auckland University of Technology (AUT)
- Massey University
- The Centre for Research Evaluation and Social Assessment (CRESA)
- University of Auckland
- University of Canterbury
- University of Otago
- University of Waikato
- Victoria University of Wellington

In addition, AgResearch is a collaboration partner and will likely participate in future research programmes. The track records and skills of individual groups are outlined in Section 2.3, associated with each project, and the international connections in Section 2.4.2. The Challenge's integration with Māori research and the Māori community are given in Section 1.1.3.

## 2.4.2. International linkages

International linkages for projects are summarised in Table 9.

**Table 9 International linkages**

Project/Programme Name	Funder	Person(s)	Organisation	Nature of relationship
		Prof. Chris Phillipson	University of Manchester	Project advisor
HMIInfo (Housing Modification Information) Specialist Research Review Panel	Commonwealth Govt Australia	Multiple contributors	University of New South Wales	Kay Saville-Smith on Advisory Expert Research Review Panel
Age Friendly Banking	Federal Reserve Bank of San Francisco	Dr Rob Wiener (Director)	California Coalition for Rural Housing	Collaborative research including on MBIE funded Downsizing research
Find the Best Fit	MBIE with direct funding from BRANZ and Commission for Financial Capability	Prof. Susan Smith Prof Bruce Judd Dr Rob Wiener	Social and Economic Geography, Cambridge University of New South Wales University of California, Davis	IAP Members
Research Excellence on the Finance and Economics of Primary Health Care	Multiple Sources	Multiple personnel	UTS, Sydney	Jackie Cumming, Victoria Uni. on International Advisory Panel
Sustainability of Health Systems	Canadian Institute of Health	Multiple personnel	Canadian Institute of Health	Jackie Cumming, Victoria Uni. is Co-investigator
Migration, filial piety and transnational aged care: A cross-national study of Chinese families caring for older parents across borders	Chiang Ching-kuo Foundation	Prof. Norah Chiang	National Taiwan University	Elsie Ho, University of Auckland is Principal Investigator
Health and Retirement Study	National Institute of Ageing, USA	Jacque Smith, Toni Antonucci, Heidi Guyer	University of Michigan	Consultation
Women's Health Australia	Australian government	Christina Lee, Julie Byles	University of Queensland and Newcastle University	Consultation and collaboration.
The Older Workers and Care-giving Project	ARC Centre of Excellence in Population Ageing Research Worldwide Universities Network	Kate O'Loughlin Janet Fast Sue Yeandle Hal Kendig	University of Sydney University of Alberta University of Leeds	Collaboration
Gender and health impacts of policies extending working life in western countries	COST European Cooperation in the field of Scientific and Technical Research	Aine Ni Leime	National University of Ireland, Galway Irish Centre for Social Gerontology	Collaboration
Risk Stratification for Older People: Validation and Influence on Clinical Decision Making	Australian NHMRC	R. Hubbard (AI)	University of Queensland, Australia	A Prof Hubbard is currently Chief Investigator on an NHMRC Project Grant (\$285,511) titled Risk Stratification for Older People: Validation and Influence on

				Clinical Decision Making. Funding \$250,000. This is an interRAI-based project on frailty.
<b>Australian Centre for Research Excellence in Telehealth</b>	Department of Social Services, Australia  NHMRC Australia	L. Gray (AI)	University of Queensland, Australia	Development of the interRAI Acute Care Screener - \$770,000 Investigation of the efficacy of a telemedicine intervention in long term care (pragmatic RCT) - \$990,000 Centre for Research Excellence in Telehealth -\$2,500,000 funding (PI Prof Gray) Professor Gray will advise on interRAI interpretation to.
<b>Changing Long Term Care in America: Policies, Markets, Strategies, and Outcome</b>	National Institute on Ageing (US) NIA	V. Mor (AI)	Brown University, USA	Prof Mor will advise our project, based on his extensive career in interRAI in the US, his advice to NZ on establishing the NZ National Data Warehouse, and his current NIA work on the project “Changing Long Term Care in America: Policies, Markets, Strategies, and Outcomes” has funding of \$US1.3 million.
	Public Health Association of Canada	J. Hirdes (AI)	University of Waterloo, Canada	Professor Hirdes has over \$3 million in Canadian government grants primarily to do with using interRAI data to improve patient care.
<b>Medicines and Ageing</b>	NHMRC (Australia)	Le Couteur (AI) Other investigators in this study are	University of Sydney	\$2,444,505 NHMRC grant to investigate altered pharmacokinetics and the effect of polypharmacy in ageing. Professor Le Couteur is an AI on both the projects. The results from the proposed study would be incorporated into the pharmacoepidemiological aspects of the Australian study.
<b>High risk prescribing in older Australians: prevalence, outcomes and potential intervention</b>	NHMRC (Australia)	Hilmer (AI) Le Couteur (AI)	University of Sydney	\$577,181 grant to fund a de-prescribing trial. Professor Le Couteur and Professor Hilmer are both AIs in this trial. The information from our DBI trial may help guide the de-prescribing trial.
<b>TULIP consortium</b>		Prof Jacobin Gossekloo	LUMC	Longitudinal investigation of older people in Leiden, the Netherlands
		Prof Steve Illiffe	UCL	Professor of Primary Care for Older People specialise in health (exercise) promotion in later life. Advisor in study design and promotion of physical activity.
		Prof Ian Cameron	University of Sydney	Chair in Rehabilitation Medicine. Advisor in frailty
		Assoc Prof Matteo Cesari	Centre Hospitalier Universitaire de Toulouse	Advisor in lifestyle intervention for frail older adults.
<b>USA Women’s Health in Ageing &amp; Health, Ageing &amp; Body Composition studies</b>		Prof Abernethy	FDA	Provision of access to the NIA-funded Women’s Health in Ageing & Health, Ageing & Body Composition studies

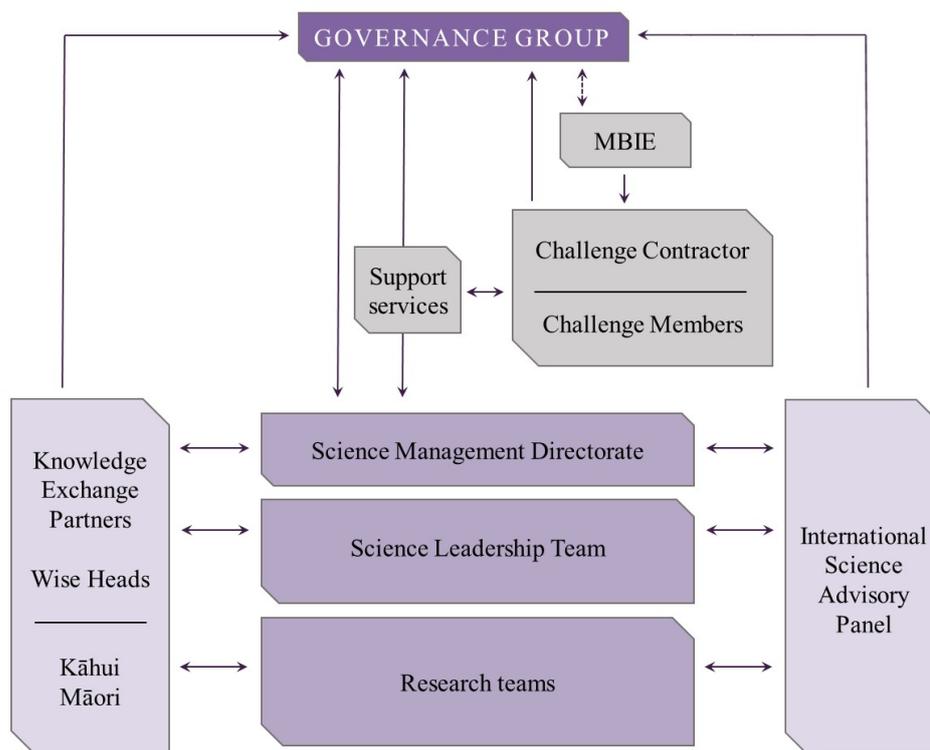
# BUSINESS PLAN

### 3. BUSINESS PLAN

#### 3.1. Challenge structure

The *Ageing Well* Collaborators revised governance and management structure (on the basis of previous feedback from the Science Board) is outlined in Figure 7. The Governance Group will be led by an independent chair, Ms Norah Barlow (see Appendix 4) who will report to the Vice-Chancellor of the University of Otago (as the contract holding institution) on behalf of the Group. The Group will operate under principles agreed by all the Collaborating Parties in the overarching Collaboration Agreement.

**Figure 7 Proposed governance and management structure for *Ageing Well***



#### 3.2. Governance arrangements

The Governance Group has been established and held its first meetings in June. Four members including an independent Chair, Ms Norah Barlow, have been appointed (see Figure 8 and Appendix 4). The appointment of other members is currently under consideration to ensure a balance of skills, relevant experience and connections.

**Figure 8 Governance Group members**



**Ms Norah Barlow** (Chair)  
Merseyside Limited



**Professor Peter Crampton**  
University of Otago



**Catherine Fyfe**  
Upland Consulting Ltd



**Peter Stanes**  
Methven Ltd

The Governance Group, via the Chair, will report to the Vice-Chancellor of the University of Otago (as the Challenge Contractor) on behalf of the Group. The Group will operate under principles agreed by all the Challenge members in the *Ageing Well* Collaboration Agreement.

The Governance Group will comprise a maximum of 7 members with skills and capability relevant to the Challenge (strategy development, risk management, stakeholder perspectives, governance, Māori and Pacific engagement and perspectives, business, financial and legal matters, science and science management, clinical practice and health services delivery, and community relationships). The Chair will be independent and other members will include at least two independent members (Peter Stanes of Methven Ltd, and Catherine Fyfe of Upland Consulting Ltd have been appointed), one Māori member, one Pacific Peoples member, one representative of the Challenge Contractor (Professor Peter Crampton, ProVice Chancellor for Health Sciences, University of Otago) and one representative of the other Challenge Members (to be agreed between other Challenge Members). Some members may be joint appointments across other Challenges to facilitate strategy, co-operation, and activity between Challenges at governance level. Board meetings may also be attended by an MBIE observer and the Challenge Director.

Terms of reference are in progress and their current state is provided in Appendix 3. The role of the Governance Group will be to:

- Ensure that *Ageing Well* activities address the outcomes sought and that a robust prioritisation process is adopted;
- Recommend on the appointment of, and provide feedback on the performance of, the Director, Deputy-Director, other members of the Science Management Directorate and the Science Leadership Team;
- Review and approve strategic plans, including the research plan and science investment recommendations from the Director and Science Leadership Group;
- Oversee the implementation and delivery of *Ageing Well* research projects, performance and achievement of the outcomes;
- Encourage activities for leveraging external opportunities and connections;
- Champion the work of *Ageing Well* in the wider community;
- Participate in MBIE reviews as required.

### 3.3. Management arrangements

#### 3.3.1. Science Leadership Team and Science Management Directorate

The Challenge will be led by an overarching Director (0.5FTE, Professor David Baxter, see Section 1.2.1) who will chair the Science Leadership Team and Science Management Directorate (as a subset of the Leadership Team comprising the Director, Deputy Director (0.2FTE) and two additional members (0.1FTE each). The Science Management Directorate will be formally appointed by 31<sup>st</sup> December 2015, through normal HR processes, including advertising with a formal job description and scrutiny of candidates by the Governance Group.

The Interim Science Leadership Team is listed in Appendix 5; it is envisaged that they will form the inaugural Science Leadership Team. All Science Leadership Team appointments will be fixed term, with staggered end-dates, and planned rotation of membership; a succession strategy will be in place by 31<sup>st</sup> December 2015.

Science Management Directorate meetings will occur fortnightly via teleconference. The Operations Manager (see Section 3.3.2) will attend Directorate meetings.

The Science Management Directorate will be responsible for:

- Implementation of the research plan (2015-2019) and the 10 year strategic plan,
- Proposing any changes in research priorities, activities and funding or related activities required to deliver outcomes and impact expected by MBIE.
- Implementation of the agreed research plan;
- Coordinating the work of *Ageing Well* and monitoring performance of projects to ensure delivery of milestones and overall Challenge outcomes;
- Reporting on all aspects of the research and management to the Governance Group.

Science Leadership Team meetings will be held four times a year. The non-directorate members of this Group will receive a per diem and relevant expenses to attend meetings.

The Science Leadership Team will be responsible for:

- Oversight of the research plan (2015-2019) and the 10 year strategic plan,
- Recommendation of projects for funding for presentation to the Governance Group (the Interim Science Leadership Team, see below, has done this for the first tranche of core funding);
- Recommending any changes in research priorities, activities and funding or related activities required to deliver outcomes and impact expected by MBIE to the Governance Group;

### 3.3.2. Operations

The Director, Deputy Director and Science Management Directorate will be supported by an Operations Manager. The Operations Manager will be responsible for:

- Day-to-day management;
- Actioning decisions of the Science Management Directorate;
- Establishing and implementing Challenge policies and processes including
  - Contestable funding rounds;
  - Communications;
  - Events.
- Reporting:
  - To the Science Management Directorate fortnightly;
  - To the Science Leadership Team four times a year;
  - To the Governance Group four times a year;
  - To MBIE as per the contract, including an annual report;
- Managing projects and associated funding:
  - Ensuring that funding is allocated through appropriate contracts with external parties;
  - Co-ordination and receipt of reports on research projects.

An Operations Manager, Simon Crack, has been appointed and will commence work in July 2015. Simon will return to New Zealand from working in an operational role in the National Health Service (NHS) in England. Originally from Dunedin, Simon graduated from the University of Otago with a BA (Hons) and MA (with Distinction) in Human Geography. Simon held a management role in the Ministry of Social Development in Wellington – including working as a Private Secretary for a senior Cabinet Minister – before embarking for England where he held operational, strategy and advisory roles in the United Kingdom’s civil service. Simon has a proven record of providing practical operations advice and support. He has developed expertise in designing and delivering governance, accountability, monitoring and reporting systems and processes to help support and underpin delivery in the United Kingdom’s Department for Education, Department of Health and latterly NHS England's work programmes.

### 3.4. Agreements

The University of Otago, as the Challenge Contractor, has entered into a National Science Investment Contract with MBIE for delivery of the *Ageing Well* Challenge as well as a Challenge Programme Agreement for the commencement phase of the Challenge. One of the deliverables of the commencement phase is to provide an agreed draft of a Collaboration Agreement, acceptable to all the Challenge Members and the Ministry by 8 June 2015. The Collaboration Agreement specifies how the *Ageing Well* Challenge will operate and includes such matters as roles and responsibilities and appointment of a Governance Group and the Director, allocation of funding, conflict resolution process, and principles for IP management.

The Collaboration Agreement will be executed following final approval from the MBIE Science Board and subject to any feedback or conditions of MBIE and the MBIE Science Board.

The Collaboration Agreement will supersede the previously signed Heads of Agreement.

### 3.5. Financial management

The Challenge Members are all significant research organisations with a history of financial stability and accountability. Each are independently audited for the use of public funds according to the standards of the Office of the Auditor General and Controller.

The funds for the *Ageing Well* Challenge will be managed by the University of Otago (Otago). The University has considerable experience with management of public research funds with a turnover of such funds in excess of \$80M pa. All expenditure will be subject to Governance Group approval (or under Governance Group approved delegation). Otago will provide regular financial reporting to the Director and the Chair of the Governance Group.

*Ageing Well* will be supported by the University's financial and research project management processes including research contracting, IT, HR and other internal systems and infrastructure. The University of Otago will establish discrete accounts within the financial management system and will distribute funding to the parties and other research organisations as appropriate through fit for purpose subcontracts. Expenditure of funds within the University is monitored on a monthly basis and any unusual expenditure against budget must be explained by account holders.

*Ageing Well* will operate with sound governance, science leadership, management and business processes. Budget considerations have had to take into account a balance between resourcing these functions, investment in research as well as stakeholder engagement and public outreach. We anticipate confirming the budget following approval of the MBIE Science Board and, at the time of contracting, a Challenge Programme Agreement with MBIE for the first research funding period.

The indicative budget for the first funding period up to 30 June 2019 is \$14.1M (available funding of \$14.6M minus commencement phase funding of \$466K), and \$20.3M for the period 1 July 2019-30 June 2024. This budget has been put together assuming research funding will start from October 2015 (if funding is approved) with \$2.8M available for a contestable funding round in 2015/16 (see Appendix 2).

In summary, the budget allows for fees and direct costs for the independent members of the Governance Group and direct costs for other members. There is provision for salary and salary related costs (including overheads) for a Director (0.5FTE), Deputy Director (0.2FTE) and 0.1FTE each for additional members of a Science Management Directorate. Non-directorate members of the Science Leadership Team will receive a per diem and relevant expenses to attend meetings. A fulltime Manager is costed in to provide adequate support for the operation of the Challenge with administration support provided by the University of Otago.

It is expected that there will be significant interaction and engagement (face to face meetings, hui, tele- and video-conferencing) between management, governance, the Science Leadership Team, advisory groups (International Science Advisory Panel, Kāhui Māori, stakeholders), and with the broader *Ageing Well* Challenge citizenship as well as the general public over time. The budget includes costs for travel (flights, accommodation, taxis) to meetings and workshops, costs for venue hire and catering, and for ongoing communications costs for both tele- and video-conferencing and other communications (activities as outlined in the Communications Plan Appendix 11).

Research projects have been costed, applying personnel rates and overhead rates, based on established practice relevant to each research institution. PIs are expected to contribute 0.2FTE to a project unless specifically justified at a lower amount in order to provide leadership. There was a clear expectation given that the funding should be applied to the cost of research, rather than creating a large leadership group.

*Ageing Well* has a contestable funding pool of \$2.8M and will seek matched and other sponsored funding to increase this pool. The most likely co-funder is the HRC and there is agreement in principle to explore options and areas of mutual interest for funding. There is also the possibility of co-funding initiatives between *Ageing Well* and aligned Centres of Research Excellence and Challenges such as Brain Research New Zealand - *Rangahau Roro Aotearoa*, *Ngā Pae o te Māramatanga*, *Science for Technological Innovation*, *Healthier Lives*, *High Value Nutrition* and *A Better Start*.

The indicative budget does not include co-funding for research projects from third parties that is not received by *Ageing Well* as this funding is or will be received and managed by the party receiving the funding. Current co-funding for research projects is detailed by project (Section 2.1).

### 3.6. Risk management

Risk Category and Description		Potential Impact	Likelihood	Consequence	Risk Profile	Proposed Risk Management/ Mitigation strategy	Responsibility
1	Failure or significant delay in recruiting high quality independent Governance Group (GG) Chair.	Lack of independence in commencement phase processes Delay in appointing Governance Group Delay in appointing Director Delay in getting input to Challenge Governance and Management arrangements Reputational risk to the Challenge	Unlikely	Moderate		Parties use existing networks to identify prospective candidates Move quickly to appoint GG Chair Continue to rely on Establishment Oversight Group (EoG) Agreed, open and transparent process for appointment of Chair	EoG
2	Failure or significant delay in recruiting Governance Group members.	Lack of independence in commencement phase processes Delay in getting input to Challenge Governance and Management arrangements	Unlikely	Moderate		Use networks of GG Chair, MBIE, key stakeholders and Parties to identify prospective candidates  Kāhui Māori has provided recommendations for a Māori appointment	GG Chair, EoG
3	Failure or significant delay in recruiting high quality Director.	Slower progress in implementing the Challenge Inability to meet Challenge deliverables within acceptable timetable Reputational risk to the Challenge	Possible	Moderate		Agree Job Description at an early stage and begin recruitment during commencement phase Continue to rely on Acting Director or appoint alternative Acting Director Continue to rely on Interim support including Science Leadership Team, and operational staff to maintain Challenge momentum	GG, University of Otago
4	Failure to maintain the new approach to <i>Ageing Well</i> research (as articulated in Outline) during research plan development.	Loss of support from parties who have been involved in the submission of the application and Outline. Rejection of research plan by MBIE Science Board or by assessment panel Loss of support for the Challenge from MBIE	Unlikely	Severe		Maintain clear separation from 'business as usual' activities, building on the intent set out in the Outline Ongoing and regular engagement of parties in development of research plan, building on existing approach Regular engagement with MBIE during development process Continuation of engagement with Strategic Advisor	Acting Director, Science Leadership Team, EoG/GG
5	Failure to agree on process for prioritisation of research projects	Loss of support from parties who have been involved in the submission of the application and Outline. Rejection of research plan by MBIE Science Board or assessment panel	Unlikely	Severe		Early and regular engagement on developing process with all Parties in a fully transparent way Utilise influence of GG Chair Seek assistance of Strategic Advisor and other external advice if required	GG Chair and GG

6	Failure to get agreement of all Parties to Collaboration Agreement.	Relationships break down leading to fragmentation of expertise and reputational damage Challenge proceeds with less than full complement of national expertise	Unlikely	Severe	Early engagement on terms and conditions of collaboration agreement and leverage off work to date on agreed draft collaboration agreement template Continue to engage in constructive dialogue with all Parties in a fully transparent way at least monthly Utilise influence of GG Chair Invoke interim dispute resolution process as a last resort	University of Otago, GG/EoG  GG Chair Acting Director, Parties in dispute
7	Scientific hypotheses are not proven	Particular aspects of programme do not lead to significant outcomes	Likely	Low	Diverse portfolio Strong existing evidence base for research Use of existing cohorts and databases Experienced researchers	Science Leadership Team, Project Leaders

### 3.7. Open data

*Ageing Well* will manage data and access to data generated through Challenge work in a way that enhances ongoing value to New Zealand. Any data management plans will address permanent storage, accessibility, and reusability of data; collaborative arrangements with other relevant organisations to maximise the shared use of the data; and conditions for the use of data by the public. Management plans will have to include consideration of stakeholder and any co-funder commitments, legislative requirements and cost/benefit analysis.

The data generated by the wider *Ageing Well* team is expected to be freely available for partners within the Challenge whilst adhering to any ethical or regulatory constraints that apply to gathering and generating such information. For example, there are often limitations on circulation of human clinical trial due to ethical constraints. In all other respects, any data generated by the Challenge would be made available in line with NZ Government Open Access & Licensing Framework (NZGOAL).

### 3.8. IP management

The *Ageing Well* Challenge Members recognise the public good nature of the research to be undertaken in the Challenge. The outcomes of Challenge depend on the use of the research findings and tools generated by it. It is anticipated that much of the research output of *Ageing Well* will be made publically available to enable knowledge transfer into the health and community sectors and to all Challenge Members for non-commercial research.

The approach to IP management reflects the imperative of knowledge transfer and is designed to promote access to research results and the tools developed. Not all IP matters and cultural property issues are evident at the beginning of a research endeavour, particularly where the research method involves strong engagement with end-users and communities. The Challenge Members have agreed a set of Intellectual Property (IP) management principles based on those in the draft collaboration agreement to guide decisions on the protection and commercialisation of IP created through Challenge research projects (Appendix 10).

In summary, project IP will be owned by the creating party and they will be responsible for its protection, management and commercialisation. Jointly created IP will be the responsibility of a managing party by agreement between all parties involved in its creation. Benefits will be shared between the creating partners to reflect the relative input to the IP, including background IP, inventorship, and commercialisation. Where project IP is developed in collaboration with co-funders, industry partners, or end-users, appropriate acknowledgements and agreements will be negotiated prior to commencement of activities with the external party to ensure IP is developed to advance the purpose of the Challenge.

The starting point for all IP documentation will be in project reporting (all project IP will be reported to the Director who will maintain an IP register) and in addition research providers have formal processes for IP disclosure. There will be an agreed approach and protocols to project IP management in alignment with Challenge IP management

principles. This will include arrangements around publishing (including authorship protocol) and dissemination will need to take into account the contribution and involvement of researchers and endusers as well as community related issues and emerging cultural property. If needed, and on a project by project basis, an IP review will be instituted in the last quarter of the project term to ensure IP is appropriately reported and managed

### 3.9. Infrastructure

The *Ageing Well* Challenge will be hosted by the University of Otago, and physically based within a dedicated Challenge Office suite adjacent to the University's Centre for Health Activity and Rehabilitation Research. An open plan office will be provided for the Director, the Manager and any administrative staff. The Challenge will also have access to research-related support services such as marketing and communication, social media, research office, and financial governance through the Centre.

Item	Location/Ownership	Use
Transcranial magnetic stimulation machine	Anatomy Department, University of Otago	Once a fortnight
Physiotherapy teaching laboratory	School of Physiotherapy	Used for delivering intensive rehabilitation programme
COMPASS Research Centre	University of Auckland	Remote access facility to Statistics NZ Datalab which hosts official data, e.g. NZ Longitudinal Census, and IDI
Technical specialised software	CRESA, Victoria University, Natalie Jackson Demographics, University of Auckland	Statistical Analysis, Network Mapping, Demographic Analysis
Data protection	CRESA, PP&R, Victoria University, University of Auckland, Natalie Jackson Demographics, Katoa Ltd	Prevention of inappropriate data use or loss
Secure data storage	CRESA, PP&R, Victoria University, University of Auckland, Natalie Jackson Demographics, Katoa Ltd	Confidential maintenance and protection of field notes and electronic data.
Neurological clinic	AUT	Trial facilities
Kitchen facilities	Anglican Care Whangarei	Facilitating Senior Chef programme
Office facilities	Tauranga Research Centre	Recruitment, enrollment and assessment of participants, facilitating Senior Chef & SAYGO programmes (non-Māori)
Office facilities	Cardiac Clinic, Tauranga	Recruitment, enrollment and assessment of participants, facilitating Senior Chef & SAYGO programmes (Māori)
Phone/IT/online research facilities	AUT, CRESA, University of Auckland, Massey University, University of Otago, Victoria University	
Meeting rooms, office space	AUT, Canterbury District Health Board, University of Auckland, Massey University, University of Otago, Victoria University	

### 3.10. Monitoring of performance and evaluation of impact

A draft Challenge-specific performance framework has been developed, indicating a progressive set of outputs/outcomes/impacts with performance indicators and targets (Appendix 12). This framework complements the generic framework developed by MBIE to monitor performance across all Challenges. The *Ageing Well* Governance Group will consider the Framework in the near future. It is important that the framework delivers to governance expectations, as it will allow the Governance Group to monitor, review and potentially redirect Challenge work.

The Challenge-specific indicators and targets particularly reflect pathways to achieving social and health and well-being outcomes, the effectiveness of knowledge exchange and linkages with knowledge users. Indicators of other Challenge characteristics, such as science quality, quality of the team and collaboration, effectiveness of management and governance are contained in the MBIE developed framework.

At a project level, progress and performance will be assessed against project milestones and performance indicators; this will form the basis of review and award of ongoing funding for individual projects, and to researchers, and

research groups. Failure to achieve milestones according to timelines would require explanation and remedial action taken where appropriate. Ongoing non-performance will be grounds for disinvestment.

The key performance indicators will measure the long term Challenge outcomes relate to housing options, workforce participation and the proportion of older people in residential care. These indicators are measures of components of the active concept, i.e. security (housing options), participation (workforce participation) and health (proportion of people in residential care). Intermediate outcomes measures are indicative of key components of the pathways to reaching the high level outcomes; that is the development of an evidence base and scalable interventions, and engagement and implementation by appropriate end-users, as evidenced by generation of guidelines and policy inputs.

# APPENDICES

## APPENDIX 1 ALIGNMENT WITH MBIE FEEDBACK

	MBIE Requirement	Section
1	Name governance/ management individuals	1.2 The <i>Ageing Well</i> Team Appendix 4 Governance Group profiles Appendix 5 Interim Science Leadership Team Profiles
2	Initial & ongoing funding allocation	2.1 Project Portfolio Appendix 2 Budget & cost breakdowns
3	Criteria & processes for investment of funding across research activities, including specific details about priorities, processes & funding levels for the contestable refresh mechanism	1.4.7 Prioritisation and contestable funding
4	How the research relates to existing international research & the world view & literature related to <i>Ageing Well</i>	1.1.4 Research Strands and their fit in the national research landscape 1.4.3 Linkages to international research
5	National research landscape, related science required for the Challenge to deliver its Objective and where that is located, mechanisms used to influence funders & researchers who will contribute to achieving the Challenge objective	1.1.4 Research Strands and their fit in the national research landscape 1.4.1 Big data 1.4.9 New approaches, higher risk research, dynamism & refresh 1.4.4 Linkages to other NZ research
6	How a research team will be created & maintained across the Challenge	1.2.1 Science Leadership 1.4.4 Linkages to other NZ research
7	How VM outcomes will be driven & ensured to be achieved in practice	1.3 Vision Mātauranga
8	Knowledge exchange framework to be used & how this will contribute to Challenge outcomes and impacts as a whole	1.2.5 Stakeholder engagement & Knowledge Exchange Transfer Framework Appendix 11 Communications Plan
9	Reporting/monitoring framework, review schedule, Challenge-specific KPIs	1.6 Impact & Benefits 3.10 Monitoring of performance and evaluation of impact

## APPENDIX 2 BUDGET & COST BREAKDOWNS

Draft budget for Ageing Well: GST exclusive and in \$000's									
	Y1	Y2	Y3	Y4	Y5	Total			Y6-10
	2015	2016	2017	2018	2019	\$	%		2019-2024
<b>Science Leadership</b>									
Director (0.5FTE) and Deputy Director (0.2FTE)	147	364	364	364	182	1,421			
Science Management Directorate (2x0.1FTE)	33	79	79	79	40	310			
Science Leadership Team	13	30	30	30	15	118			
<b>subtotal</b>	193	473	473	473	237	1,849	13.1		2,034
<b>Governance and advisory</b>									
Governance Group fees and meeting costs	15	30	30	30	15	120			
Advisory group costs	15	30	30	30	15	120			
<b>subtotal</b>	30	60	60	60	30	240	1.7		264
<b>Management and Administration</b>									
Manager (1.0FTE)	83	198	198	198	99	776			
Administrator (0.5 FTE uncharged)	0	0	0	0	0	0			
<b>subtotal</b>	83	198	198	198	99	776	5.5		854
<b>Communications/stakeholder liaison, travel and outreach</b>									
Event management, communications	20	45	45	48	25	183			
Travel	20	48	48	48	25	189			
<b>subtotal</b>	40	93	93	96	50	372	2.6		410
<b>Research funding</b>									
Project funding	540	2,159	2,159	2,159	1,080	8,097	57.3		
Contestable funding		1,000	1,000	800		2,800	19.8		
<b>subtotal</b>	540	3,159	3,159	2,959	1,080	10,897	77.1		16,738
<b>TOTAL</b>	<b>886</b>	<b>3,983</b>	<b>3,983</b>	<b>3,786</b>	<b>1,496</b>	<b>14,134</b>	<b>100.0</b>		<b>20,300</b>
<b>Total first 5 years</b>	<b>14,134</b>								
<b>Total second 5 years</b>	<b>20,300</b>								
<b>GRAND TOTAL</b>	<b>34,434</b>								
Notes:									
Overheads and salary related costs budgeted at 113% and 7.27% of salary respectively for leadership and management									
Assumption made that research funding will start from October 2015 (Y1) and be completed by early 2019 (Y5)									
Available funding for first funding period is \$14.1M (\$14.6M minus commencement phase of \$466K)									
Available funding for second funding period is \$20.3M. Total available funding to 2024 is \$34.9M (466K+14.1M+20.3M)									
Acknowledged that available funding cannot be moved between five year periods and is only available until the end of a five year period									

## APPENDIX 3 GOVERNANCE GROUP TERMS OF REFERENCE

### Establishment of the Governance Group

The Parties of the *Ageing Well* National Science Challenge (the Challenge) have executed an agreement (the Collaboration Agreement) that sets out how they will work together to deliver the NSC Investment Contract (NSCIC or NSC Investment Contract) for the Challenge. The NSC Investment Contract is between the Ministry of Business, Employment and Innovation (the Ministry) and the University of Otago as Challenge Contractor for the Challenge. The Collaboration Agreement specifies the establishment of a Governance Group to manage the Challenge. The composition, functions and responsibilities of the Governance Group are primarily set out in clauses 11.5, 11.6 and 12.0 of the Collaboration Agreement and these clauses and any others of relevance should be read in conjunction with these Terms of Reference (TOR). For the avoidance of doubt if any clause or element or inference in these TOR differ from the Collaboration Agreement then the Collaboration Agreement shall have priority.

### Overarching Governance Group Framework

The members of the Governance Group shall be required to act in the best interests of the Challenge and Challenges and not in the interests of a particular Challenge Party or stakeholder. It is acknowledged that the interests of the Challenge Parties are legitimate concerns for the Challenge and Governance Group members may legitimately raise them for consideration by the Governance Group.

The Governance Group shall work within, and where relevant give effect to, the Collaboration Agreement and the NSC Investment Contract.

The Governance Group is also required to have consideration to upholding the reputation of the Challenge and all Parties to the Collaboration Agreement.

The Governance Group will be responsible for those matters set out in Clause 12.1 of the Collaboration Agreement and such related matters as are reasonably required to give effect to those matters and to perform any other activities or roles of the Governance Group as described within the Collaboration Agreement.

For the avoidance of doubt, the Governance Group shall have no powers or authority in relation to the Other Funds described in Clause 16.9 of the Collaboration Agreement nor for those matters expressly excluded in Clause 12.1 (financial management of funds, health and safety, ethics, infrastructure, staff employment/HR/misconduct and individual performance management matters) of the Collaboration Agreement.

The Governance Group shall adopt and give effect to the Conflicts of Interest Policy and Process for the Challenge as described in Appendix 1 of the Collaboration Agreement.

### Governance Group Operating Procedures

#### *Notice of Meeting*

The Governance Group shall meet at least three to four times per year on a schedule agreed with the members at its first meeting and at such other times as at least two members of the Governance Group request a meeting.

A member of the Governance Group may convene a meeting of the Governance Group by giving notice in accordance with clauses 3.3 to 3.6.

Not less than five Business Days notice of a meeting of the Governance Group must be given to every member of the Governance Group (and any alternate notified to the Governance Group and to any observer appointed by the Ministry in accordance with the NSC Investment Contract). The notice must include the date, time and place of the meeting and the matters to be discussed.

The failure to give a notice of a meeting or an irregularity in the notice is waived if all members of the Governance Group (and all observers) entitled to receive notice of the meeting attend the meeting without protest as to the irregularity or if all members of the Governance Group (and all observers) entitled to receive notice of the meeting agree to the waiver.

Notice of a meeting may be given by any means, including by telephone. Notice given by a letter addressed to a member at his or her last known residential address will be deemed to have been given on the day following the day the letter is posted.

#### *Method of holding meetings*

A meeting of the Governance Group may be held either:

- by a number of members of the Governance Group sufficient to form a quorum, being assembled together at the place, date, and time appointed for the meeting; or
- by means of audio, or audio and visual communication, by which all the members of the Governance Group (and any observers) participating in the meeting and constituting a quorum, can simultaneously hear each other throughout the meeting.

Where a meeting of the Governance Group is held under clause 3.7(b), at the commencement of the meeting each member (and each observer) participating must acknowledge his or her presence to all the other members participating. A member may not leave the meeting by disconnecting his or her means of communication unless he or she has previously obtained the express consent of the Chair.

#### *Quorum*

A quorum for a meeting of the Governance Group is the majority of the Governance Group members including vacancies which shall be four members, and including at least two independent members.

No business shall be transacted at a Governance Group meeting if a quorum is not present however, those members present may discuss Governance Group business and prepare preliminary decisions which may be ratified by a duly quorate Governance Group meeting called for that purpose.

#### *Voting*

Each Governance Group member has one vote and any business of the Governance Group requiring a decision will be determined by a simple majority of the members present.

The Chair (in his or her capacity as a Governance Group Member) has one vote and does not have a casting vote. The Chair is tasked with encouraging consensus in voting where possible and may choose not to call a vote if a matter requires further discussion and consideration. In the event of a deadlock in voting, then Chair will approach the Vice-Chancellors and CEOs of the Challenge Parties who will have one vote each which will be added to the Governance Group votes to determine a majority. If the additional votes are unable to be obtained during the duration of any meeting where a deadlock occurs, then voting on that matter will be suspended until the Vice Chancellor's and CEO's votes have been obtained and tallied. The Chair will report back to the Governance Group as to the outcome of voting due to the additional votes either at the next meeting or in writing, whichever is the most expedient. If, following this process the vote is still deadlocked the matter will not be resolved and the Governance Group members will be asked to review the matter and seek to find an alternative path forward.

#### *Minutes*

The Governance Group must ensure that full and accurate minutes are kept of all proceedings at Governance Group meetings.

Minutes of proceedings of the Governance Group which have been signed correct by the Chair are prima facie evidence of the proceedings.

### Qualifications of Governance Group members

The following persons are disqualified from being appointed or holding office as a member of the Governance Group:

- a person who is under 18 years of age;
- a person who is an undischarged bankrupt;
- a person who is prohibited from being a director or promoter of or being concerned or taking part in the management of a company under section 382 or section 383 or section 385 of the Companies Act 1993;
- a person who is prohibited from being a director or promoter of, or being concerned or taking part in the management of, an incorporated or unincorporated body under the Securities Act 1978 or the Securities Markets Act 1988 or the Takeovers Act 1993 (or any successor legislation).

### Attendance of Non-Governance Group members

It is expected that the Challenge Director shall attend all Governance Group meetings and report such matters to the Governance Group required by the Governance Group to perform its role. In addition, a minute secretary (or equivalent) shall normally attend all meetings of the Governance Group to record the minutes. The Governance Group may however, seek to hold a session in committee in which neither the Director nor any other non-Governance Group members are present to discuss any matters it wishes.

The meetings of the Governance Group may include other attendees by invitation for all or part of any meeting by agreement between the Chair and Director to help facilitate the business of the Governance Group.

### Delegation of Governance Group Responsibilities

The Governance Group may choose to establish subcommittees of the Governance Group of not less than three members for specific purposes as it sees fit. In such cases any decisions of the subcommittee must be unanimous for them to be considered decisions of the Governance Group and should be reported back to the Governance Group at its next meeting.

The Governance Group may also choose to delegate specific responsibilities of a low risk nature to the Director to facilitate the efficient operation of the Challenge. These could include (but is not limited to) approval of investments and expenses below a set threshold. In all such cases the Director's decision will be considered the Governance Group's decision and must be reported to the next meeting of the Governance Group.

## APPENDIX 4 GOVERNANCE GROUP PROFILES

### Norah Barlow

Norah is an accountant by profession, qualifying at Victoria University. She worked in taxation in the IRD and at NZ Guardian Trust and subsequently formed her own practice. In 1999 Norah joined the fledgling retirement village developer and operator, Summerset, as the Group Accountant. In 2002 Norah was appointed to the CEO position and oversaw the significant growth of the company. Norah retired from her role as Managing Director and CEO in 2014, and remains on the Board. She continues to hold directorships in companies and voluntary groups.

Norah also holds advisory positions on the National Advisory Council for the Employment of Women, Allied Health, Science & Technical Workforces Taskforce Governance Group, and in 2015 was appointed to this role of chair of the Governance Group for the National Science Challenge: *Ageing Well*.

Norah is passionate about ensuring that New Zealand recognises the value that older people bring to society, and in particular older women. Older women are often under recognised for a lifetime's achievement in supporting a family, as well as any contribution they have made directly to the workforce.

Norah, and Summerset, have been recognised in numerous awards:

- Norah received an ONZM in the Queen's Birthday Honours, 2014
- Summerset has been awarded the Best Retirement Village Operator in Australasia from 2011-2014
- Norah won the inaugural Women in Governance award, 2013
- Summerset won the Supporting Gold category of the Wellington awards, and Norah was named the Wellington Business person of the Year, 2013
- Norah was awarded the Best CEO in the retirement village sector globally, in a ceremony in London in November 2013

### Peter Stanes

Peter is currently an independent director of Methven Ltd (retiring 15 July 2015). He has many years of experience running international manufacturing and marketing companies, both as an executive and a director. In addition, he is a past Director of Rembrandt Suits Limited, ZESPRI Group Limited, Wellington Drive Technologies Limited, Aragorn Limited and High Society Limited. He was Managing Director of Trigon Industries Limited, overseeing several years of rapid international expansion. Peter was also Managing Director of Feltex NZ Limited, Executive Chairman of the renamed Feltrax International Limited and, through his Feltex/Feltrax involvement, was for a time a director of their then major shareholder, Equiticorp Holdings Limited. He also held senior roles at Alex Harvey Industries Limited. Other interests include: family, tennis, tutoring lower stream secondary school pupils, pilates, mineralogy, motorsport, wine, and generally maintaining an active, constructive and stimulating existence.

### Catherine Fyfe

Catherine is an independent consultant based in Wellington and Arrowtown. She has extensive experience in both the corporate and non-for-profit sectors. Catherine has also been employed in the private sector until 2014, having had executive management roles as Human Resources Director for Summerset Group Holdings Ltd (2010-2014), Sovereign (1998-2002) and The National Bank of NZ (1989-1998). As a Senior Consultant for a Global Management Company Catherine provided advice to an extensive range of private and public sector organisations together with extensive work with the Order of St John. Other governance interests include service as a Council member for The Catholic Institute (national Catholic tertiary entity) and Trustee for the New Zealand Gynaecological Cancer Foundation.

### Professor Peter Crampton

Professor Peter Crampton is Pro-Vice-Chancellor of the Division of Health Sciences and Dean of the Otago School of Medicine at the University of Otago. Prior to taking up his current position he was Dean and Head of Campus at the University of Otago Wellington. Peter started his professional life as a GP at the Porirua Union and Community Health Service, and later specialised in public health medicine. His research is focused on social indicators and social epidemiology, health care policy, and health care organisation and funding.

Professor Crampton has served on numerous government advisory panels in a variety of policy areas related to public health, health services, and health workforce, and has taught undergraduate and postgraduate courses related to public health, health systems and health services management.

## APPENDIX 5 INTERIM SCIENCE LEADERSHIP TEAM PROFILES

### Professor David Baxter (Director for Commencement Phase)

Professor David Baxter TD is Dean of the School of Physiotherapy, and Deputy Pro-Vice-Chancellor for Health Sciences, at the University of Otago, New Zealand; he is also a Visiting Professor at the University of Ulster (UK), where he completed his undergraduate and doctoral training. David previously led the University of Otago's multidisciplinary Research Theme on *Rehabilitation and Disability* (2007–2011), and is currently Director for the New Zealand National Science Challenge research consortium for *Ageing Well*. David has extensive experience in academic leadership in the UK and New Zealand (including an MBA in Higher Education Management from the Institute of Education), and in developing high impact multidisciplinary research teams, including the University of Otago's Research Theme on *Rehabilitation and Disability* (2007-2011).

David's research expertise includes physical activity and health, physical rehabilitation, management of chronic pain as well as medical devices. His current projects include physical activity screening and interventions in various settings and populations and clinical trials on osteoarthritis and lymphodema. Professor Baxter has authored or co-authored over 200 peer-reviewed research papers in high-impact peer-reviewed journals, and contributed to various books. He is the Editor in Chief of *Physical Therapy Reviews*, and a member of the Editorial Boards of a number of other international peer-reviewed journals. He has presented multiple platform or poster presentations and educational workshops at national and international meetings. David has been recognised as a Fellow of the *Royal Academy of Medicine in Ireland*, and the *American Society for Lasers in Medicine and Surgery*; he is also an honorary life member of the *Acupuncture Association of Chartered Physiotherapists*.

### Professor Richard Bedford

Professor Richard Bedford QSO, FRSNZ is Emeritus Professor at the University of Waikato and Professor of Migration Studies at the Auckland University of Technology. He is a population geographer who specialises in migration research. Since the mid-1960s he has been researching processes of population movement and demographic change in the Asia-Pacific region. His major research interests are circular forms of population mobility within and between countries, immigration policy, and the relationships between population movement and social and economic transformation in rural and urban areas in New Zealand and the Pacific. Professor Bedford is currently working on implications for New Zealand and Australia of population developments and migration trends in the Asia-Pacific region over the next 30–40 years, including the impact of climate change on migration.

### Professor Fiona Alpass

Professor Fiona Alpass is a professor of psychology and co-founder of the Health and Ageing Research Team (HART) in the School of Psychology at Massey University. She co-leads the Health, Work and Retirement longitudinal study of ageing, a population-level study which aims to identify the health, economic, and social factors underpinning successful ageing in New Zealand's community dwelling population. She has been an advisor to the World Health Organisation on healthy ageing, and is a founding member of the Australian and New Zealand Ageing Research Consortium. Professor Alpass's particular research interests are how older New Zealanders reconcile work and care roles, and the health impacts of the transition from work to retirement.

### Professor Martin Connolly

Professor Martin Connolly has been Freemasons' Professor of Geriatric Medicine at the University of Auckland and Geriatrician at Waitemata District Health Board since March 2006. He is also Assistant Dean, Waitemata Campus, University of Auckland. He is currently a member of the New Zealand Executive of the Australia and New Zealand Society of Geriatric Medicine.

Professor Connolly originates from Manchester (UK) and qualified with Honours at the University of Newcastle-upon-Tyne in 1980. He obtained his MD from the University of Newcastle-upon-Tyne in 1990 on the subject of bronchial responsiveness in asthma. Before being appointed to his present position he was Senior Lecturer in Geriatric Medicine at the University of Manchester from 1991 to 2006. He was a member of the Guidelines Group for the UK National Institutes of Clinical Excellence COPD Guidelines and sat on and chaired numerous British Geriatrics Society and British Thoracic Society Committees over 15 years.

Professor Connolly's research interests are around chronic obstructive pulmonary disease in older people, long-term conditions management, the organisation of care (including residential aged care) for the very old, quality of life in the very old, and the frailty syndrome. He has authored or co-authored over 250 scientific papers.

### Professor Valery Feigin

Professor Valery Feigin, MD, MSc, PhD, FAAN is the Director and Professor of the National Institute for Stroke and Applied Neurosciences, Faculty of Health and Environmental Sciences at the AUT University of Auckland, and Affiliate Professor of the Department of Global Health at the Institute for Health Metrics and Evaluation (IHME) at the University of Washington. He is also Honorary Professor of the Novosibirsk State Medical University, Russia. He graduated in medicine from the Novosibirsk Medical University, Russia, and undertook advanced training in neurology and clinical epidemiology at the Mayo Clinic, Rochester, MN, USA and Erasmus University, Rotterdam, The Netherlands.

In his role as affiliate faculty, Dr Feigin is a member of the IHME CORE Analytic Team. As Chairman of the Neurology Section of the GBD 2013 study, and also Chairman of the Stroke and TBI Expert Panels, he is coordinating activities of experts within the panels, including planning, preparation and writing papers for leading medical journals.

Professor Feigin's prime research interest is in the epidemiology, prevention and management of stroke and traumatic brain injury. He has published over 400 research articles (including 23 in *The Lancet* and *The Lancet Neurology*), 12 handbooks and 15 book chapters (as of October 2014, his publications were cited over 12,500 times; h-index 39). Professor Feigin is Editor-in-Chief of the journal *Neuroepidemiology* and a member of the Editorial Boards of 10 international medical journals. He is also a Director on the Board of Directors of the World Stroke Organisation and a member of the Advisory Working Group on Stroke for the WHO ICD-11 version.

He and his team at AUT University recently developed a unique Stroke Riskometer™ App endorsed by the World Stroke Organisation (Lite version), World Federation of Neurology and International Association of Neurology and Epidemiology (Lite and Pro versions) to help to reduce the burden of stroke and other non-communicable disorders (NCD) worldwide. The international collaborative epidemiological studies of stroke and other major NCD based on this app are expected to be the largest in the world and are likely to significantly improve our knowledge on the prevalence and determinants of NCD across the world. In October 2014 he was awarded the World Stroke Organisation President's Award for outstanding contribution to stroke research.

### Professor Ngaire Kerse

Professor Kerse is a GP in Auckland, and Professor of General Practice and Primary Health Care and Head of the School of Population Health, University of Auckland. She has built a programme of research throughout New Zealand over the last two decades, after training in primary care in New Zealand, Australia, and the USA, completing a Geriatric Medicine Fellowship at the University of Pennsylvania, and a PhD at the University of Melbourne.

Professor Kerse's research areas include promoting activity and function in residential care, residential care organisational culture and outcomes, promoting physical activity in community dwelling older people, activity for depression in the very old, staying upright (preventing falls and injury) in older people in all settings, improving prescribing in primary care, and a large cohort of Māori and non-Māori in advanced age.

Professor Kerse is a member of expert advisory and steering groups for the Health and Quality Safety Commission on preventing harm from falls, the Ministry of Health on comprehensive assessment techniques and roll out of the InterRAI, and the Integrated Performance and Incentives Framework development. She is active in the Brain Research New Zealand CoRE in the University of Auckland and works as a GP at the Auckland City Mission.

### Dr Tahu Kukutai

Dr Tahu Kukutai (Waikato-Maniapoto, Te Aupōuri) is Senior Research Fellow at the National Institute of Demographic and Economic Analysis at the University of Waikato. She has degrees in history and demography from the University of Waikato and a PhD in sociology from Stanford University. She is a 2014 World Social Science Fellow and former Fulbright recipient.

Dr Kukutai specialises in Māori and Indigenous demographic research and has written extensively on issues of Māori population change, identity, and inequality. She has worked on a wide range of demographic projects for

hapū, iwi and Māori communities and has ongoing collaborations with researchers at the Centre for Sami Research, Umeå University (Sweden) and the Centre for Aboriginal Economic Policy Research at the Australian National University.

Dr Kukutai currently leads a major project on ethnic classification in Censuses worldwide, and is part of a research team, funded by the Swedish Research Council, that is investigating the impacts of colonisation on Indigenous population health in Sweden, Australia and New Zealand. She is Vice President of the Population Association of New Zealand and serves on numerous advisory groups.

### Associate Professor John Reynolds

John Reynolds is an Associate Professor in Neuroscience in the Department of Anatomy at University of Otago in New Zealand. His research team studies the application of neuroplasticity approaches to the treatment of Parkinson's disease and stroke. Assoc. Professor Reynolds graduated in Medicine in 1994, practiced medicine in Northland and then completed a PhD in Neuroscience at the University of Otago. He has received an international Brain Research Young Investigator Award and a National Tertiary Teaching Award, and he currently holds a Rutherford Discovery Fellowship from the Royal Society of New Zealand. He chairs the Scientific Advisory Committee of the Neurological Foundation of New Zealand and is on the Directorate of the Brain Research New Zealand – Rangahau Roro Aotearoa Centre of Research Excellence.

### Kay Saville-Smith

Kay Saville-Smith is a sociologist whose research focuses on the interface between households, communities, and the industries that service them and government. Prior to establishing the Centre for Research, Evaluation and Social Assessment, Kay was an academic, a policy manager, and a ministerial adviser.

She has extensive experience in quantitative and qualitative research design, evaluation, and policy analysis. Her research ranges over social and community development, housing markets, service/programme delivery, older people, disability, health, neighbourhoods, the built environment household resource use and sustainability. She specialises in research designed to work across sectors, closely engaging with end-users and developing evidence-based tools to enable change. Kay serves on the HMInfo Specialist Research Review Panel, University of Sydney, which supports better pathways to home modifications and enabling environments.

Over the last decade she has led a wide range of public good science programmes related to ageing: Finding the Best Fit: Housing Downsizing and Older People in a Changing Society; Community Resilience and Good Ageing: Doing Better in Bad Times; Ageing in Place: Empowering Older People to Repair & Maintain Safe and Comfortable Houses in Their Communities. She has also served on a variety of ministerial and other advisory groups related to housing, fuel poverty and warm homes, and planning.

### Associate Professor Debra Waters

Associate Professor Debra Waters is an Associate Professor in the Department of Preventive and Social Medicine, Dunedin School of Medicine, University of Otago. She also holds a research appointment at the University of New Mexico Health Sciences Center in the US, and collaborates with the Institute on Ageing at the University of Toulouse, France. She has been conducting gerontology research since 1996 with a focus on sarcopenia, frailty, and falls. She is the South Island Executive Representative for the New Zealand Association of Gerontology and a member of the Southern Wide Multi-Sector Falls Governance Group, the South Island Fall and Fracture Liaison Service, the US National Council on Ageing Falls Prevention Coalition, and the Otago Partners for Elder Needs (OPEN)—a multi-sectorial group based in Dunedin. She also chairs the University of Otago Collaboration of Ageing Research Excellence (CARE)—a broad network of researchers engaged in gerontology research.

## APPENDIX 6 INTERNATIONAL SCIENCE ADVISORY PANEL TERMS OF REFERENCE

### Background

The New Zealand Government has established National Science Challenges to focus its investment in science on nationally significant issues. This model of mission-led research funding represents a major change in the funding model for New Zealand, requiring the development of coordinated nation-wide research partnerships, working collaboratively to achieve their mission.

The Vision of *Ageing Well - Kia eke kairangi ki te taikaumātuatanga* is: *add years to life for older New Zealanders.*

We aim to accomplish this through our Mission: *push back disability thresholds to enable all New Zealanders to reach their full potential through the life course with particular reference to the latter years of life.*

The Mission will be achieved through delivery of a programme of research, underpinned by:

- Creating an environment that encourages collaboration between researchers who specialise in Ageing research, so as to develop the innovative strategies needed for realising the potential of the longevity dividend (five interlinking strands of research);
- Engaging continuously with consumers and stakeholders from the health and disability, voluntary and community services sectors who are at the front line of support for New Zealand's older people in an increasingly diverse and complex Ageing society (the emphasis on co-production of research and an integrated knowledge transfer model);
- Infusing the research programme with the principles of *Vision Mātauranga* which seek to transform the burden of poor ageing that falls disproportionately on Māori, and give expression to the long and rich tradition of Māori valuing and using older people's knowledge and wisdom.

The *Ageing Well* Challenge is being undertaken by a national research collaboration involving nine institutions: AgResearch; CRESA; Auckland Institute of Technology; Massey University; University of Canterbury; University of Auckland; University of Otago; Victoria University of Wellington; and University of Waikato. The University of Otago is the contract holder with Government and hosts the head office.

The Challenge operates as a 'virtual centre of excellence' with researchers drawn from across New Zealand. The *Ageing Well* Governance Group provides oversight of the governance of the Challenge, its Science Leadership Team and the subset of the Leadership Group the Management Directorate, which has a day-to-day management function. The Challenge Director chairs the Science Leadership Team and reports to the Chair of the Governance Group.

A Science Advisory Panel (SAP) of high international standing has been established to provide advice to the Challenge on matters relating to the quality of scientific research.

This document outlines the roles and expectations of SAP Members.

### Membership

The *Ageing Well* SAP will be comprised of up to eight eminent international science researchers, serving in an individual capacity. Appointments will be for a term of 5 years, renewable by mutual agreement. Any Member may tender their resignation at any time.

Appointment to the *Ageing Well* SAP will be made by invitation from the Governance Group on the recommendation of the Science Leadership Team. Members will be selected to cover the breadth of science relevant to *Ageing Well*.

### Roles and Functions

Members of the *Ageing Well* SAP are asked to:

- provide independent and robust advice to assist the Challenge to achieve its mission by delivering scientific research of the highest possible quality;
- promote the *Ageing Well* Challenge in appropriate international fora and facilitate relevant international research collaborations in a collegial way.

The primary point of contact between the SAP and *Ageing Well* will be via the Challenge Director (who may chair meetings of the SAP). If the *Ageing Well* Governance Group requires independent advice, the Chair of the Governance Group may also liaise directly with SAP Members to coordinate such advice.

Any advice given by the SAP either to the Director and Science Leadership Group or to the Governance Group will be transparent and available to both governance and management of *Ageing Well*.

Members of the SAP may provide advice on:

- Science strategies underpinning research plans developed for *Ageing Well*, including their international positioning or relevance;
- The quality of the science proposed in research plans or proposals developed for *Ageing Well*, including benchmarking against internationally comparable research;
- The quality of research performed with *Ageing Well*'s funds against the expectations that had been set and international standards of excellence;
- Opportunities for international collaboration that would advance *Ageing Well*'s ability to achieve its mission and enhance its international reputation and influence.
- Other matters that may be agreed from time to time of relevance to the quality assurance of science within *Ageing Well*.

### Processes

*Ageing Well* may be funded in three tranches: a commencement phase in which detailed research plans are developed, followed by two investment phases in which research is funded and monitored. The timeframes for these phases are:

Commencement Phase:	22 February – 21 August 2015
First funding period:	2015 to 2019
Second funding Period:	2019 to 2024

SAP Members may be involved in a range of processes over each of these phases, including:

- review and assessment of research proposals against structured criteria to inform the prioritisation of research and investment decisions;
- annual or biennial review of research that is underway to provide an independent critique of its progress;
- input to a major review of *Ageing Well* that may be conducted towards the end of the first funding period;
- site visits to review research, arranged to coincide with a *Ageing Well* Science Colloquium to which SAP Members may be asked to contribute.

There may also be times when SAP Members are asked to provide input or advice to some aspect of the *Ageing Well* science processes on an ad hoc basis. However, these will be kept to a minimum.

SAP Members may decline any request for advice or assistance if they are not able to assist on that occasion.

### Expenses

SAP Members will provide their advice to *Ageing Well* on a pro bono basis. If Members are asked to travel on *Ageing Well* business, the Challenge may arrange or pay for actual travel and accommodation expenses that have been approved in advance by the Director but not for SAP Members' time. Preference will be given to *Ageing Well* making such arrangements but reimbursement of costs may be made on presentation of original receipts.

### Conflict of interest

SAP Members will provide honest, impartial and expert advice at all times. While not a decision making group, advice from SAP Members will be influential and Members will communicate any potential or actual conflicts of interest when giving advice.

## APPENDIX 7 INTERNATIONAL SCIENCE ADVISORY PANEL PROFILES

This panel provides an independent perspective on research plans and strategies, reviews the quality and potential impact of research, as well as translational activities. It will ensure that the science is innovative, meets international best practice, and may provide advice on new or evolving research opportunities. The panel also brings connections with international research programmes and networks.

### Dr Ger Craddock

Dr Ger Craddock has a postgraduate diploma in Social and Vocational Rehabilitation Studies from University College Dublin (UCD), followed by an engineering PhD investigating the impact of Assistive Technology on Students with Disabilities. He has been Chief Officer of the Centre for Excellence in Universal Design since April 2007. He is also a visiting lecturer in the UCD Education and Engineering Departments and the Dublin Institute of Technology (DIT) Kevin Street Engineering Department.

Dr Craddock previously worked in the Central Remedial Clinic and led the Client Technical Services Department for 14 years. He is Past-President of the Association for the Advancement of Assistive Technology in Europe (AAATE) and currently sits on their Board. He is also chair of the 24 Hour Universal Design Challenge.

Dr Craddock has led several EU projects:

- Keeping Pace with Technology (KPT)
- Education for Employment (E4)
- Inclusive Learning through Technology (ILT)
- Reuse Technology (RT) Centre

### Professor Leon Flicker

Leon Flicker became the inaugural Professor of Geriatric Medicine at the University of Western Australia in 1998. He completed clinical and research training in Sydney, Newcastle and Melbourne. In 2006, he co-founded the Western Australian Centre for Health and Ageing. Leon has led the reorganisation of undergraduate and postgraduate education in geriatric medicine in Western Australia. He remains a practising geriatrician and is Head of Inner City Geriatric Services based at Royal Perth Hospital.

### Professor Jacobijn Gussekloo

Professor Gussekloo originally trained as a GP and undertook her medical training at Leiden University Medical Centre (LUMC), Netherlands, where she is now Professor of Primary Care (appointed 2005). She is also head of the Research Section of the Department of Public Health and Primary Care of LUMC. In Dec 2011 Professor Gussekloo was appointed chair of the Association Council of Dutch College of General Practitioners. Her research interests include gaps in evidence for clinical practice in handling unhealthy ageing in primary care.

### Professor Thang Leng Leng

Professor Leng works in the Department of Japanese Studies, National University of Singapore. She is also Deputy Director of the Faculty's Centre for Family and Population Research, and Fellow (honorary) of the College of Alice and Peter Tan, University Tan, and an Associate of Asia Research Institute.

In addition to teaching Professor Leng's research interests include: Japan-Singapore socio-cultural issues, intergenerational relations and programming, ageing, family, retirement, gender with a focus on Japan and Singapore, as well as Asia in general. Her research on ageing covers a wide spectrum including active ageing, volunteering among seniors, resilience among living-alone seniors, lifelong learning, grandparent-grandchildren relationships, later-life migration, environmental gerontology and ageing-in-place.

Professor Leng serves as a board member for groups including:

- President of Fei Yue Family Service Management Board
- Management Board of Fei Yue Community Services and Centre for Seniors
- Families for Life Council (Ministry of Social and Family Development)

### Professor Suzanne McDonough

Suzanne is Professor of Health and Rehabilitation at the University of Ulster, Northern Ireland, and a co-investigator in the United Kingdom Clinical Research Collaboration (UKCRC) Centre of Excellence for Public Health (Northern Ireland). She trained as a physiotherapist and has a PhD in neurophysiology from University of Newcastle. She completed a higher diploma in healthcare (Acupuncture) in 2002 from University College Dublin, Ireland. Professor McDonough leads the Centre for Health and Rehabilitation Technologies (CHaRT), Institute of Nursing and Health Research, at the University of Ulster. She was William Evans Fellow at the University of Otago School of Physiotherapy in November and December 2014.

Her research interests include public health approaches to musculoskeletal conditions, electrotherapy/acupuncture and developing technologies used for musculoskeletal and neurological rehabilitation. Professor McDonough has published widely in her areas of expertise (over 80 full papers) and obtained funding from a variety of prestigious external agencies. She completed a Northern Ireland survey of complementary and alternative medicine use, and several clinical trials and systematic reviews in the area of acupuncture and laser acupuncture. Suzanne has been involved in a number of Cochrane reviews, a current review is on the use of herbal medicinal products / preparations for neuropathic pain. Professor McDonough teaches clinical research techniques at undergraduate and postgraduate level and has supervised 24 PhD students to completion. She has published several book chapters on acupuncture and, more recently, laser acupuncture.

### Professor Christine Milligan

Professor Christine Milligan is Director of the Lancaster University Centre for Ageing Research. She is Associate Dean for Postgraduate Studies with responsibility for the strategic development and oversight of the postgraduate taught and research programmes. She co-chairs the Faculty's Teaching Committee and sits on the University's Academic Standards and Quality Committee, the Dean of Graduate School's Advisory Group, and the University Fees and Target Setting Committee.

Professor Milligan's main area of expertise is on health and geographical perspectives on ageing. She has three areas of current research interest:

- Projects that focus around the needs and wellbeing of different groups of family care-givers caring for older and dying people and the importance of home in the care-giving experience
- The role of gendered activity interventions for older men
- Technology innovation to support independence and self-reliance amongst older people

Her current work involves the development of new technologies to support wound care for older people, and those with dementia, in the home. This work is being undertaken in collaboration with the Universities of Leeds and Liverpool and includes practice-based and industrial partners.

### Professor Peter Schofield

From 2004 Professor Schofield has been Executive Director and Chief Executive Officer at Neuroscience Research Australia. He graduated with a BScAgr(Hons) from the University of Sydney, with the University Medal, and was awarded a PhD in genetics from The Australian National University in 1985. He undertook postdoctoral positions in biotechnology in the US and the University of Heidelberg, Centre for Molecular Biology. He was appointed a National Health and Medical Research Council (NHMRC) Senior Research Fellow at the Garvan Institute in 1993, becoming head of the Neurobiology Research Program in 1999. From 1998-2004 he was Founder and Managing Director of PsyGene Pty Ltd. From 2000 he has been Professor, Faculty of Medicine, University of New South Wales. He is also currently Chief Investigator, Genetic Repositories Australia.

His research interests focus on identifying genes that lead to mental illness and to dementia. He has achieved significant recognition for his research:

- 1982 The University Medal, Faculty of Agriculture, University of Sydney
- 1990 A.W. Campbell Award, Australian Neuroscience Society
- 1991 Elsie Waltham Thompson Award, National Heart Foundation
- 1995 Boehringer-Mannheim Medal, Australian Society for Biochemistry and Molecular Biology Inc.
- 1997 Gottschalk Medal, Australian Academy of Science
- 2006 Research Australia Medical Media Award

## APPENDIX 8 KĀHUI MĀORI TERMS OF REFERENCE

### Background

A key element of the National Science Challenges is the expectation they will give effect to the government's *Vision Mātauranga* (VM) policy:

The VM policy aims to unlock the science and innovation potential of Māori knowledge, resources and people for the benefit of New Zealand. It focus on four themes:

- (a) Indigenous Innovation – contributing to economic growth through distinctive science and innovation.
- (b) Taiao/Environment – achieving environmental sustainability through iwi and hapū relationships with land and sea.
- (c) Hauora/health – improving health and social wellbeing.
- (d) Mātauranga – exploring indigenous knowledge and science and innovation.

It is expected that researchers/research organisations, end users and /or stakeholders will play a vital role in the delivery of the Challenge at all levels. In giving effect to the VM policy, demonstrate how the proposed research responds to distinctive issues and needs of Māori and Māori communities and identify how Māori, both individually and collectively, can participate in research initiatives to achieve the outcomes sought.

It is important to assess VM-related research opportunities and methodologies in the early stages of research planning for the Challenge. This will require strong leadership of VM initiatives to ensure that VM is integrated within a Challenge collaboration, and not in an isolated manner. Explain how you will integrate Māori knowledge and perspectives into the Challenge and identify research with potential to deliver VM outcomes. These VM outcomes may include, depending on the Challenge:

- distinctive products, services, or systems derived from Māori knowledge
- new knowledge to support kaitiakitanga
- approaches and solutions to Māori health and social well being
- enhanced capability of Māori businesses to increase productivity.

In developing the initial research plans for the three Health and Wellbeing related National Science Challenges the Collaborating Parties (13 in total working through an Establishment Oversight Group (EOG) agreed to the following principles relevant to the VM aspects of the Challenge and to how we intend to engage and consult with Māori:

Support Vision Mātauranga Policy objectives for the benefit of New Zealand through a commitment to:

- Māori and non- Māori inclusion at the governance level, consistent with Te Tiriti o Waitangi.
- Employing Māori worldviews, tikanga, knowledge and language where relevant and practicable.
- Meaningful involvement of Māori in decision making in the planning, implementation, evaluation and dissemination of the Challenge research.
- Building long-term positive relationships and consulting as appropriate with Māori stakeholders.
- Include Māori research methodologies and protect and enhance Māori knowledge of healthy wellbeing.
- Undertaking future-focused interdisciplinary research that will inform equitable transformation of health, education, and well-being for Māori and all New Zealanders.
- Helping to build Māori research capacity, capability and research leadership.

During the development of the initial research plans, some of the Māori researchers involved formed a Kāhui to consider options to support the three related Challenges, give effect to *Vision Mātauranga* and to capture synergies between research areas and communities of interest involving Māori; this is additional to researcher and stakeholder support provided within each Challenge and through a *Tira Rangahau Haora* collective of Māori researchers across the Challenges. Following the MBIE decisions to fund commencement or Commencement phases for each Challenge, the EOG providing interim governance oversight for these related Challenges have agreed to support an *Interim* Kāhui to facilitate the next stages of each Challenge by undertaking dialogue with MBIE and the Science Teams, in the spirit of good-will and to ensure that the Challenges are optimally positioned in relation to *Vision Mātauranga* and engagement with Māori communities and agencies during the Establishment or Commencement Phases.

This document sets out a proposed Terms of Reference for the establishment, roles and functioning of the Interim Kāhui in support of the Health and Wellbeing National Science Challenges.

## Kāhui Membership

### The Interim Kāhui

The EOG approved the membership of the Interim Kāhui to be comprised of the following volunteers as members noting that they have expertise relevant to the three Challenges and that they are all independent of any direct involvement in the research of the Challenges:

- Helen Moewaka Barnes (Chair)
- Moe Milne
- Garrick Cooper
- Richard Faull

Interim Kāhui members must not be playing any other active role in the Challenge such as direct research or governance or management roles or as paid consultants (or similar) in delivery of Challenge services or activities. Members will also be under a duty to act independently of any grouping and not represent the interests of any particular groups but to support achievement of the objectives of the Challenges and the *Vision Mātauranga* Policy. The Interim Kāhui may co-opt further members in agreement with the EOG.

The Interim Kāhui will remain in place until such time as it is replaced by a permanent Kāhui as outlined below or if the three H&W Challenges are not funded beyond their establishment or commencement phases by MBIE.

### Transition to Kāhui Tuturu

The Interim Kāhui will work with the Chairs, Directors and Science Leadership Teams of the three H&W Challenges to propose the membership of any subsequent Kāhui (Kāhui Tuturu) that will be active beyond their establishment or commencement phases (this should be completed within 3 months). This permanent Kāhui should be comprised of up to five members with knowledge of both the research sector and strong working relationships with the relevant Māori communities and agencies likely to be involved with the Challenges.

The Directors shall consult with the Interim Kāhui on the Terms of Reference for the permanent Kāhui and recommend them to the three Governance Group Chairs for approval. The Chairs will consult with their full Governance Groups and may seek changes prior to approval. It is likely that the future Terms of Reference will be based on the principles agreed by the Challenge Parties and these Terms of Reference. The membership of the permanent Kāhui will be approved by the Chairs of the three H&W Challenges after consultation with their Boards and Challenge Members and formally appointed by the Challenge Hosts. The Members of the Kāhui will meet with the Challenge Board Chairs to agree the Chair of the Kāhui.

The Chairs may take advice from the Challenge Directors in making their decisions on all these matters.

### Roles and Functions of the Interim Kāhui

The EOG and Interim Kāhui have agreed that the roles of the Interim Kāhui during the establishment or commencement phases of the Challenges shall be strategic, facilitatory and consultative. These roles are further defined here to ensure clarity of expectations. They are not intended to replace the responsibilities of the Challenge Governance Groups or Management but to support and work alongside them.

#### a. Strategic advisory functions

The Interim Kāhui shall have the opportunity to review and provide feedback or advice on draft Research and Business plans for each Challenge prior to submission to the relevant Board, therefore prior to submission to MBIE and in sufficient time to allow the advice to be considered and incorporated into the final plans where appropriate. The advice or feedback shall be focused on the aspects of the Challenge that give effect to *Vision Mātauranga*, engagement with Māori communities and agencies and equitable transformation of health, education, and well-being for Māori and all New Zealanders. The advice shall be given to both the Directors (and Science Leadership Teams) and the Establishment Oversight Subgroups. While the advice is not binding it shall be considered in good faith according to the principles and commitments set out by the Collaborating Parties in their 2014 Heads of Agreement (and to be embodied in the NSCIC and Collaboration Agreement).

The Interim Kāhui shall have the opportunity to advise on Māori membership of the proposed permanent Governance Group, the permanent Science Leadership Team, the Science Advisory Panel and any other named appointments (as appropriate) within the Research or Business Plans in relation to ensuring their capability to enact VM policy and assure effective Māori engagement and consultation.

The Interim Kāhui may be asked to provide input on other matters from time to time by mutual agreement with the Directors and or Governance Group Chairs.

#### b. Facilitatory functions

The Interim Kāhui may act as a facilitator between the Challenges and any groups representing Māori interests relevant to the Challenge by mutual agreement with the Directors or Chairs where they are able to add value as an independent group with skills in Māori engagement and facilitation.

The Interim Kāhui may assist with discussions between the Challenges and MBIE over the approach to *Vision Mātauranga* and Māori engagement or consultation by mutual agreement with the Directors or Chairs.

#### c. Consultative functions

The Kāhui may assist with developing and reviewing processes for engaging with specific Māori stakeholders, communities, groups, entities or agencies in relation to the development, execution and potential uptake of any research.

#### d. Other roles

The Interim Kāhui may take on other roles from time to time by specific agreement with the Directors or Chairs

### Suggested Operation and Resourcing of the Kāhui

#### a. Meetings

The Interim Kāhui should meet as a group to develop any feedback or advice to the Challenges on their draft Research and Business Plans and provide feedback on nominations of relevant Challenge appointments (if this cannot be achieved face to face then by tele- or video conference).

At the first meeting the Interim Kāhui should establish a work plan to meet its other roles during the establishment or commencement phases of the Challenges, informed by prior discussion with the Directors of each Challenge. The resulting work plan should be provided to the Directors to arrive at a mutual agreement, to ensure it is workable for all parties.

#### b. Resourcing

a. As volunteers, the Interim Kāhui members' time is unpaid (as is the case with Science Advisory Panel members for comparison). However, the costs of travel and accommodation for attending approved meetings or activities on the agreed work plan shall be met by the Challenges in a mechanism to be determined by the Directors.

## APPENDIX 9 STAKEHOLDER ORGANISATIONS

A myriad of organisations have been linked to the *Ageing Well* Challenge in either the development of the *Ageing Well* Challenge proposal, in the development of this Research Plan or through specific projects that the *Ageing Well* Challenge is funding in its first tranche. These stretch across:

- The organisations that older people themselves establish to promote their own and others well-being: Age Concern, Grey Power, Grandparents Raising Grandchildren Trust NZ, MENZSheds, U3A.
- The health sector funders, providers and consumer organisations:
  - District Health Boards – who have responsibilities for the funding and provision of health services to older people and who are stakeholders in pushing back the disability threshold (see inset of DHBs).
  - Consumer and charitable trusts - Alzheimer's Charitable Trust, Alzheimer's NZ, Arthritis NZ, Neurological Foundation, Heart Foundation of NZ, Osteoporosis NZ, Parkinson's NZ, NZ Stroke Foundation.
  - Primary health care providers such as Auckland PHO Alliance Health Plus, Pacific Perspectives, Pegasus Health, Physio Studio (Aged Care).
  - Professional and industry associations such as General Practice NZ, Occupational Therapy NZ, Medical Industry Association of New Zealand, NZ Health ITB.
- Local and central government agencies including:
  - Councils – Auckland Council, Dunedin City Council, Marlborough District Council, Nelson City Council, Tasman District Council, Kawerau District Council, Wellington City Council.
  - Government departments and ministries – Business, Innovation and Employment, Health, Pacific Island Affairs, Social Development.
  - Offices, authorities and commissions including the Community Housing Regulatory Authority, Office for Senior Citizens, Commission for Financial Capability, and the Productivity Commission.
- Community, housing and service sectors including non-profit and profit organisations as well as industry associations including: Community Housing Aotearoa, Council for Christian Social Services, Elder Law, Lifemark, Retirement Villages Association, NZPIA, Rural Women NZ, Salvation Army.
- Māori organisations including: Iwi Chairs Forum, Māori Women's Welfare League, Rauawaawa Kaumatua Charitable Trust
- Organisations supporting cultural groups and new settlers.



In addition, seventeen research organisations and research associations have been active stakeholders in the development of the Challenge as a whole or its components: AgResearch, Auckland University of Technology, Brain Health CoRE, Callaghan Innovation, Centre for Research, Evaluation and Social Assessment (CRESA), Health Research Council of New Zealand, Lincoln University, Massey University, Malaghan Institute of Medical Research, Performance Lab, Public Policy & Research (PP&R), Research and Strategy Consulting, SuPERU, NZ Association of Gerontology, University of Auckland, University of Canterbury, University of Otago, University of Waikato, Victoria University of Wellington.

## APPENDIX 10 IP MANAGEMENT

- i. This plan is subject to any relevant provisions of the NSC Investment Contract
- ii. Project IP will be owned by the Party or Parties that creates it (and according to any internal policies for its assignment), who will be responsible for decisions concerning protection, management and commercialisation of the Intellectual Property that arises.
- iii. Where Project IP is created by more than one of the Parties, the Parties who created it shall agree which of them shall be the Managing Party. The Managing Party will be responsible for decisions concerning protection, management and commercialisation of the Project IP. Generally, for the purposes of guidance, the Managing Party will be the Party which is best placed to create value from the Project IP and/or with any other parties involved in the project consistent with the mission and objectives. Benefits will be shared between the creating Parties (after costs of commercialisation have been deducted) in shares reflecting the relative input to the Project IP, including Background IP and know how provided, inventorship and costs of commercialisation and after recognising the relative risks of the different Parties (this may include the additional financial risks of the Managing Party).
- iv. Parties will report all Project IP to the Director, who will keep a register of reported Intellectual Property to support reporting to the Ministry.
- v. It is acknowledged that where Project IP is developed in collaboration with co-funders / industry partners the regime set out in clauses 1.1 and 1.2 may not apply and it is expected that the Parties involved will enter into appropriate agreements with the co-funders / industry partners to:
  - a. ensure Project IP is developed in a manner that will advance the purposes of the Challenge; and
  - b. agree commercialisation and revenue sharing arrangements.
- vi. Subject to confidentiality provisions defined in the Collaboration Agreement, Project IP will be licensed non-exclusively and royalty free to all Parties for the purposes of Research and/or Related Activities as well as educational activities.
- vii. The underlying purpose of the Challenge is to create benefit for New Zealand. Each Party will give consideration to the Intellectual Property Policies and Principles set out in the Collaboration Agreement when making decisions about the management of any Project IP.
- viii. Progress on commercialisation or translation or implementation plans shall be reported annually to the Director, Science Leadership Team, and the Governance Group for the purposes of reporting outcomes to the Ministry. Such reporting shall be subject to ensuring protection of commercially sensitive or confidential information.
- ix. Post contract reporting to the Ministry by the Challenge Contractor may be required to allow the Ministry to review or evaluate the delivery of the outcomes of the Challenge. The Parties shall maintain, and provide to the Challenge Contractor on reasonable notice, sufficient information and reports to allow the Ministry to review the delivery of outcomes by the Challenge for a period of at least 7 years after the end of the Challenge, or such other period specified in any Subcontracts or the NSC Investment Contract.
- x. Unless agreed otherwise, for the avoidance of doubt, each Party retains ownership of its Background IP. Parties will grant a non-exclusive, royalty-free, non-transferable license of relevant Background IP to each other, to the extent that they are able, unless there are reasonable grounds not to grant such a license. Such license shall be solely for the purposes of the Research and/or Related Activities. Any commercial use of Background IP shall require the grant of a separate license which shall be negotiated between the interested Parties.
- xi. References in this plan to the Collaboration Agreement are to the Collaboration Agreement to be entered into between the *Ageing Well* Challenge members. Definitions used in this plan will have the same meaning as in the Collaboration Agreement.

## APPENDIX 11 COMMUNICATIONS PLAN

### Introduction

The objective of the *Ageing Well Kia eke kairangi ki te taikaumatatanga* National Science Challenge is to harness science to sustain health and well-being into the later years of life. In line with the objective is the Challenge's Vision, *add life to years for all older New Zealanders*, and the Mission, *to push back disability thresholds to enable all New Zealanders to reach their full potential through the life course with particular reference to the latter years of life*.

It is critical that there are robust mechanisms for two-way communications between *Ageing Well* and stakeholders, or Knowledge Exchange Partners if the objective, vision and mission are to be achieved and the research programme is to be effective in the long-term. Similarly, the Challenge requires genuine engagement and the ability to refine strategies as the Challenge develops in concert with Partners' needs, in order to:

- Increase the likelihood of outcomes achieving their aims when they are rolled out in the community; and
- Give end-users ownership in the programme's overall success.

This communications plan covers three phases:

- Commencement phase – up until September 2015; and
- September 2015 to February 2016;
- 2016-2019 – the details of the communications will develop as the Challenge builds momentum. However the principles in this Plan apply to the long term activities of the Challenge.

### Audiences

There are many stakeholders involved in *Ageing Well* and their specific communication needs vary, as do the objectives of our communications with them. We have identified a range of internal and external audiences in order to target our communications appropriately, based on similarities in their communication needs and our communication objectives (see Table 10 below).

We have separated Knowledge Exchange Partners into 'audiences', firstly based on whether they are internal or external to the Challenge and secondly, based on their level of engagement:

#### Internal Knowledge Exchange Partners

- Science Leadership Team
- Governance Group
- MBIE
- Research teams

#### External Knowledge Exchange Partners

- *Engaged Partners* i.e. those who are actively participating in the Challenge, including:
  - Health delivery professionals
  - Kāhui Māori
  - Government agencies
  - District Health Boards and Public Health Organisations
  - Non-government agencies
  - Māori health organisations
  - Pacific health organisations
- *Interested Partners* i.e. those who currently wish to be informed of Challenge activities and successes, rather than being more actively engaged (this may change at any time)
  - *Ageing Well* National Science Challenge partner organisations
  - Related research groups and researchers
  - International Science Advisory Panel
  - Other National Science Challenges and Centres of Research Excellence (CoREs)

- General Public

The general public is an important audience, particularly as the challenge progresses. A detailed communications plan will be developed for the general public beyond February 2016 (Phase 3).

### Communications objectives

Each audience requires different information, with regard to communications objectives, content, level of detail and frequency.

**Table 10 Communications objectives, by audience**

	Audience Group	Communications Objective	Communications Frequency
Internal	Science Leadership Team	To be kept abreast of Challenge progress against its research goals To be sufficiently informed to monitor and redirect Challenge research strategy	Meeting in person/via phone or video link 4 times annually including with Science Management Directorate
	Governance Group	To be kept abreast of Challenge progress against its goals, including financial To be sufficiently informed to monitor and redirect Challenge activities at the highest level	Meeting in person/via phone or video link 3-4 times annually
	MBIE	To be kept abreast of Challenge progress against its goals, including financial To receive required communications as detailed in the contract	As required. Full details of MBIE's reporting requirements are still to be confirmed
	<i>Ageing Well</i> research teams	To be kept abreast of all matters related to <i>Ageing Well</i> research, including overall direction, news, deadlines, etc.	Approximately two monthly
External	Engaged partners	Full engagement in the challenge, including progress and successes Open two-way dialogue Communicate a clear pathway to implementation	Approximately two monthly
	Interested partners	To be kept informed in a less regular, but timely, manner (this group self-selects to receive less frequent communications) To ensure access to relevant information relating to <i>Ageing Well</i> is readily accessible at any time	Annually
	General public	The Challenge concepts were first aired with the general public and it is essential that the Challenges remain in touch with public interests and provide the public with information as to Challenge successes	At least quarterly, but with increasing frequency as the Challenge develops

### Communications to date

Consistent with our emphasis on meaningful two-way dialogue *Ageing Well* has already undertaken significant consultation with key external stakeholders as shown in Table 11.

**Table 11 Communications undertaken to date**

Audience	Communications up till 29 May 2015		
Internal	Sector liaison group meetings	Wellington Auckland Dunedin	24 February 2014 25 February 2014 26 February 2014
	Kāhui Māori Hui (alongside the other two National Health Challenge teams)	Auckland	April 2014
	<i>Ageing Well</i> strategic workshop (facilitated by MBIE)	Wellington	24 September 2014
	<i>Ageing Well</i> Challenge launch	Dunedin	4 March 2015
	Stakeholders' meeting, scheduled alongside the annual Age Concern national meeting	Wellington	20 April 2015

	Researchers' Meeting	Wellington	26 May 2015
	Social media engagement underway for dissemination to researchers and stakeholders, including a Twitter account, interim web site; development of a Facebook page underway.		

Table 12 summarises the audiences, activities, channels and timings for the *Ageing Well* communications activity.

**Table 12 Communications plan, by audience**

Audience	Activity & Communication Channel	Timing
All Audiences	<i>Ageing Well</i> website (include ability for people to receive an alert when new information added to the site, including newsletters)	Interim web site running. Permanent web site constructed by August 2015
	<i>Ageing Well</i> annual science colloquium	First colloquium scheduled for 14 August 2015 in Wellington
	<i>Ageing Well</i> public newsletter – available as a pdf on website – includes progress and successes	Approximately two-monthly, from September 2015
	Media releases	Internal request for “story ideas” every two months, as potential media releases
	Other media articles	From February 2016 we will engage with health-specific media and encourage key researchers to connect with relevant health-specific journalists
	Social media communications	Twitter account (@ageingwellnz) and interim web site ( <a href="http://www.otago.ac.nz/ageing-well/index.html">http://www.otago.ac.nz/ageing-well/index.html</a> ) live; development of a Facebook page underway.  These will be of more significance as the Challenge increases the scale of its public communications. We will learn from the experience of other Challenges, particularly the health Challenges
	Communications with Māori and Pacific media and networks	We will actively build connections with Māori and Pacific media personnel
	Annual plan	End of July
Science Leadership Team	Quarterly reports	Quarterly
Governance Group	Quarterly reports	Quarterly
MBIE	Reports as contractually required	TBC
<i>Ageing Well</i> research teams	Email research-centric newsletter	Approximately two monthly (more/less regularly, if required)
	Direct involvement in annual science colloquium	Annually
	Individual researchers within <i>Ageing Well</i> research teams encouraged to present on the Challenge when presenting at conferences	As opportunities arise
	Email copies of media releases, as distributed to media	As released
	Receive electronic copy of annual plan	Annual
	Email update that specifically encourages feedback	Fortnightly

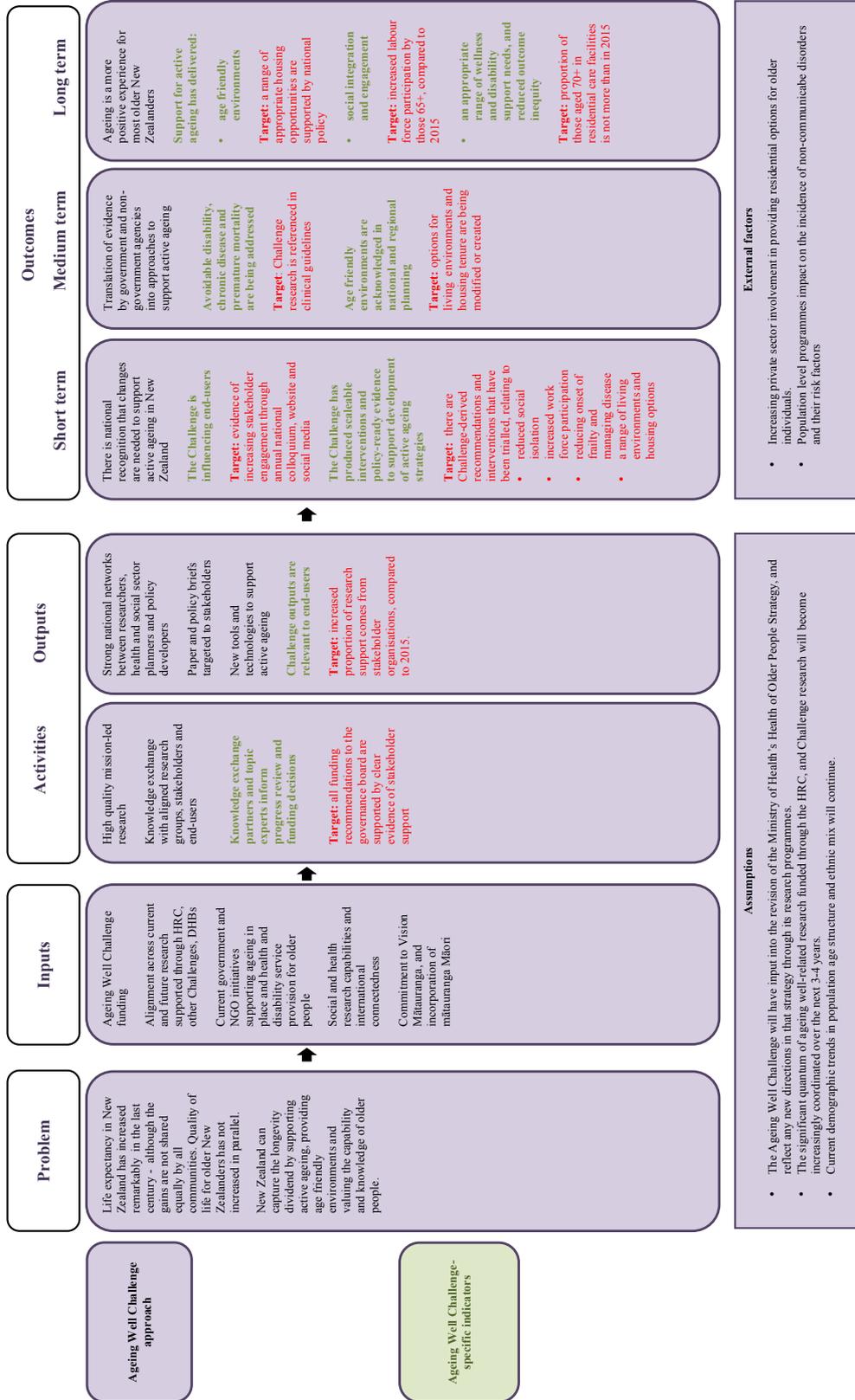
<b>Engaged partners</b>	<i>Ageing Well</i> public newsletter emailed directly with covering note that encourages feedback and engagement	Approximately two monthly
	Invite to annual science colloquium	Annually
	Email copies of media releases, as distributed to media	As released
	Electronic copy of annual plan	Annually
<b>Interested partners</b>	Email the <i>Ageing Well</i> public newsletter initially, with covering note offering opportunity to opt in/out at any time	Approximately two monthly – review
	Electronic copy of annual plan	Annually
<b>General Public</b>	Outreach events, such as national roadshows and talks to relevant community groups, as well as broader public interest groups.	
	Coordinating with other Challenges and CoREs in areas of mutual communications interest, particularly where joint initiatives will leverage greater activity and benefit to the public.	
	Identifying key high needs groups relevant to the priorities of the Challenge and building relationships with them, particularly Māori and Pacific communities.	
	Developing educational links with and communicating Challenge outcomes to schools and the community, e.g. via existing secondary school outreach activities facilitated by universities.	

*Budget:* Costs related to specific communications activities will be confirmed in September 2015 as the Challenge budget is confirmed. By that time measures of success will be determined which will be monitored. To that end, Google alert has been put in place to capture any mainstream media and on-line mention of the *Ageing Well* National Science Challenge.

*Review:* February 2016 – this communications plan will be reviewed and feedback sought on the channels, content and timeliness of communications as well as more detailed forward plans are being created. It will be reviewed annually thereafter for inclusion in the Challenge’s annual plan.

## APPENDIX 12 DRAFT CHALLENGE PERFORMANCE FRAMEWORK

This Performance Framework is a draft which will be revised and improved by the Science Leadership Team and Governance Group and agreed on formally by 31 December 2015.



## APPENDIX 13 CONFLICT OF INTEREST POLICY

The *Ageing Well* collaborators take the issue of conflict of interest very seriously. All involved in the Challenge including staff of the Collaboration Agreement Parties, Challenge Director, members of the Science Leadership Team, the Governance Group, and any members or appointees to advisory groups or panels must follow a rigorous process to maintain the credibility of the investment and other decisions and to assure all stakeholders that their proposals or other matters are given fair and reasonable consideration.

- The collaborative nature of the *Ageing Well* Science Challenge means that there is a high level of engagement among organisations and expert researchers. A pragmatic approach is necessary in order to make best use of the expertise of all involved in the Challenge. This may occur at all levels including the Governance Group, Director and Science Leadership Team and any others involved in making decisions including, but not limited to assessing proposals for project funding and any funding or investment decisions. Individuals may assist in the assessment of proposals and investment decisions where they have no direct interest and limited indirect interest in the proposal. In all cases, conflicts of interest or potential conflicts of interest will be recorded and decisions around the management of perceived conflicts of interest will be minuted.
- Conflicts of interest may occur in different ways, as outlined below.
- Direct Conflicts of Interest:
  - This occurs where a person in a position to influence the funding outcome is directly involved with the proposal (as a participant, manager, mentor, or partner) or has a close personal relationship with the applicants e.g. family or close friend. It also occurs when this person is a collaborator, or is in some way involved with the applicant's research programme.
  - In these cases, the person must declare the conflict of interest, take no part in the assessment of the proposal or decisions around funding, and leave the room while the discussion takes place at their own volition, at the request of the Chair or any other member of the committee, panel, or group undertaking that assessment.
- Indirect Conflicts of Interest:
  - This can occur where a person in a position to influence the funding outcome is employed by an organisation involved in the proposal but is not part of the applicant's research programme. An indirect conflict can also occur where a member of a panel considering the proposal has a personal and/or professional relationship with one of the applicants, e.g. an acquaintance.
  - For indirect conflicts, the person must declare the conflict of interest and, at the discretion of the Chair (or equivalent senior member of the Governance Group who is present who shall consult with other members of the committee, panel or group undertaking that assessment or decision who shall consult with other members of committee, panel or group who are present, either that the individual or individuals conflicted:
    - leave the room;
    - stay but remain silent unless asked to respond to a direct question; or
    - contribute to the assessment of the proposal or decision.
- Involvement in a competing proposal or business activity:
  - Such conflicts of interest occur where a person has an involvement (direct or indirect) with a proposal that is in direct competition with a proposal being considered by a panel or where the outcomes proposed by a proposal under discussion may compete with a person's personal business interests. In such cases, the panel member must declare the conflict of interest and, at the discretion of the Chair (or equivalent senior member of the Governance Group present) who shall consult with other members of the committee, panel or group undertaking that assessment or decision who are present, either that the individual or individuals conflicted:
    - leave the room;
    - stay but remain silent unless asked to respond to a direct question; or
    - contribute to the assessment of the proposal.
- Involvement in strategy development:
  - Members of the Governance Group and Science Leadership Team of the Challenge are likely to be involved in determining the strategic direction and priorities of the Challenge which may be perceived as affecting future participation of different collaborators. It is not the intention to exclude these collaborators from these processes and their input is expected to ensure the

perspective of all collaborators to the Challenge are included in strategy and priority setting. In these situations the conflicts of members representing collaborators should be noted. In addition:

- in the case of the Science Leadership Team, the Director shall monitor discussions and raise any concerns over the degree of representation occurring and ultimately moderate any perceived bias in developing recommendations to the Governance Group;
- in the case of the Governance Group, the Chair shall monitor discussions and raise any concerns over the degree of representation occurring. If the Chair believes the Governance Group is unable to moderate any representation bias, in the interests of the Challenge, he or she may take the matter under discussion into an ad hoc sub-committee of the Governance Group comprised of not less than three independent or uninterested members to make final decisions and such decisions will be the decisions of the full Governance Group.
- All conflicts of interest no matter how significant must be declared and recorded. If any individual feels they have a conflict with a proposal, or other decision that they have been asked to consider, they should contact either the Governance Group Chair or Director immediately to declare the conflict and seek advice on what action is required.
- When the Chair has any conflict of interest, a Deputy Chair must be appointed to take on the duties of chairing any meeting to consider any matter where this conflict of interest is relevant.
- When the Director or any other person has a direct conflict of interest, such as may occur when his or her own research is being considered for funding by the Challenge, the Director or other person shall be excluded and a process for independent assessment of any such proposals, broadly equivalent to how other proposals are assessed, shall be determined by the Governance Group who shall make any funding decisions on the same basis as for any other proposal.

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