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### National SCIENCE Challenges

#### AGEING WELL

Kia eke kairangi ki te taikaumātuatanga

# Celebrating Ageing Well

The first five years of the Ageing Well National Science Challenge





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#### **OUR COLLABORATING PARTIES**

**JNIVERSITY OF** 

CANTERBURY



Cover: Ms Pare Meha testing an element of Ageing Well's Well Balanced Exhibit at the 2019 Kaumātua Olympics in Hamilton.

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Our Journey Towards the Aspirations of Vision Mātuaranga Moving Beyond Competition: collaborations propelling us forward

Big Data Proves We Are Overmedicating Older New Zealanders

- Stopping the Stroke Tsunami Professor Valery Feigin

Te Whakahaumitanga – Dr Kirsten Gabel

Exploring the Needs of Pacific Families Affected by Age-Related Cognitive Impairment – Professor Pauline Norris

### **ABOUT US**

Ageing Well — Kia eke kairangi ki te taikaumātuatanga — is a across the nation tackling the most important ageing-related issues facing our generation.

We are working together — between disciplines, across institutions, and beyond the normal barriers of scientific competition — to combat the challenges of, and capitalise on the opportunities presented by, ageing in Aotearoa New Zealand.

wellbeing into the later years of life. Together, as one team and with one goal, we seek to ensure all New Zealanders age well.

Ageing Well is hosted by the University of Otago.



#### AGEING WELL





#### Kia eke kairangi ki te taikaumātuatanga

National **SCIENCE** Challenges



AGEING WELL

Kia eke kairangi ki te taikaumātuatanga

## **TIMELINE OF OUR ORGANISATION**

2017 Charging Abead

**2018** Future Strategy

**2014** Planning Phase



2016 Building Phase

#### **2014: Planning Phase**

- Investigated the need for investment into ageing-related research.
- Development of the initial investment plan and preliminary work by Collaborating Parties and management team in preparation for the launch of Ageing Well National Science Challenge.

#### 2015: Launch Phase

- University of Otago approved as Host of Ageing Well on behalf of the Collaborating Parties.
- MBIE funds awarded and Ageing Well is established.
- Ageing Well launched on March 4 to great fanfare, as one of three health-based National Science Challenges.

#### 2016: Building Phase

- Set up our Governance, Kāhui, Science Leadership teams, as well as our International Science Advisory Panel; established an office and organisational support.
- Initial research projects contracted and research commenced.

### 2017: Charging Ahead

- Contestable Round funds: allocated \$3.25M to innovative projects that emphasized co-creation, co-designed projects focusing on Māori and Pacific experiences.
- Ageing Well brought together people from different Co-governance model integrated the Kāhui and disciplines to get to know each other, explored Governance Group as one governing group. their expertise, and formed multi-disciplinary Embedded the Kāhui way of thinking into the collaborations. This approach added value to their governance of the organisation, forming a structure projects and to ageing research. that is inclusive and diverse. This approach was novel and significant at the time. Phase 2 commenced with two focus areas of

### 2018: Future Strategy

- Consultation on Ageing Well potential future research investment to be implemented in Phase 2. This involved robust strategic discussions on the direction of Ageing Well.
- Ageing Well's Future Strategy document signed off by MBIE.
- Phase 2 is a go!



# 2019 Focusing our Mahi

#### 2019: Focusing our Mahi

- We refined the purpose and mission into more focused areas of research, ones that highlighted IMPACT, and built on the collaborations and outcomes of the first phase.
- funding: Ageing and Māori, and Health and Wellbeing in Ageing, plus an additional strategic investment initiative for collaborations of mutual benefit that fulfills Ageing Well's mission.

## CHALLENGE **OBJECTIVE:**

To harness science to sustain health and wellbeing into the later years of life.

### CHALLENGE **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.

### **CHALLENGE** THEMES

**1.** Enabling independence and autonomy / tino rangatiratanga of older individuals and their whānau/families

**2.** Ensuring a meaningful life through social integration and engagement

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

#### 4. Reducing disability

**5.** Developing age-friendly environments



### **CHAIR'S WELCOME**

In 2014, then Science and Innovation Minister Steven Joyce launched the National Science Challenges. Eleven Challenges were established to tackle the most pressing science-based issues and opportunities facing Aotearoa New Zealand.

On 4 March 2015, Ageing Well officially opened with an objective to "sustain health and wellbeing into the later years in life." Our mandate, in other words, was to improve the lives of all older Kiwis.

To achieve our objective, Ageing Well funded 18 innovative projects that individually-and as a wholesought to address some of the most serious problems facing older New Zealanders.

Over the past five years, it has been exciting to see the depth and breadth of the research that we supported come to fruition. Together, our projects have all contributed to us achieving our mission, and many have evolved into work that continues in our current research phase, or has received funding from other bodies such as the Health Research Council.

This book tells the stories of our research. But more than that, it takes a look at the stakeholders who engaged with us, the community partners that worked with our researchers and the wider impact that our projects have had over the first years of our Challenge (2015-19). Although almost all projects are now complete, the impact, translation and difference-making that these projects are achieving is still ongoing.

The story of penicillin illustrates the time it can take for new scientific discoveries to be fully realised. Yet, even at this early stage, our research is beginning to show profitable results.

The knowledge, tools, therapies and more that we are developing are making an impact. Indeed, as you will read our research has already contributed to the creation of National Frailty Guidelines, the verification of a drug scale to monitor overmedication, a pioneering therapy that speeds up stroke rehabilitation, and so much more.



Dr Di McCarthy CNZM, CRSNZ Challenge Chair 2016 - 2020

I would like to thank everyone who has engaged with us so far. (Many people were instrumental in the development of, and work of, the Challenge and as a small token of our appreciation we acknowledge their amazing contributions in the With Thanks section).

We look forward to continuing the mission of Ageing Well together in our current phase, and hopefully beyond. Community engagement and partnerships have been at the very heart of the Challenge, and the community is who we are here to help and serve.

Dr Di McCarthy

### THE CHALLENGE IN A NUTSHELL

By 2036, the population aged 65+ is estimated to

# almost double

The number of Kiwis aged 85+ is expected to more than triple, from 88,000 in 2020 to over

## 266,000 in 2048

People are living longer, yet life expectancy has not been matched by an increase in healthy life expectancy

# **ENTER AGEING WELL:**

we do science differently. And here's how:

•Multi-disciplinary, mission-led research

- Two-way knowledge transfer
- Engagement with community stakeholders, and researchers
  - Innovative collaborations
- Co-create research with communities
  - Commitment to equity for all
  - Forward-thinking leadership

We investigate the key issues affecting older New Zealanders



We harness science to sustain health and wellbeing into the later years of life.

## **KEY RESEARCH THEMES**:

Value older people in all settings

Enhance age-friendly environments

AGEING WELL

**Reduce disability** & the impact of disability



Maintain wellness, independence & autonomy

Promote social integration & engagement

### **OUR JOURNEY TOWARDS THE ASPIRATIONS OF VISION** MĀTAURANGA

Supporting Māori success is a key focus of the New Zealand government. To advance this goal in the science sphere, the Vision Mātauranga policy was born. In a nutshell, this policy sought to "unlock the science and innovation potential of Māori knowledge, resources and people".

By investing in Māori-relevant science, building Māori science capabilities, and fostering collaboration between Māori and the wider science industry, Vision Mātauranga actively seeks to further the interests of Māori in science. Vision Mātauranga is critical to Ageing Well for several reasons: the importance of older Māori (kaumātua), their knowledge and lived experiences; because of the disproportionate burden of ageing that falls on Māori populations; the commitment of Māori communities to support older people to age positively in place; and

improving the health and wellbeing of older Māori is a key Challenge objective.

Taking stock of our progress over the first five years, it is clear to see that Ageing Well made progress towards meeting the aspirations of Vision Mātauranga, slowly at first but with increasingly momentum as the Challenge entered its second five-year phase. Big strides were made, for example, in the reorganisation of our Governance Group, in our Contestable Funding Round, and in working with Māori communities.

Such was the progress made that, by the end of our second five years of research, we envisage and aspire that Vision Mātauranga will be thoroughly embedded in everything we do.



#### **1. MAKING MĀORI DECISION MAKERS**

Originally, all Challenges were set up with a Governance Group and Kāhui Rōpū (a group of prominent Māori advisors). The former made the decisions and the latter provided advice. Acknowledging the aspirations of Vision Mātauranga, and the importance of delivering for older Māori, Ageing Well decided that both groups should be combined so that Kāhui Māori members got to exercise an equal role in decision making. This was a novel approach which other Challenges have sought to follow.

In March 2017, we formalised a proposal to combine the Governance Group and Kāhui Rōpū functions into a single governing body. As then Ageing Well Chair Dr Di McCarthy explained at the time, the implementation of such a single governance model will see "the emergence of a more cohesive, efficient, inclusive, and culturally effective



Governance Group to provide strong leadership for the Challenge". Dr Will Edwards (Ngāruahine, Taranaki, Tāngahoe, Pakakohi, Ngāti Ruanui) was selected as Deputy Chair of the Governance Group.

The combined Governance Group shepherded Ageing Well through its planning for Phase 2 (2019-2024), which saw more focus on research affecting Māori and Pacific communities.

In 2018, Ageing Well started to paddle our waka towards Hata Temo. Since that time, Koro Hata has been welcomed as Ageing Well's kaumātua. He has been an invaluable member and supporter of our organisation and we sincerely value his guidance and vision leading us into the future.



## 2. INVESTING IN MĀORI AND PACIFIC RESEARCH

In 2016, Ageing Well embarked on a Contestable Funding Round that sought to address the "specific challenges and opportunities faced by Māori and Pacific peoples to age well". We made \$3.25 million available to researchers and communities. Four projects were funded, as well as one postdoctoral fellowship. The successful projects were:

1. Kaumātua Mana Motuhake: Kaumātua managing life transitions through tuakana-teina/peer education, Professor Brendan Hokowhitu, Waikato University \$915,000;

2. *Pacific Islands Families: Healthy Pacific Grandparents* (*PIF:HPG*) *Study*, Associate Professor El-Shadan (Dan) Tautolo, Auckland University of Technology, \$940,000;

**3.** *Tapinga 'a Maama': Pacific Life and Death in Advanced Age*, Dr Ofa Dewes, University of Auckland, \$450,000;

4. Loneliness and Social Isolation Among Older Māori and Pacific People: Critical processes, events and mitigating factors, Mr Charles Waldegrave and Ms Taimalieutu Kiwi Tamasese, Family Centre Social Policy Research Unit (FCSPRU), and Professor Chris Cunningham, Massey University, \$945,000.

The successful projects looked at areas across all stages of life, including intergenerational relationships, and the experiences of the older generations, and were led by researchers from universities and community agencies. For the Māori projects, it was important to acknowledge the value in Mātauranga Māori and in Kaupapa Māori research approaches.

Inaugural Ageing Well Director, Professor Dave Baxter, commented that he was delighted with the quality and quantity of the applications received through the Contestable Round, and welcomed the outcome which represented a significant funding boost to this area of research.



#### 3. BUILDING TRUST WITHIN MĀORI COMMUNITIES

The project Kaumātua Mana Motuhake (see the story later in the book) was ground-breaking in that it was jointly run by community organisation Rauawaawa Kaumātua Charitable Trust. The Trust was responsible for building the bridges between local kaumātua in Hamilton and researchers from Waikato University, and assisting in designing a culturally safe project. Without the leadership of the Trust, and their mana within the community, it would have been hard for the project to gain the traction it did.

Ageing Well has also been active in supporting Māori hui. In November 2018, we were a key sponsor and participant of the Kaumātua Service Providers Conference in Taranaki. Over 300 kaumātua experts attended the event, entitled "Together We Can Achieve More".

#### 4. ADVANCING WITH VISION MĀTAURANGA AS OUR GUIDING PRINCIPLE

Looking ahead to our next five years, Vision Mātauranga plays a critical role in everything the Challenge seeks to do. An entire Māori investment stream, Ageing and Māori, is dedicated to researching the health and wellbeing needs of older Māori.

Scholarships have been created to develop the next generation of Māori researchers.

Participation in marquee Māori events, like the Kaumātua Olympics and Te Matatini, are now staples of our community engagement.





### MOVING BEYOND COMPETITION: COLLABORATIONS PROPELLING US FORWARD

#### TAKING TEAMWORK TO ANOTHER LEVEL

Teamwork is the lifeblood of modern science. As a national organisation, Ageing Well has benefitted tremendously from joining forces with local and international collaborators. These 'teammates' have partnered with us to combine resources, share expertise, and achieve our mutual missions. In coupling with other research teams and setting aside the normal rules of academic competition, Ageing Well is "doing science differently".

We thank our collaborators for joining us in mutually supported projects, and look forward to seeing our projects come to fruition.

#### NATIONAL COLLABORATIONS BRAIN RESEARCH NEW ZEALAND

A major focus of Ageing Well's research is to ensure positive brain health for all older New Zealanders. It was a natural fit, then, to partner with Brain Research New Zealand – Rangahau Roro Aotearoa (BRNZ). Together with BRNZ, we agreed to co-fund three research projects, awarding a total of \$277,339. The projects, which focus, entirely or in part, on Māori and Pacific communities, drew on the specialist expertise of the BRNZ investigators. Dealing with issues such as cognitive impairments, Cognitive Stimulation Therapy, and Health and Wellness Coaching (see the stories later in the book), the studies all contribute to our mutual mission to find novel ways to improve brain health.







#### A BETTER START, HEALTHIER LIVES – NATIONAL SCIENCE CHALLENGES

Ageing Well has always worked closely with the other health and wellbeing Science Challenges, A Better Start and Healthier Lives. Although we each focus on a different part of a human's life, there are always interesting areas of overlap, which become apparent when health and wellbeing are examined as a whole. Some of our shared learnings were communicated at a jointly-organised national lifecourse symposium, *He Ora te Whakapiri*. As we continue into our current phase of research, working together with our Science Challenge partners remains a top priority.



#### HEALTH QUALITY SAFETY COMMISSION

Ageing Well researcher Dr Michal Boyd developed National Frailty Guidelines, which were commissioned by, and created in collaboration with, the Health Quality Safety Commission, a government agency tasked with improving health and safety in New Zealand. The guidelines are available online, and serve to provide caregivers and nurses support to ensure they provide best care to older New Zealanders. They are expected to become the default documents for residential aged care facilities across the nation.

### INTERNATIONAL COLLABORATION

#### NEW ZEALAND-CHINA NON-COMMUNICABLE DISEASES COLLABORATION CENTRE

China is fast becoming a leading player in medical research. Like New Zealand, they also have an ageing population, albeit on an enormous scale hard to comprehend. By 2050, over 360 million people older than 65 will reside in China, which represents more people than the population of the United States. Taking care of their older citizens will be an important mission as the new century progresses.

Sharing a common interest in ensuring our citizens are healthy, New Zealand and China formed an international collaboration in 2016 — The New Zealand-China Non-Communicable Diseases Collaboration Centre. All three health-focused National Science Challenges are part of this collaboration.

The centre focuses on addressing devastating diseases like cancer, diabetes, Alzheimer's and stroke. As then Challenge Director Professor David Baxter noted at the time of the announcement in 2016, the collaboration brings Ageing Well closer to achieving its mission of working together with leading researchers in China: "The scale of China offers many opportunities to assess strategies to reduce the degree of disability that noncommunicable diseases contribute to, and to enhance the independence, engagement and living environment of our older people." Scientists were provided the tools and support to engage with researchers in China.

Associate Professor Louise Parr-Brownlie, then Deputy Director of Ageing Well, visited China as part of an outreach tour, as did Assistant Research Fellow Dr Lizhou Liu, who also received a travel grant to visit Chengdu province twice in 2019.

Funding for the collaboration has recently been renewed and we continue to work to maximise the gains of international collaborative research. The groundwork has been laid to successfully enhance our international collaboration with China.

Ageing Well's local and international collaborations have allowed us to deepen and widen the scale of our impact. As we enter our next phase of research and translation, we hope to sustain and build upon our collaborations further.





#### **COMMUNITY ENGAGEMENT**

Community engagement has been at the very heart of our Challenge. Everything we do at Ageing Well is to improve the health and wellbeing of people across the communities of this nation, and to support those organisations at the forefront of providing the very best evidence-based solutions for older New Zealanders. We take this opportunity to thank everyone who has engaged with us up to this point, who have all improved the direction and outcomes of our research and impact.

## CALIBRATING OUR RESEARCH TO COMMUNITY NEEDS

During our first five years, Ageing Well strived to reach out to different parts of our communities. As part of our brief to "do science differently", we sought community feedback on their priorities for improving older people's health and wellbeing. All views were welcome and considered in setting our research directions.

To achieve this lofty aspiration, in 2016 and 2017 we launched our Stakeholder Network Action Programme (SNAP), in which a small team toured around New Zealand meeting with local groups to discuss what research they wanted to see. Essentially, we held workshops in which we canvassed people's views on what our future research priorities should be. Anyone was able to show up and express their opinions in these open forums. The meetings attracted a variety of stakeholders – government analysts, academics, caregivers, city council members, and older members of the community. Participants worked together to brainstorm ideas and areas that we might tackle.

Although there were an extraordinary number of views communicated over the full course of the five roadshows in our major cities (Dunedin, Christchurch, Wellington, Hamilton, Auckland), by actively engaging older adults and community stakeholders in setting our future priorities, the Challenge gained a unique opportunity to understand the key areas that older adults think important. We thank the 133 participants that gave up their time to provide us such valuable insight.

Ageing Well published an article about this novel, entitled 'Supporting Ageing Well Research: Findings from a research priority setting exercise' in the *Australasian Journal of Ageing*.

#### WELL BALANCED EXHIBIT

As humans, we take our ability to stay upright for granted. Over time, however, our balance and core strength deteriorates, and falls become more common. Sadly, falls among our older adults are a big problem in New Zealand, as they often rob individuals of their independence.

This reality inspired Ageing Well to develop the Well Balanced exhibit, which is designed to be showcased at museums and community events. Well Balanced is made up a series of interactive, educational challenges that teach the public about how balance and strength change as we age. The activities test participants' physical functions like grip, muscle strength, and of course, balance.

The exhibit then provides participants with information on their strength and balance compared with others of a similar age, as well as offering suggestions on what to do to maintain or improve strength and balance. Well Balanced was first exhibited at the Otago Museum in Dunedin. It is estimated that over 7000 people visited the exhibit during its run in 2017. Since then, it has been showcased in a number of ways. It was used to promote the launch of Accident Compensation Corporation's (ACC) 'Live Stronger for Longer' campaign to educate attendees at Age Concern's national conference in 2018; as well as engaging visitors at our stall at Te Matatini.

As part of ACC's Live Stronger for Longer campaign, the exhibit was used to launch their marquee campaign; as well as a device to train their staff to understand the balance issues facing older New Zealanders. Ageing Well was happy to offer our expertise to help one of our key stakeholder's to promote their campaign.

The exhibit is fully transportable. Our goal is for as many groups as possible to use the exhibit and get the great benefits of this entertaining and educational resource.







#### Te Matatini

One of the most rewarding parts of our mission is engaging with our diverse communities to share our story and explain our work. In 2019, Ageing Well had an opportunity to do just that at Te Matatini.

Te Matatini is the national Kapa Haka festival held every two years. It represents the pinnacle in Māori performing arts. An estimated 60,000 visitors descended onto Wellington's Westpac Stadium for the cultural competition. The event provided Ageing Well's Co-Director at the time, Associate Professor Louise Parr-Brownlie, with an unparalleled opportunity to engage with Māori communities from across Aotearoa, and to promote the next five years of our mission.

Together with Brain Research New Zealand, we shared a stall at the event, fielding questions about who we are and what we do. These questions provided us a chance to talk about the research we are undertaking, including our next two Focus Areas – Ageing and Māori, and Health and Wellbeing in Ageing.

Stall visitors were heartened to know that Ageing Well has prioritised half of our funding for research on Ageing and Māori. In addition to the usual leaflets and posters, we also took items from our Well Balanced exhibit to encourage visitors to our stall to have a go at our Nimble Fingers challenge. Naturally, plenty of tamariki plus their tūpuna or mātua wanted to try, which resulted in whānau competitions and a lot of laughter.

Overall, Te Matatini provided us with a wonderful opportunity to engage with Māori communities across Aotearoa and promote our research. Building these relationships and establishing trust with the community is an essential prerequisite for achieving our mission.



#### SPREADING NEW KNOWLEDGE

One of the best parts of our mission is the opportunity to share our progress with people — whether they are curious members of the public, scientists, policymakers, or government ministers. Ageing is something in which everyone has a stake, so there is always interest in our work.

We held several conferences and symposia over our first five years. In telling our story, we didn't just want to regale people with academic lectures about the research we were undertaking, but show everyone how that research was being used as a stepping-stone to achieving realworld impact. In short, we wanted to offer our attendees not just a progress update but a unique learning experience.

#### **RESEARCH IMPACT CONFERENCE**: **Realising the Potential (2017)**

Our first national conference, co-hosted with two research centres at Otago University, focused on achieving impact. It looked at the many ways new research can be translated into impact, in its varying guises.

Over one hundred academics, researchers, policymakers, and stakeholders gathered in Dunedin to discuss, debate and learn about meaningful research impact. Entitled *Realising the Potential,* the conference showcased how best to reap the rewards of scientific research so that it yields profitable results for our communities, partners, and end users.

The conference examined impact from many perspectives. International keynote speakers described best practice; academics and stakeholders illustrated successful models of collaboration and community engagement; and interactive workshops offered attendees the chance to think about achieving impact, whether that be through the commercialisation of research, influencing policy change, or delivering new health care for our communities.

The final session of the conference, a panel discussion between the three health-related National Science Challenges (Ageing Well, A Better Start, and Healthier Lives), looked at how researchers are proactively engaging with Māori communities.

#### **Steady As You Go**

The conference curtain-raiser was a public lecture: "For the People, By the People: falls prevention and the story of Steady As You Go (SAYGO)". A packed Dunedin Public Art Gallery auditorium was treated to a combined presentation from the Age Concern team responsible for this hugely successful falls prevention programme where participants improve their balance, leg strength, flexibility, general fitness and wellbeing.

Representatives from Age Concern, Margaret Dando and Susan Davidson, and Ageing Well's former Director Debra Waters, explained how the SAYGO collaboration came to fruition and where it is heading. Six SAYGO peer-leaders also shared their experience of the programme and the impact it has had on them. Afterwards, over drinks and nibbles, there was a chance to reflect on the social as well as physical benefits of programmes like SAYGO. All felt this was a perfect way to open the conference as it highlighted a very successful research-informed, community programme that has greatly improved the lives of New Zealand's older population. A happy marriage of research and community engagement.

Overall, the Research Impact Conference was a unique event that allowed everyone involved in, and who uses and benefits from, research to go away with a better understanding of how to realise the potential of research - how it can be put to work to measurably and meaningfully improve health and wellbeing for all New Zealanders.

#### **HE ORA TE WHAKAPIRI (2018)**

Whilst many health issues and opportunities are unique to a particular age group or stage in life, there is still tremendous benefit to looking at health and wellness across the continuum of an individual's life. This was the inspiration for hosting our national symposium He Ora te Whakapiri at Te Papa Museum in Wellington.

He Ora te Whakapiri — "there is strength in unity" paired together the three health and wellbeing National Science Challenges: A Better Start, Ageing Well, and Healthier Lives. Combining the expertise of all three Challenges, the symposium looked at the life course and sought to highlight the key health issues for New Zealanders from birth through to later life. Over 200 people attended He Ora te Whakapiri.







#### AGEING WELL TOGETHER: SCIENCE, POLICY, TRANSLATION (2019)

The culmination of our first phase of research was a conference at which teams from all of our 18 projects had the opportunity to talk about their research.

Opened by the Hon. Tracy Martin, then Minister for Seniors, our conference, entitled *Science, Policy and Translation,* looked at our research achievements. The programme included formal and interactive sessions, such as short presentations by our Principal Investigators, and round-table discussions about particular projects, including translation, knowledge exchange, and implementation of our research.

This book constitutes a written record of the research presented at the conference. But it is far more than a simple record of research achievements: it provides a look at our activities as a whole and the impact that is already evident, and additionally charts the course of our current research programmes.

#### **OTHER COMMUNITY ACTIVITIES**

We not only held and co-hosted conferences and symposia, we also participated and supported those of our stakeholders. Our team of researchers actively presented at conferences all over New Zealand - and across the world. Whether at a local Age Concern branch meeting or presenting an award-winning paper to the Gerontological Society of America (the world's largest and most prestigious international conference on ageing), Ageing Well researchers were there. In addition to conferences and symposia, Ageing Well participated in a range of other community activities. We have been active in supporting the Kaumātua Olympics, which is an initiative that encourages Māori to stay fit in older age.

We were also invited by the Ministry of Business, Innovation and Employment's (MBIE) chief economist to hold a stall at the All of Government Showcase, as an example of what MBIE was investing in. We appreciated being selected as a lead example of the innovative ways MBIE is utilising tax-payer money, and the chance to show people how our research and activities are making a difference in Aotearoa New Zealand. Whilst this primarily involved government employees learning about our organisation, it directly led to future collaborations with the Inland Revenue Department (IRD).









### CONNECTING THE DOTS: OUR RESEARCH AND IMPACT

At the start of our journey, Ageing Well was tasked with "doing science differently". Unlike other scientific endeavours, our work is mission-led, which means we started with an ambitious goal (think Manhattan Project or going to the moon). In the case of Ageing Well, our mission was "to harness science to sustain health and wellbeing into the later years of life." Put another way, our objective is to improve the lives of older Kiwis.

Indeed, despite our ambitious aim to tackle a wide variety of ageing-related issues out of the gate, certain themes emerged that have shaped our current investigations.

Although all of our researchers worked on different aspects of this mission (e.g., brain health, living conditions, loneliness and social isolation), their singular focus was to improve the health and wellbeing of our seniors. Often, their research was like a patchwork, with individual projects the cloth that was slowly stitched together, sometimes overlapping.

One of the most important and poignant discoveries was the extent to which older New Zealanders report being lonely, and the significant mental and physical toll this silent epidemic is causing older people. Data and figures often feel opaque and impersonal, but it is heartwrenching to imagine the thousands of older Kiwis in New Zealand who are currently alone and isolated, some of whom confided to our researchers that they don't even want funerals because they don't think anyone would come. Understanding loneliness and social isolation - and finding new and innovative ways to encourage connection - emerged as a key task for researchers and policymakers. Naturally, this has become a significant theme of our current work and the work we are undertaking in phase two of our research.

Another discovery was the importance of working inclusively with the diverse populations we seek to help, especially Māori and Pacific peoples. This might sound obvious, but so few research projects are created jointly with end-users.

And the benefits of such an approach were many. One project, that worked with Māori and Pacific peoples, realised that Western measures of loneliness weren't sufficiently accurate for kin and clan-based cultures. This discovery had significant implications for policymakers, as Māori are more lonely than we realised. Another project drew on Kaumātua to provide peer-support for other older Māori navigating through challenging life events.





Working with local iwi and giving them the tools to make change proved more effective because the end-users led, and had a stake in, the research.

Another novel aspect of our research was tackling issues from multiple perspectives. Take brain health as an example: Ageing Well wanted to improve older Kiwis' lives by investing in stroke research as it is fast becoming the leading cause of death and disability worldwide. Two projects were funded, one that looked at prevention and one that focused on rehabilitation. Essentially, we were working at both ends of the stroke journey.

Preventing strokes and assisting people living with the ongoing effects of a stroke to rehabilitate would dramatically improve the lives of older New Zealanders. Together, our researchers are contributing towards achieving these twin goals.

Assembling the best research team and working with stakeholders from the outset was also a novelty, at least on the scale that we operate. An example of this is our research on social connection. One project partnered with non-government organisation (NGO) Age Concern to assess the effectiveness of its programmes to support

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lonely older people. Another project drew upon district health board and external university colleagues to mine tens of thousands of pieces of clinical patient data to assess the impact loneliness had upon older people entering aged care facilities. Our projects demonstrated that impact is better when research is "co-created" with end-users - right from the start, and not as an afterthought.

Our most hopeful discovery during our first phase of research is that mission-led science can work. It certainly isn't easy. Ageing Well's senior leadership team has acted like a conductor trying to keep the orchestra sections in harmony. We marshalled diverse research teams — from different universities, research centres, community groups, and NGOs — to ensure they working cooperatively rather than in competition.

Ageing Well has made solid progress to date, as seen in MBIE's Mid-Way Review of our Challenge. Now we look to use our initial findings as a launchpad to make transformational progress in our current phase. **Building upon what we have learned thus far, so we can achieve our mission and ensure all older New Zealanders age well.** 







### **'BIG DATA' PROVES WE ARE OVERMEDICATING OLDER NEW ZEALANDERS, WITH DIRE CONSEQUENCES**

Medicines are a marvel of modern science. They can cure ailments, treat diseases, and even stave off death. New medications seem to appear daily, offering up an endless supply of antidotes to every possible affliction. As this plethora of drugs becomes more readily accessible, people — especially older New Zealanders — are increasingly taking more medications and supplements than ever before, all with a view to increasing longevity and quality of life.

However this trend may be more harmful than good. The practice of taking many medications at once is known as 'polypharmacy', and it has been the source of rigorous debate amongst health professionals. All medications have benefits and side effects which doctors carefully weigh against each other when prescribing medication to individuals already taking multiple pills, it is hard for a doctor to fully comprehend potential adverse interactions between so many drugs.

To tackle this problem, the Drug Burden Index (DBI) was developed in 2007. The DBI is an early warning system, a tool that calculates the total exposure of medications that sedate or affect cognition, and the adverse effects they might have on a patient. Essentially, it is a scale that adds up the side effects of medications and presents it in an easily understandable way for health professionals.

Researchers found that a high DBI score — that is, individuals on several sedative and / or cognitive medications at once — was associated with poor clinical outcomes for the individual. Subsequent studies proved the DBI to be a reliable tool, and therefore the scale could potentially be used to ensure patients were not on dangerously excessive medication regimens, and inappropriate prescribing could be curtailed.



Ageing Well Principal Investigator, Dr Hamish Jamieson (University of Otago, Christchurch; Canterbury District Health Board)

All medications have benefits and side effects which doctors carefully weigh against each other...



And this is where Ageing Well Principal Investigator Dr Hamish Jamieson came in. Dr Jamieson, a geriatrician with the Canterbury District Health Board and a Senior Lecturer at the University of Otago, Christchurch, wondered if the DBI tool could also be used to predict falls and fractures.

To answer this question, Dr Jamieson drew upon big data. Specifically, he tapped into a world-leading New Zealand asset: International Resident Assessment Instrument (interRAI). InterRAI is an evidenced-based clinical assessment questionnaire, which was identified by the Ministry of Health in 2003 as the best tool for evaluating the health and social needs of older adults, and is used widely across the nation. Dr Jamieson realised that the Home Care assessment (interRAI-HC), used to help older New Zealanders stay at home or plan for their care in residential facilities, could shed light on how often older adults suffered falls, and, more importantly, whether polypharmacy contributed. "We had an opportunity to examine this through use of the big data available in New Zealand's interRAI database on older people. The key advantage of using the interRAI data is that potential confounding factors can be accounted for," Dr Jamieson said. That's because interRAI would better allow researchers to separate the actual causes of falls and fractures from other noncontributing factors that can sometimes appear.

Excluding these factors allowed the project to verify the DBI's efficacy — a ground-breaking achievement. Mining big data is challenging: Harnessing the myriad tributaries of data and channelling them into one stream which can then be explored, is pain-staking work. Dr Jamieson and his team analysed interRAI data from over 71,000 older New Zealanders to measure the impact of multiple medications on the incidence of fractures. Using another national pharmaceutical database, they then matched and compared the participants medical and medication history.



C Those taking three or more Drug Burden Index medications were almost twice as likely to fall and break their hip.

The results were staggering. Dr Jamieson's team found that those taking three or more high- scoring DBI medications (especially sedative and cognitive medications) were almost twice as likely to fall and break their hip. Ninety percent of fractures were the result of a fall, and between 20-30% of those fall victims died within a year. Up to half of those over the age of 60 were on at least one DBI medication, Dr Jamieson noted. Ultimately, the very drugs tasked with improving older adults lives were often negatively interacting with each other and causing falls.

The impact of falls and fractures are immense. Individuals can lose mobility, independence, endure a poor quality of life, and even require early admission into a residential care facility. In the worst case scenario, it can lead to hospitalisation and death.

The issue of falls is a pressing one in New Zealand. The Accident Compensation Corporation (ACC) reports that, of the one in seven New Zealanders over 65, around 30% to 60% suffer a fall each year. And 10-20% will end up in hospital with a fracture. Falls prevention is such an important matter that ACC co-launched a campaign to stem the tide of older New Zealanders falling so frequently: Live Stronger for Longer. Ageing Well's Well Balanced Exhibit was part of that initial launch campaign.

Dr Jamieson and his team were awarded a \$1.1 million Health Research Council grant to continue this study.

### But why were these drugs collectively such a danger to older New Zealanders?

The reason multiple medications cause falls is because of the side effects of the drugs and how each medication reacts with others creating additional, often unforeseen, consequences. The side effects of the medications could include drowsiness, blurred vision, dizziness, and confusion, Dr Jamieson says. And a number of factors predispose older people to medication side effects, including not being able to metabolise medications as effectively as young people.

The ramifications of Dr Jamieson's study are significant for both the New Zealand public and policymakers. Most importantly, Dr Jamieson recommends older patients regularly visit their GP to ensure that the combination of prescribed medication is examined. The study also provides evidence that the DBI could be a valuable tool for clinicians to use alongside electronic prescribing systems to help reduce falls in older people. Since completing the project, a flurry of studies have built—or are building— on this Ageing Well research, including a prestigious \$1.1 million Health Research Council grant for Dr Jamieson and his team to continue their important research.

### **DYING WELL** Dementia, palliative care, and the development of National Frailty Guidelines

'Rest homes' have become our unofficial hospices. More older people than ever before are living and dying — in Residential Aged Care facilities.

Almost half of all New Zealanders over 65 now spend their final years there, and a staggering 70% of them die as a result of complex cognitive conditions such as dementia and stroke, diseases that these facilities traditionally were not equipped to handle on such a scale. Most residents require round-the-clock care before death. And, as our ageing population continues to mushroom, this trend will only continue. By 2040, the number of residents dying over 85 will have almost quadrupled. Such dramatic changes raise important questions about how best to look after terminally ill people in Residential Aged Care facilities.

Ageing Well Principal Investigator, Associate Professor Michal Boyd, set out to tackle these important (but relatively unexplored) questions. An academic at the University of Auckland's School of Nursing, Associate Professor Boyd has spent her career caring for, and researching, older adults. As a postgraduate biology student, she volunteered at a hospice and witnessed the "profound impact" nurses had caring for people at the most significant moments of their lives. An epiphany of sorts occurred and she changed direction, retraining as a Registered Nurse, and ultimately completing a a PhD in Nursing. Now, as a Nurse Practitioner and academic, Associate Professor Boyd's research seeks to improve care for older people, and to support residential aged care workers to implement these advancements.



Ageing Well Principal Investigator Associate Professor Michal Boyd (University of Auckland)

However, as a result (in part) of New Zealand's aspirational commitment to 'ageing in place' – where older adults remain in the community for as long as they are able – Associate Professor Boyd had noticed a new pattern in the sector. "When older people enter residential aged care, they are more frail and have higher dependency than ever before," she said.

A whopping third of all of these admissions die within six months of entering the new care facility. How frail and terminally ill residents are cared for, especially



those with cognitive impairments like dementia, is therefore critical given the expanded role many residential care facilities are now playing. It is also important because the Palliative Care Council of New Zealand argues that almost half of people dying in such facilities would benefit from specialised palliative care.

Yet very little is known about how well we care for those with advanced frailty that are near the end of their lives. Importantly, then, the study was driven by a desire to know what end-of-life care worked well in the residential care facilities, but also where quality improvements could be made.

What makes Associate Professor Boyd's study new and interesting is that she looked at the issue of end-of-life care from multiple perspectives — family members, General Practitioners (GPs), and Nurses. She said the families and staff reacted "very positively" to being involved in the study, and whānau in particular often appreciated the chance to talk through what had often been a very difficult process. The staff, too, understood the importance of the research, despite the added pressure it placed on them.

### 66

To ensure the highest quality of end-of-life care the philosophy of palliative care needs to be fully integrated within older people's nursing. During the investigation, important questions arose such as:

Are Health Care Assistants' adequately prepared to care *for people with dementia?* 

Do nurses have enough support and knowledge when integrating the philosophy of palliative care into gerontology?

As Associate Professor Boyd discovered, to ensure the highest quality of end-of-life care the philosophy of palliative care needs to be fully integrated within older people's nursing. Positively, the study found that overall end-of-life care in New Zealand is similar or better when benchmarked against other developed countries.

However, there was still room for improvement. And there were differences in end-of-life experiences depending on whether a dying resident had cancer, a chronic illness or dementia. It was found that those with dementia appeared to experience more physical distress for a longer period of time than those with, for instance, cancer. Cancer residents, however, received more support from the community hospice. That is for historical reasons: as Professor Merryn Gott (another investigator on the project) points out, palliative care "grew out" of the need to provide end-of-life care to cancer patients. "However, increasingly people are dying at older ages, often with multiple chronic conditions, frailty, and possibly dementia."

For Māori, who have a higher risk of living with dementia, little was known about their end of life experience in Western literature. The study uncovered that "spiritual needs" were the highest priority for Māori when facing terminal illness. Staff, too, who held strong religious or spiritual beliefs were less likely to face burnout, the study found.

Associate Professor Boyd's pioneering study yielded fruitful results. With the feedback from family members, GPs, and Nurses, she was able to enrich a key document that will provide a best-practice playbook for nurses and others in the residential aged care sector: Frailty Care Guides / Ngā Aratohu Maimoa Hauwarea. She developed this guide in collaboration with the Health Quality & Safety Commission, the government agency that works to improve health and disability support services.

Associate Professor Boyd's study enabled her to develop Frailty Care Guides / Ngā Aratohu Maimoa Hauwarea in collaboration with the Health Quality & Safety Commission. **11** 





### KAUMĀTUA MANA MOTUHAKE Empowering older Māori through peer education



Ageing Well Principal Investigator, Professor Brendon Hokowhitu (University of Waikato)



Rangimahora Reddy CEO, Rauawaawa Kaumātua Charitable Trust

Surviving the slings and arrows of life is never easy, irrespective of age. But, as people grow older, the volleys can be harder to hold at bay, especially for Māori. Social inequities, poorer access to healthcare, and a history of systemic racism all mount a relentless assault on Māori health and wellbeing.

Addressing—and redressing—the specific challenges Māori face was a key component of Ageing Well's Contestable Funding Round in 2016. Inherent in that process was a desire to draw upon the opportunities open to Māori.

Ageing Well Principal Investigator, Professor Brendon Hokowhitu (Ngāti Pūkenga), knew exactly what that meant:

Empower kaumātua (those Māori 55 and over), to age independently, with dignity, and based on their own worldview. More crucially, to draw upon Māori themselves, their strengths and knowledge (mātauranga), to make it happen.

Fighting against a pervasive belief that older people are a "burden" and drain on the nation's coffers, Professor Hokowhitu, Dean of Faculty of Māori and Indigenous Studies at the University of Waikato, wanted to show that older people can and do contribute to our society. In the process, he aspired to reframe how we think about ageing.

For Māori generally, ageing is a positive development: the older you are, the more you have to contribute. And they do want to contribute.



In this study, Professor Hokowhitu's team wanted to see if a peer-mentorship programme — a "for kaumātua, by kaumātua" intervention — could meet the health and social service needs of a group of selected older Māori in Hamilton. Essentially, one group of experienced kaumātua would shepherd younger peers through challenging situations.

The project not only aimed to empower individual kaumātua involved in the programme (and benefit their whānau, hapū, and iwi), but also offer an "opportunity for not just Māori but all of New Zealand to reframe the discourses surrounding our ageing population," Professor Hokowhitu explained.

#### SO WHAT HAPPENED?

Professor Hokowhitu's team partnered with local organisation Rauawaawa Kaumātua Charitable Trust, whose CEO, Rangimahora Reddy, was actively involved in the research. Open dialogue with the Trust ensured that the project was "contextual" and "culturally safe", Professor Hokowhitu says. Working side-by-side, the research team and Rauawaawa built a partnership that provided the traction needed within the community. Together, they developed the peer-support programme for kaumātua. Experienced kaumātua (tuakana) were trained to help their younger peers (teina) undergoing a significant life transition—for instance, loss of a spouse, loss of independence, or changing health conditions. To successfully navigate these moments, Professor Hokowhitu argues, having senior kaumātua work with their peers was a win-win situation.

"Kaumātua who have experienced a 'significant transition' are the best people to be working with and mentoring other kaumātua who may be experiencing something very similar. It's a strength-based approach that respects the knowledge and skills kaumātua have in abundance," Professor Hokowhitu said.

After an initial orientation, the tuakana peer educators had three conversations with up to six teina, and acted as wayfarers leading their teina through the sometimes treacherous storms of ageing. They also provided the teina with key information about health and social services available.



#### RESULTS

Encouraging experienced kaumātua to help their younger peers through life's challenges proved successful and cost-effective.

A total of 180 kaumātua were recruited to the intervention with 121 completing the study. Participants completed assessments of health and mana motuhake (autonomy and self-actualisation) measures consistent with Māori worldviews prior to and following the peer education intervention. Additionally, qualitative evaluations were given including open-ended questions and participation in five focus groups.

Positive improvements occurred after the teina had finished their conversations with tuakana. Of particular note were the statistically significant intervention effects upon teina's 'tribal identity', and 'trouble paying bills', Professor Hokowhitu noted. Tuakana also proved to be effective communicators, whose abilities were rated highly by both teina and independent assessors.

Teaching appears to be good for their health and wellbeing, too: Kaumātua reported an improved sense of purpose after finishing the programme. When benchmarked against the conventional threshold of cost-effectiveness, this intervention was "definitely costeffective", Professor Hokowhitu reported.

The findings show that kaumātua strengths and knowledge can be successfully deployed to improve

The findings show that kaumātua strengths and knowledge can be successfully deployed to improve health and social outcomes of their peers, Professor Hokowhitu concluded.

#### OUTCOMES

This research did not occur in a sterile, white lab. Embedded in the heart of the community, the researchers worked hand-in-hand with a local service provider — Hamilton's Rauawaawa Kaumātua Charitable Trust.

The cooperation provided the project traction and momentum with the community and participants. Like other Ageing Well projects, it demonstrated the importance of working in partnership with the people you strive to help.

Upon completion of this project, Ageing Well National Science Challenge awarded a new grant of \$2.5 million to the team to expand the scope and reach of the project. Titled Kaumātua Mana Motuhake Pōi, the new research will involve up to 350 Māori kaumātua from across Aotearoa. In addition to the tuakana-teina peer intervention, the project will also trial an intergenerational model for increasing physical activity and cultural knowledge exchange (mātauranga), including te reo Māori. Professor Hokowhitu wanted to show that older people can and do contribute to our society. In the process, he aspired to reframe how we think about ageing.
Ageing Well awarded the research team a \$2.5 million grant to expand the scope and reach of the project. Titled 'Kaumātua Mana Motuhake Pōi' the new research will involve up to 350 Māori Kaumātua from across Aotearoa.

#### CONCLUSION

Professor Hokowhitu's project is a welcome tonic in the dismissive age of "OK, Boomer". It offers a clarion call to policymakers and New Zealanders at large: older Kiwis do and can contribute to our society.

Drawing on the strengths of older kaumātua — their experience, wisdom and eagerness to contribute — the younger peers were successfully shepherded through some of the most difficult moments of an older person's life.

And everybody wins in this model: the kaumātua peer educators gained a greater sense of purpose; the younger peers learned ways to cope with the slings and arrows of life; and both groups' health and wellbeing soared.

The bottom line is that this project has created a cost-effective, community-led, kaumatua-administered health intervention improving the lives of older Māori.

### GLOSSARY

Kaumātua: Māori over age 55.

**Tuakana:** Experienced kaumātua. For the study, these were people who had undergone significant life transition.

**Teina:** younger peers of kaumātua. For the study, these were people experiencing a significant life transition.

### THE LONELINESS EPIDEMIC How isolation and loneliness are putting older New Zealanders at risk

Loneliness is a silent and effective killer. Everyone experiences it at some point, but few New Zealanders would ever consider loneliness to be a serious health problem.

In an era where high profile diseases like cancer and Alzheimer's stalk older New Zealanders, loneliness is often trivialised as just part of life. But it is a strange quirk of twenty-first century life that in an increasingly connected world, some older Kiwis are feeling more disconnected and isolated than ever before. Worse still, the physical and mental toll of this isolation and loneliness on our older people is largely going unnoticed—and it is devastating.

What makes loneliness a particularly difficult challenge to tackle is that it is a largely unseen "epidemic", to use the provocative term of former US Surgeon General Dr Vivek Murthy. Outside of academic circles, few people are talking about loneliness in the same terms as they are about obesity or addiction.

But we should. Here in Aotearoa New Zealand, approximately 10% of people over the age of 65 are lonely all or most of the time, and this rises to 50% amongst those over 80. In the most serious cases, one in five frail adults is 'chronically lonely'. And this loneliness is hazardous: almost a quarter of those people who are lonely may be at risk of premature death. Previous research has equated the reduction in life span as a result of severe loneliness to smoking 15 cigarettes a day.

On the international stage, there has been a growing focus on loneliness as a serious health issue. In 2016, for instance, the UK created the world's first Minister for Loneliness. But in New Zealand the matter has been relatively overlooked, particularly in regards to Māori and minority groups.



Ageing Well Principal Investigator, Professor Merryn Gott (University of Auckland)

This oversight inspired Ageing Well Principal Investigator Professor Merryn Gott to take action. Professor Gott, of the University of Auckland, sought to rectify this gap in our understanding with a two-pronged project: first, her research team conducted interviews with different ethnic groups (especially Asian, Māori and Pacific peoples) to gauge how they experienced and understood loneliness; and second, they evaluated Age Concern's Accredited Visiting Service (AVS), which seeks to provide companionship and reduce loneliness amongst socially isolated older people.

In collaboration with Age Concern, Professor Gott's team analysed this information to assess the effectiveness of the programme, and suggested areas where they might adapt their service so that it can better meet the needs of New Zealand's multi-cultural population.



Forty-four older people were interviewed, and a further 32 attended focus group sessions. What they shared was always poignant and "often upsetting", related Professor Gott. Loneliness and social isolation were a "significant concern" for older people. Their accounts resonated with a previous study the team conducted which found many older people are choosing not to hold funerals as they did not believe anyone would attend.

Embarrassment about being lonely, and a desire not to be a burden on family members, were two of the biggest psychological barriers to social engagement, the study found. Professor Gott noted there is a real stigma about identifying as being lonely or socially isolated, and this prevented people from coming forward to seek companionship or help.

Many older people feel their isolation and loneliness is their "own fault" or a reflection of their family or whānau's "unwillingness or inability" to care enough for them, she said. Most study participants lived alone or with only a spouse, providing fertile ground for isolation. And in a sad irony, Asian migrants often sought to preserve family relationships by avoiding

Study researcher, Dr Tess Moeke-Maxwell, with a study participant.

- being a burden—thus perpetuating the loneliness experienced.
- Though older people are incredibly resilient in their attempts to lessen their loneliness, the study found, physical barriers like mobility issues, loss of a driver's license, and an inability to leave the house contributed to isolation and loneliness.
- These physical impediments can have a significant psychological impact: a home or rental accommodation can often feel like a prison cell. Many vulnerable older people spent days by themselves, which could result in depression. One participant compared loneliness to being "in the dark place". In stark contrast, getting out of the house was associated with "feelings of belonging".
- Many issues contributed to older adults' social isolation and loneliness, Professor Gott discovered, and different cultural groups experienced isolation and loneliness for a variety of reasons. So any solutions to these problems will need to be as multifaceted as New Zealand is multicultural.



55 The study found embarrassment about being lonely, and a desire not to be a burden on family members, were two of the biggest psychological barriers to social engagement. 99 And that's where the second part of Professor Gott's project is crucial. In collaboration with Age Concern, an NGO dedicated to supporting people over 65, the research team investigated the effectiveness of the AVS. The study found the AVS was particularly successful when relationships between the volunteer and the isolated individual were based on mutual respect and shared cultural knowledge. Older adults wanted to be valued for their contribution to a relationship, and preferred friendships to be genuine rather than "transactional".

Participants agreed that the befriending service helped reduce social isolation and loneliness and that supportive services to foster connection are needed. More importantly, the study verified Age Concern's AVS is making a difference. With the additional learnings gleaned from the study, the AVS will be able to grow purposefully and gain momentum.

The study also has some very important lessons for New Zealand as a whole, and we should be taking notes. Older people are more lonely and more isolated than ever before, but are often too embarrassed or physically unable to do much about it.

This often leads to illnesses such as depression and, in the worst case scenario, even premature death. Investing in ways to promote social connection and reduce loneliness would yield huge cost savings. Given New Zealand's increasingly constrained health and social care budgets, such information will be critical for policymakers and health economists. This study found that the visiting service is cost effective and "there will be a strong argument for integrating them into DHB and council service provision." By investing in services such as the AVS that aligns to services, promotes social engagement and values the older person, "the health benefits will be huge, and the cost of stemming the tide of loneliness will be repaid many times over", Professor Gott concludes.

What Professor Gott and her team have discovered is worthy of a public health campaign that helps to destigmatise loneliness."It is important to get people talking about loneliness and normalising it," she says The team collaborated on a short film, Elder Birdsong, and utilises study participants' own words to convey the effects and feelings of social isolation and loneliness. It was shortlisted in the World Health Organisation's Inaugural Health for All Film Festival in 2019.

For now, as part of her project, her team collaborated with filmmaking colleagues from the Faculty of Arts to create an animation short film, Elder Birdsong. This film powerfully draws upon study participants' own words to convey the effects and feelings of social isolation and loneliness. The film was shortlisted in the World Health Organisation's Inaugural Health for All film festival in 2019.

Professor Merryn Gott and her team are undertaking an extension of this study in Phase 2, entitled 'Promoting social connection through challenging public attitudes'. This will continue the intergenerational collaboration and produce a second film that furthers the conversation about social isolation and loneliness in older people.

This ground-breaking project has shone a spotlight on loneliness as a serious health problem experienced differently between diverse ethnic groups. Positively, it also showed that programmes like Age Concern's AVS, when conducted in a culturally appropriate manner based on mutual respect and understanding between the volunteer and individual, can begin to help us to tackle the silent and deadly epidemic of loneliness in New Zealand.

### **A BRAINY IDEA** A new stroke therapy device offers hope

Every hour of every day a New Zealander suffers a stroke. When not fatal — and strokes kill thousands of Kiwis annually, making them one of Aotearoa's biggest killers — they can be debilitating. Stroke survivors often require months of rehabilitation.

Unfortunately, even with extensive rehabilitation, around a third of survivors never fully regain control over their bodies. That means that many of a stroke's effects can last a lifetime, affecting a survivor's independence. With the New Zealand Stroke Foundation estimating that there are 60,000 survivors in New Zealand, finding a way to enhance stroke rehabilitation, and thus ease the effects on function, would greatly improve many lives.

Now, in a world-first trial, Ageing Well Principal Investigator Professor John Reynolds has made promising strides in the right direction. Professor Revnolds, a neuroscientist at University of Otago, has spent his career unravelling the mysteries of the human brain. Together with pioneering Belgian brain surgeon Professor Dirk de Ridder, Professor Reynolds has devised a novel stroke brain stimulation therapy that went against conventional scientific thinking.

#### ANATOMY OF A STROKE

Strokes are brain attacks. They are caused by an interruption of normal blood flow within the brain, which results in the death of brain cells in that area. The dead brain cells impair a person's normal brain functions, and this can manifest in a drooped face, slurred speech, and arm incapacitation. How severe a stroke is depends on the area of the brain affected, and the type of cerebrovascular accident — to use the medical term for a stroke — experienced.



Ageing Well Principal Investigator, Professor John Reynolds (University of Otago).

Conventional brain stimulation approaches made to improve stroke recovery had used a particular pattern of periodic bursting stimulation applied using electrical and magnetic stimulation on the diseased side of the brain, near the epicentre of the stroke. However, this approach has so far not produced a reliable degree of lasting improvement.

So instead, Professor Reynolds' study targeted the healthy side of the brain using the bursting electrical stimulation usually applied to the damaged side. Based on work he had done with experimental stroke models, he suspected that, after the trauma of a stroke, this type of stimulation applied to the healthy side of the brain would reduce the 'overdrive' that was restricting recovery of the damaged part of the brain.

**Collaborating with pioneering Belgian brain surgeon Professor** Dirk de Ridder, Professor Reynolds devised a novel stroke brain stimulation therapy that went against conventional scientific thinking.

To maximise recovery, the surviving brain cells closest to the damaged area need to take over the lost function. Yet after a stroke, this is difficult to achieve due to the overactivity of the electrical circuits that tend to 'turn off' or inhibit these surviving areas. Using an electrical stimulator implanted onto the brain opposite the stroke, Professor Reynolds hoped that the diseased side of the brain could begin to "awaken" and maximise its ability to recover function through rehabilitation therapy.

One of the few neurosurgeons who could help and the only one at the time with the ability to obtain the specific stimulation technology required — was Belgian brain surgeon, Professor Dirk de Ridder. Fortuitously, Professor de Ridder had recently moved to University of Otago in Dunedin, and he had also been trying to treat the damaged side of strokeaffected brains without success.

"So when John Reynolds came up with this new idea to treat the healthy part of the brain in order to influence the diseased part, I thought it was a brilliant idea," Professor de Ridder recalled.





#### Pioneering brain surgeon Professor Dirk de Ridder (University of Otago)

### THE NOVEL IMPLANTED STIMULATION APPROACH

With Ageing Well funding, the neuroscientist and the neurosurgeon developed a novel stimulation approach together. The researchers placed an electrode on the dura which covers the motor cortex (that controls body movement) on the healthy side of the brain, "to change the messages from the healthy side to the stroke side", explains Professor de Ridder. A wire is tunnelled under the skin to an implanted stimulator in the chest, similar to a pacemaker. This device is only activated during rehabilitation sessions, and by the standards of brain surgery, very safe.

The new electrical stimulator has already begun to improve the life of Paul Robertson-Linch. Mr Robertson-Linch was one of two men who volunteered to trial the device. Several years ago he had a stroke at work, which initially robbed him of his speech, and all movement down his right side.

"That was pretty scary," Mr Robertson-Linch recalls, "I remember thinking is this going to be life now? Is this it?". Despite undergoing extensive physiotherapy rehabilitation, he still could not use his right arm and hand. Sadly, this is an all too familiar story: around 85% of all stroke surviviors never regain arm and hand movement.

But, as a result of the electrical stimulator, Mr Robertson-Linch started to make significant improvements. When Paul and his fellow trial participant started, they could not grip anything. By the end, they could squeeze 7kg weight with their hands. In the process, they had also regained fine motor skills, which were lost as a result of the stroke.

For Mr Robertson-Linch, the unconventional therapy has been life-changing. "I couldn't hold my toothbrush when I came here. Now I can hold it and get it up to my face...I can open and close the door. It's fantastic."

Professor Reynolds is excited by the results and hopes that this trial is just the tip of an exciting new phase of stroke therapy treatments. He is now trialling electrical burst stimulation applied using a novel external stimulator system, to provide a therapy which is hopefully more acceptable to many more New Zealanders. Electrical stimulation, Professor Reynolds is quick to point out, is not the cure but rather a tool to achieving faster stroke recovery. The stimulator prevents the healthy brain from accidentally stifling its own recovery: "The stimulator doesn't make them better – it's the rehabilitation. What we are trying to do is to allow parts of the brain to wake up during that session and form new connections".

Professor Reynolds cautions that neurostimulation will not replace traditional rehabilitation therapy, which remains the standard stroke treatment. But rather, neurostimulation will complement and dramatically enhance it. In the meantime, Professor Reynolds and his team will be looking to find a method that will "maximise the gains" that can be obtained from such promising therapies. We are closer, then, to a future where neurostimulation can aid stroke recovery and improve the lives of many New Zealanders.

I couldn't hold my toothbrush when I came here.
Now I can hold it and get it up to my face... I can open and close the door. It's fantastic.
Paul Robertson-Linch







Study participant Paul Robertson-Linch with Professor Reynolds

CHALLENGING WESTERN PERSPECTIVES New ways of measuring loneliness and social isolation amongst older Māori and Pacific Peoples

Scientists obsess over measurements. They are the bedrock of modern scientific investigation, and often buttress decision making and policymaking at the highest levels of our government. Gross Domestic Product, life expectancy, and educational achievement are classic examples of keystone governmental measurements.

But what happens when the way scientists have measured something, such as loneliness, appears to be imprecise or inadequate? Such was the situation Ageing Well Principal Investigators Charles Waldegrave, Professor Chris Cunningham, and Taimalieutu Kiwi Tamasese found themselves in when they began to explore loneliness in older Māori and Pacific Peoples. Waldegrave, the co-ordinator at the Family Centre Social Policy Research Unit (FCSPRU), an independent research agency located in Lower Hutt, Wellington, wanted to develop an 'early detection system' for signs of loneliness and social isolation among these groups.

However, Waldegrave's team began to survey older Māori and Pacific peoples about loneliness, they discovered some participants who they suspected were lonely were not showing as such on a prominent international scale.

The scale in guestion is called the De Jong Gierveld Total Loneliness Measure. Developed in the Netherlands, it is widely employed both in Aotearoa New Zealand and internationally. It is highly regarded as a reliable and accurate tool. And when it comes to "universal aspects" of loneliness, Waldegrave clarifies, it captures these exceedingly well. Yet, as the research team discovered, some culturally specific aspects of loneliness were being missed.



Ageing Well Principal Investigator, Mr Charles Waldegrave (Family Centre Social Policy Research Unit)

No measurement of loneliness will ever be one hundred per cent accurate. Everyone, after all, experiences feelings of loneliness differently. And loneliness is slippery. It is intangible – it is difficult to pin down and measure accurately. It is a state of mind and perception. But in a multicultural society, allowance should be made for cultural differences. Other research undertaken by Ageing Well demonstrated that certain ethnic groups are more susceptible to loneliness (see the work by Drs Keeling and Jamieson later in the book). It follows that certain groups may experience loneliness in ways not anticipated by the predominantly Western loneliness scales used in New Zealand.

The research team concluded that culturally specific aspects of Maori and Pacific loneliness are not being captured on standard, international measurement scales, and this may have dramatic ramifications for



policymakers. "Our perspectives need to be challenged," argues Waldegrave, "as western scales are not adequate measures of loneliness and social isolation for kin and spirituality based cultures."

To rectify this failure to account for cultural aspects of loneliness, the research team set about designing – with older Māori and Pacific peoples – co-created scales that took into account those culturally-specific factors affecting them. The co-created questions were designed to identify the specific cultural aspects of loneliness which brought the cultural nuances into sharp relief. One participant noted: "we don't focus so much on individual personal feelings like your sort of cultures. We are moved by collective experiences within our whanau and cultural communities." The co-created guestions focused on loneliness experiences related to the changing roles of older people in contemporary life, their extended family responsibilities, spirituality, and the impact of contemporary living on their cultures.

In the Māori study, 196 participants - 50 to 80+ years completed the different loneliness questionnaires. The researchers then compared the results. A considerable number of participants did not register as particularly

lonely on the De Jong Gierveld scale, whereas they did register as lonely on the responses to the co-created guestions which focused on the culturally specific aspects of loneliness that they might experience.

"The differences between the scales were statistically significant", Waldegrave explains. The new co-created loneliness scales offered a different picture of how lonely older Māori and Pacific peoples are from western ones one commonly in use. Older Māori and Pacific peoples are more lonely in different areas.

The study also identified what factors made these groups more or less likely to be susceptible to loneliness and social isolation. Depression, abuse and discrimination ranked highly as factors likely to increase the risk of loneliness and social isolation amongst participants, the study found. "Negative life course events" also raised the odds. A bounty of factors reduced the risk: secure housing, good health, higher wellbeing scores, faith and religion, social networks and connection, good material standards of living, and a safe and friendly neighbourhoods. These new insights will allow researchers to chart a path forward to minimise the impact of cultural loneliness for Māori and Pacific peoples.

The research team have also received an additional grant from Ageing Well to develop a Kaumātua Future-Proofing Tool, which will provide an evidence-based checklist for those designing 'culturally rich' services for the burgeoning, ageing Māori population.

Early detection of "common pathways" leading to loneliness or social isolation permit the team to develop ways of encouraging connectedness and enduring relationships during older age. As a result, Waldegrave envisages "better-targeted services and policies" to improve the quality of life of older Māori and Pacific people, and increased "cost- effectiveness" of services.

Social connections for older people are very important for their health and quality of life and we have a responsibility to correct western bias, Waldegrave explains. Numerous studies have shown that the effects of loneliness and social isolation "lead to greater ill-health and earlier death."

The ramifications of the study's discoveries are significant: one of the dominant measures of loneliness used in New Zealand, based on western concepts, fails to capture culture-specific aspects of Māori and Pacific loneliness. Failure to capture these aspects of loneliness creates the problematic misunderstanding that key areas of older Māori and Pacific peoples' experience of loneliness is not taken into account. It masks a problem that key decision makers do not know exists. As Waldegrave explains, "We have very few Māori measurement scales, and so our standard measures may be only capturing universal aspects of indices and not the Māori-specific aspects. This may help explain the persistent gap between Māori and non-Māori wellbeing outcomes."

This problem regarding the cultural components of loneliness has bigger implications still. It means that the raw data that policymakers, statisticians and ministries are using—the data they use to make critical funding decisions—are "blunt and imprecise" says Waldegrave. That disadvantages older Māori and Pacific peoples, as service planning for their communities will only be effective if the decision-makers have accurate data. Understandably, there was significant interest in these findings from Māori and Pacific stakeholders, end-users, and other funding agencies. Māori and Pacific groups have reached out to the FCSPRU team to work on developing programmes to incorporate these findings. Aspects of this research were also presented by Charles Waldegrave at the Gerontology Society of America 2020 Annual Scientific Meeting, the largest and most prestigious international conference on ageing, where it received the Ollie Randall Symposium Award.

The research team have also received an Emerging Opportunities Research Grant from Ageing Well National Science Challenge to expand the study further to explore the health and service needs of Māori. Collaborating with Dr Catherine Love (Te Atiawa, Taranaki, Ngati Ruanui, Nga Ruahinerangi), also of the Family Centre, and Professor Chris Cunningham (Ngāti Toa, Ngāti Raukawa), the team hope to develop a Kaumātua Future-Proofing Tool, which will provide an evidence-based checklist for people, organisations, and ministries designing 'culturally rich' services for the burgeoning, ageing Māori population.

The lessons of this study transcend its focus on loneliness and social isolation. Future research on older Māori and Pacific peoples needs to be receptive to their unique cultures, languages, and frames of reference. Using measurement scales that take into account the cultural aspects of Māori and Pacific peoples' health and wellbeing may allow New Zealand to better bridge the inequity gaps in health outcomes so that these older groups can age well.



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### **RENTING BOOMERS** How the 'Tenure Revolution' is creating a looming crisis for older Kiwis



Ageing Well Principal Investigator, Dr Kay Saville-Smith. She is also the Director of the Centre for Research, Evaluation and Social Assessment (CRESA)



#### Retirement looms for a large number of Kiwi Baby Boomers. But as they begin to enter their golden years, fewer seniors are living in their own homes.

Instead, in the thick of an acute housing shortage, more and more older New Zealanders find themselves squeezed out into an unforgiving and unresponsive rental market. And despite the media brimming with stories about the 'housing crisis' and how it has closed the door on many of the younger generation's dreams of home ownership, little attention has been paid to those at the other end of life's scales.

Yet more attention is needed. As Ageing Well Principal Investigator Dr Kay Saville-Smith predicts, by 2040 only half of all Kiwis over 65 years will own their own home. That's a staggering forecast, given that in 2001 the figure was 82 per cent. In fact, New Zealand once boasted some of the highest rates of home ownership in the western world; now, owner-occupation rates are falling rapidly to levels that prevailed in the 1930s.

The decline in home ownership is just part of the problem. Access to affordable, suitably designed accommodation is another. Pressure to supply affordable housing to seniors has been bubbling under the surface since the 1990s. Historically, social housing was delivered to New Zealanders in partnership, with central government focusing on younger families, and local councils looking after seniors.

Yet, as Dr Saville-Smith observed, "In the 90s, the old housing system was dismantled and since then no government has really stood back and looked at how the whole system works." The majority of accommodation available to older renters is provided by a private rental market. Government largely halted capital finance for social housing to councils in 1991, and since then, the stock of council-owned public housing has declined rapidly. C Dr Saville-Smith's research uncovered that older renters are twice as likely as homeowners to live in houses that are poorly maintained and twice as likely to suffer from health problems such as asthma, anxiety, and depression.

Much of the housing available in the rental market is unsuitable for older people, and most houses are not normally built incorporating the principles of universal design (e.g. doorways wide enough for wheelchairs). Older renters may also face rent increases and uncertainty of tenure. And that's the crux of this looming crisis: as the decline in suitable housing stock continues, demand from older people for rental homes is increasing, and homelessness among this group is increasing more rapidly than for other age groups.

As the focus of her Ageing Well research, Dr Saville-Smith's team explored several urgent questions relating to these problems: How will this rising reliance on the rental market impact on older people into the future? Will renting improve or hinder older people's wellbeing and independence? Will renting alleviate or exacerbate cognitive and physical impairments? And what impact, if any, will renting have on older New Zealanders' personal dignity and social engagement?

Dr Saville-Smith's research uncovered that older renters are twice as likely as homeowners to live in houses that are poorly maintained and twice as likely to suffer from health problems such as asthma, anxiety, and depression. They were also more likely to enter residential aged care rather than be supported within the community. The latter presents a significant societal risk and healthcare burden as the number of seniors in rentals rise.

Right: examples of some of the printed material from Dr Saville-Smith's research



The research team has a term for the large diaspora of people moving from home ownership into the rental market: the "Tenure Revolution". Rising dependence on rental housing for older people is a long term trend that will not be changed without significant overhaul in housing policy, Dr Saville-Smith notes. Even if changes occur, there are people currently in middle age who are destined for "rental dependence" in their later years. As a result, current short-term solutions need to focus on making the rental market more responsive to older adults' needs.

Home ownership has long been associated with a "sense of security and of place within society". But for the increasing number of seniors who are paying rent, financial pressures will certainly take a toll. For older renters, there will be a "superannuation shortfall": "Our retirement incomes are designed to give older people a good standard of living, but it assumes they're not going to be paying mortgages and not going to be paying rent," Dr Saville-Smith said.

Whereas in the past twenty years, with property prices rising, it has been assumed that the "liquidation of older people's housing wealth can be used to sustain their living standards." The Tenure Revolution exposes such assumptions as now flawed.

The findings of this wide-ranging research have informed a flurry of policymaking documents both locally and internationally. The Ministry of Social Development's Better Later Life – He Oranga Kaumātua 2019-2034 addressed housing availability; Technical Advisory Services will review its interRAI Home Assessment questionnaire; findings also assisted a UN Special Rapporteur to New Zealand's review on housing and on older people's services respectively; and contributed to the reform of the Residential Tenancies Act and the Commission For Financial Capability 2019 Review of Retirement Income: Facing the Future. This research also raised awareness among communities, landlords, property investors, and the public. Information from the research also helped develop a new tool for seniors Life When Renting – Going for Good Rent.

For older people like John Hurrell, in his 70s, who lost his business and house in the 2008 Global Financial Crisis, renting is his only option. However dealing with rising rent prices and living off superannuation has been challenging. "Because of health reasons I've had to stop working. So I'm faced now with trying to live on super in a rental market that's actually going up in terms of cost," he says.

He believes the only way to ensure that older people are properly looked after is for the Government to bring back pensioner housing. "This tsunami is just starting. I'm the beginning of the baby boomers and there's a big crowd behind me," he says.

Thanks to the research of Dr Saville-Smith and her team, policymakers and stakeholders now have the information required to begin to formulate solutions to this looming crisis, acutely aware that a large chunk of Boomers will require rental accommodation that is affordable, designed suitably for their needs, and which fosters their independence and wellbeing.



The findings of this wide-ranging research have informed policymaking, raised awareness in the community, and also helped develop a new tool for seniors: Life When Renting – Going for Good Rent.

## NGĀ KAUMĀTUA, Ō MĀTOU TAONGA

A feasiblity study to support kaumātua health in a changing world



Ageing Well Co-Principal Investigator, Associate Professor Marama Muru-Lanning (University of Auckland)



Māori look forward to ageing. Becoming a kaumātua (Māori 55 or older) is to be venerated by whānau, hapū, and iwi alike. Yet despite Māori greeting ageing positively, there is a significant discrepancy between their views on growing older and their actual health. In fact, by any metric, kaumātua are not ageing well. And it is important, as a nation, to know the reasons why.

Embarking on a short feasibility study funded by Ageing Well, Co-Principal Investigators Associate Professor Marama Muru-Lanning and Dr Tia Dawes, of the University of Auckland, wanted to explore this apparent discrepancy between positive Māori attitudes to ageing and their negative health statistics.

A critical aspect of this pilot project was to ensure that the methods employed to gather data and select participants from a diverse geographical region were fit-for-purpose. Researchers conducted the pilot study with kaumātua from two Māori communities in Te Tai Tokerau (Northland), Patuharakeke and Ngātiwai. Employing a kaupapa Māori approach (research by, and for, Māori) proved critical. Drawing upon Māori customs (tikanga) and knowledge (mātauranga), researchers collaborated with participants to design, develop and evaluate the project. This meant the project was reciprocal in nature.

The engagement process exceeded expectations. The majority of kaumātua within the Ngātiwai Kāhui Kaumātua participated in the data collection and the research team created a waitlist in an attempt to accommodate as many participants as possible. The first noho wānanga (2-day workshop) involved eight kaumātua of Patuharakeke descent and two support people; the second involved fifteen Ngātiwai kaumātua and three support people. The participants were fully engaged in the event, providing positive feedback and suggestions of co-design for future projects. Despite Māori greeting ageing positively, there is a significant discrepancy between their views on growing older and their actual health ... and it is important to understand why. Participants had the opportunity to define what it means to age well for Māori within the context of their own community, and to contribute their understandings of ageing to broader discussions around ageing within New Zealand. They also had an opportunity to voice their concerns around ageing and how they are managing both older age and the transition into older age within tribal rohe (areas).

In turn, the researchers learnt about health as kaumātua understand it, what strategies they use to maintain health, and their outlook on life. They also got insight into the role that kaumātua play within their communities as a means of wellbeing.

Findings suggest that the methods of informationgathering were effective, and the data were enlightening. A koroua (elder) taking part told researchers he had a clear understanding of the purpose of the noho wānanga and, more importantly, he felt his contribution was respected by the team and his fellow contributors. For the research team, looking to build a bridge of trust to older kaumātua, there could be no greater complement.

Based on the success of this pilot study, Ageing Well funded the larger study, 'Mā mua ka kite a muri; mā muri ka ora a mua', as part of an Emergent Opportunities grant. This follow-on project will explore intergenerational support for kaumātua health in the two Tai Tokerau communities, using a kaupapa Māori approach and including qualitative, ethnographic and oral history techniques. It seeks to examine kaumātua, whānau, iwi and health services discourse on responsibility for kaumātua health. The research also aims to probe more deeply into historic, cultural and social context of wellbeing, health and health service usage in these rohe. A koroua told researchers he had a clear understanding of the purpose of the noho wānanga and he felt his contribution was respected by the team and his fellow contributors.





Associate Professor Marama Muru-Lanning (second from right) and staff members of the James Henare Māori Research Centre with Te Hiku kaumātua and kuia from the Far North.

### VILLAGE PEOPLE Understanding the health needs of older kiwis in retirement villages

Retirement villages are popping up all across Aotearoa New Zealand. Designed as a safe, shared space for older people, retirement villages offer an appealing lifestyle for the many older people looking to downsize and stay connected with supportive peers.

A recent estimate suggests that approximately 39,000 people live in New Zealand's retirement villages, a threefold increase since 2008, and perhaps representing as many as one-eighth of all Kiwis over 75. Demand to stay at a retirement village has yet to reach its peak, as our ageing population will continue to balloon over the next few decades.

And yet, despite the increasing importance and popularity of retirement villages in New Zealand, researchers know very little about these semi-closed communities. Demographic information, social engagement, health, and disability issues – much of this remains unexplored.

Ageing Well Principal Investigator, Professor Martin Connolly, wanted to learn more. The Head of Department of Geriatric Medicine at the University of Auckland, Professor Connolly realised that obtaining this information would allow policymakers to plan prospective treatments and strategies for vulnerable residents.

"The basis for the current study", Professor Connolly relates, "was our belief that retirement village residents may have multiple unmet needs together with declining medical and functional 'trajectories', and that a targeted intervention might, for example, decrease the risk of hospitalisation."

Essentially, the research team wanted to find and help vulnerable residents with their health difficulties so that they could stay well, and avoid entry in hospital or



Ageing Well Principal Investigator, Professor Martin Connolly (University of Auckland)

aged care facilities. Such an outcome would be good for all concerned, as it would identify issues before they became too acute, and thus reduce the future demand on the healthcare system.

The project was ambitious, with three separate but connected phases. The first phase sought to conduct a survey. Residents and village managers would be asked to participate and provide a variety of information, including health and social information. The second phase drew on a cohort of participants and tracked the trajectory of their health over three years, looking for adverse outcomes. A final phase involved a Randomised Controlled Trial, which aimed to test interventions to see if they made a difference to the health and wellbeing of the most vulnerable residents identified in the second, cohort phase. Overall, the project hoped to gather data on residents, and identify and help potentially vulnerable residents. Despite the increasing importance and popularity of retirement villages in New Zealand, researchers know very little about these semiclosed communities.

However, the research was stymied slightly by a number of unforeseen factors. Recruiting a representative sample of residents from 34 Auckland villages (those who agreed to participate in the project) proved extremely difficult. New Zealand legislation prevents residents participating in research if they "lack" the capacity to consent (even when they have an appointed "Power of Attorney"). Everyone with a cognitive score under a certain level (potentially people the researchers would want to find ways to help) had to be automatically excluded.

Another stumbling block was physical access to potential study participants. Many village managers, citing resident privacy, were unwilling to let researchers recruit for the study in the planned manner. Letter drops and door-knocking were often prohibited, except in some cases where a residents' meeting agreed to them. Other recent international research has struck similar problems, Professor Connolly noted.



These barriers led to a skewed sample of potential participants. Of the 34 villages, only 11 permitted researchers to obtain a randomised sample of residents. Non-random volunteers made up the remaining participants from the other villages. Given the relatively low participation of villages (34 of 53 contacted), lack of representative sampling, and the fact that the resident response rate was low (approximately 35%) in the 11 villages with random sampling, it is likely that many more such residents were unaware of the study, or were "excluded" by village managers, Professor Connolly explains.



Even so, 578 residents from 33 villages did participate. Armed with imperfect but pioneering data, Professor Connolly's team was still able to reach important conclusions. Eighty two, for instance, was the median age of residents; only 27% were men; and 61% lived alone.

Vaunted for their sense of community spirit and peer togetherness, the study found that retirement villages were not immune to loneliness: 39% of residents described feeling lonely "sometimes", "often" or "always". As one resident put it, "we're independent, so it's left up to us [to socialise]."

Downsizing (77%), less stress (63%), and access to healthcare assistance (61%) were the most common reasons for entering villages.

Residents did not always thrive in villages. High blood pressure, heart disease, arthritis and pain were reported by over 40%. Many struggled to manage heart and lung conditions (50%) and pain (48%), which proved to be where the most "unmet need" was. Evidently, to ensure that residents' health and wellbeing thrives, new initiatives are needed.

The results provide a new opportunity to "better manage" the health conditions and care of village residents, Professor Connolly concluded. Partnership may be the key. He believes healthcare service providers and village operators could "co-operate" to introduce new initiatives that better meet residents' needs. Such an approach would benefit both sides, he argues. As noted elsewhere in some of Ageing Well's other projects (such as those run by Professor Gott and Drs Keeling and Jamieson), loneliness is a major challenge for older New Zealanders, but not something that policymakers may have thought would be an issue at retirement villages. The study recommended looking for ways to identify loneliness early, and to carry out proactive interventions that positively improved residents' wellbeing.

Retirement villages are a booming industry. They are fast becoming the de facto retirement alternative to living at home or entering an aged care facility. This timely, novel study represents the largest investigation into the health and wellbeing of residents in New Zealand retirement villages.

This research is ongoing, and the information gathered will inform policymaking and future interventions at both the local and national level. It is to be hoped that as interventions are developed as a result of this study, retirement village residents can stay healthier and connected for longer and avoid burdensome and premature entry into hospitals and aged care facilities.





#### Che study revealed that partnership between healthcare service providers and village operators may be the key to introduce new initiatives that better meet residents' needs.

### TĀPINGA 'A MAAMA Pacific families need support caring for dying relatives



Ageing Well Principal Investigator, Dr Ofa Dewes (University of Auckland)



Most Pacific Peoples wish to die at home, surrounded by aiga (family), a pioneering Ageing Well study has found. Yet, despite these wishes, and despite successive governments calling for palliative care to shift into communities, Pacific Peoples remain the "disadvantaged dying", according to Dr Ofa Dewes, the study's Principal Investigator.

Death is one of the most significant moments in a person's life. Receiving compassionate, culturally appropriate end-of-life care is fundamental for the individual, their family, and the wider community. Such care should not be a privilege but a right.

For Dr Dewes, who is a research fellow at the University of Auckland's School of Nursing, "ageing well must also include dying well". But sadly, most Pacific Peoples in Aotearoa New Zealand are not receiving the appropriate end-of-life care that they need, and many rely on aiga to fill the gap.

"Pacific older adults have high levels of unmet need and poor access to palliative care while dying," said Dr Dewes. "Little is known about their preferences for care at the end-of-life or those of their aiga carers. That is why this study is so timely and relevant."

The aim of this research was simple but vitally important: improve end-of-life care for Pacific Peoples, and for aiga supporting them. Findings would help inform government policy, and provide information to the Pacific community.

Dr Dewes embarked on a two-year study examining how, through the eyes of their bereaved aiga, 33 terminally ill Pacific people experienced death in Aotearoa New Zealand. The aiga participants were a map of the Pacific itself: Samoan, Tongan, Cook Islands Māori, Niuean, Tuvaluan, Tokelauan, iKiribati and Māori. Seventy-nine percent were female, and their average age was 48. Dr Dewes' team conducted individual and focus group interviews with the aiga carers and key stakeholders. The interviews allowed for policymakers in the public sector (through the medium of Dr Dewes' advocacy) to hear directly from the minority voices seldom heard in Aotearoa New Zealand.

#### So what did the researchers discover?

Pacific older adults overwhelmingly favour dying at home. As one woman explained, "we want to be with our family at this time." Most aiga carers want it that way too, even though "at times it wasn't easy", says study participant Reverend Suamalie Iosefa Naisali, who cared for his late wife.

Children sometimes had to quit school to look after parents and grandparents. One participant dropped out of school at 17 because "mum was struggling". She felt she "didn't have a choice" as her mum "needed me". Most don't regret this choice but concede it is



Co-investigator Malia Hamani from TOA Pacific Inc, Reverend Suamalie Iosefa Naisali, and Dr Ofa Dewes.

very disruptive to their lives. Such a choice can also be "financially challenging" and "relentless", observed Dr Dewes.

Spirituality plays a central role in supporting both the carer and loved ones through illness and age-related conditions. Some carers made a "promise to God" to look after their beloved and dropped everything in their own lives to honour that promise. Other carers would lift the spirit of an ailing relative, and themselves, by dancing, a key aspect of Pacific spirituality, and something outside the traditional spectrum of Western palliative care provision.

Flowers and gardening also provided great comfort to loved ones nearing end-of-life. Often the "Church community" stepped in to provide "informal support" so that carers can look after a loved one, Dr Dewes explains. Pacific families often 'engage' and 'draw strength' from their Church family. While many carers were unaware of support available, others found the idea of accessing support unpalatable. Dr Dewes found participants' feelings about such assistance – if they knew it existed at all (and many did not) - was "mixed". She argued strongly that family carers "must be involved in the development of Pacific-tailored interventions so that they can have confidence that their loved ones will receive 'culturally safe' and 'responsive' care."

Extensive caring tasks in the Pacific community are carried out by family members. Looking after someone with a terminal illness is a challenge, and significant support is required. Mobilising the entire family including younger members – is essential, as aiga carers will need support whilst they care for their dying loved ones. The physical and emotional demands, financial burdens, and need for support all mount up and can easily overwhelm carers. Yet in the face of these challenges, Dr Dewes said that families find ways to "cope".

Dr Dewes also noted that through the study, the team learned that Pacific Peoples are suffering from metabolic diseases. Indeed, many of the dying loved ones had type-2 diabetes, and cancer.

Study findings were presented at workshops for the Ministry of Social Development to inform the Pacific content of "Mahi Aroha: Carers' Strategy Action Plan 2019-2023", a strategic, cross-governmental action plan to support family carers. In addition to this, fonos (conferences) were held at the community, regional, national, and international levels to spread the study findings.

This project was also about giving a face and voice to Pacific Peoples who are seldom seen and heard in Aotearoa New Zealand on issues directly concerning them. Fittingly, a music video, *I'll Care For You*, was created at the suggestion of the study participants, who felt it would be the most appropriate medium to spread their message into the community.

For Pacific Peoples, music is almost spiritual in its power. Aiga carers wanted to convey the importance of supporting people in the community who care for their older relatives, especially at the end-of-life — two carers themselves appeared in the video.

**G** For Pacific Peoples, music is almost spiritual in its power and study participants helped create a music video, I'll Care For You, to spread their message into the community.

Five 'digital stories', short videos narrated by aiga carers, were also created to give voice to caregiver experiences. Each participant developed their story and spoke about the experience of caring for a dying loved one. Reverend Naisali was one of the participants who agreed to make a digital story to voice his experience of caring for his ailing wife at the end.

The powerful and poignant stories have been released across social media platforms and on Dr Dewes' website to share with the community at large the experience of aiga carers. Reverend Naisali's video has been viewed over three thousand times on Facebook alone by people here in Aotearoa New Zealand, the Pacific, and around the world. Designed as educational resources, these stories raise awareness about the challenges facing aiga carers. The music video and digital stories also tap into Dr Dewes' wider mission: making health research and advice accessible to the Pacific community.



Two key recommendations emerged from the study findings. Malia Hamani, an investigator on the study and the Chief Executive at social services agency Treasuring Older Adults (TOA Pacific Inc.), argued the government should allow funding for family carers to support them. Dr Dewes also proposed developing a pathway for aiga carers to 'transition' into the aged care workforce. "They have learnt the skills and coping with all the different responsibilities that a carer provides at end-of-life. This is a workforce that is yet untapped," she said.

Dr Dewes' study provides urgently-needed information on Pacific Peoples experiences at end-of-life. It also brings into sharp relief the challenges faced by aiga who carry out the bulk of their dying relative's care. "Carers need help". That's the message Dr Dewes believes needs to be truly heard. And hopefully as a result of this unique and poignant study, help — from the wider Pacific community and from government agencies at large — is on the way.

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### **STOPPING THE** 'STROKE TSUNAMI' **Can health and wellness** coaching be the cure?

The tragedy of strokes is that they are always devastating but rarely inevitable. Indeed, in recent years, researchers have discovered that many, if not most, strokes are preventable with a combination of medication and lifestyle changes.

Yet, unfortunately, despite being avoidable in most cases, stroke and cardiovascular disease (CVD) remain a major cause of death and disability worldwide. And the situation is only getting worse: if it maintains its current trajectory, stroke is predicted to become the leading cause of death and disability globally.

New Zealand has not been spared. Around 9,000 people suffer strokes annually, with almost a third of victims dying within a year. Tens of thousands of survivors often need round-the-clock support and rehabilitation as a result). And we compare poorly with our neighbours across the Tasman.

Recent studies have shown that, on average, per 100,000 people, 119 Kiwis suffer strokes compared with 76 Australians.

### So how did we get here?

Part of this situation may be explained by the fact that public awareness about stroke is low, particularly in lower socioeconomic and minority communities. Our demographics are also not working in our favour. Although a stroke can occur at any age (and, troublingly, they are increasingly affecting younger people) the disproportionate number of them occur in older adults and Māori and Pacific people. Such statistics do not bode well for a nation with a booming ageing population.



Ageing Well Principal Investigator, Professor Valery Feigin (Auckland University of Technology)

Researchers have shown that up to 80% of strokes are preventable. With lifestyle changes (such as healthier eating and getting more exercise), medication where appropriate, and a reduction in risk factors such as high blood-pressure, every New Zealander could dramatically lessen their chance of having a stroke.

Though strokes are preventable, the number of people suffering the disease — the 'burden' of stroke — has skyrocketed since the beginning of the twenty-first century. As a result, scientists and physicians are now in a race against time to stop a looming 'stroke tsunami'.

Ageing Well Principal Investigator, Professor Valery Feigin, of Auckland University of Technology, believes there needs to be a sea change in how countries engage in stroke prevention. A recipient of the Royal Society of New Zealand's prestigious MacDiarmid Medal, Professor Feigin developed a ground-breaking app, Stroke Riskometer™, which allows anyone to assess their risk of stroke, and provides them advice to reduce that risk. The app is free, easy to use, and was voted the best health app in the world for 2015. The app is also a unique window into how Professor Feigin would like us to think about stroke prevention.

The current management of stroke risk "has not been sufficiently effective", Professor Feigin explains, "as the focus at present is on high-risk prevention, which aims to identify those most at risk of stroke, yet the most acute cardiovascular disease events occur in people with low to moderate risk." Those who fall into this category were basically given a faulty reassurance of a low risk that did not motivate them to control their risk factors, and the treatment preventative strategies were largely reserved for those deemed high risk.

For this reason and others, Professor Feigin and colleagues have been advocating that stroke prevention should be occurring at all levels of risk - what is known as "population-wide" prevention strategies. This approach focuses on seeking to identify and reverse stroke risk in all people before it is too late. The strategy relies on a psychological approach spread the word about stroke, find those at risk, and encourage behavioural changes that prevent stroke. But there is a problem.

### MOTIVATION

Making lifestyle changes like switching to a healthy diet, stopping smoking, and getting regular exercise are often difficult to sustain. Professor Feigin notes that sticking to the "recommended medications" to reduce blood pressure and adopting "healthy lifestyle" changes "seem the main obstacle to effective CVD prevention". And yet, making these critical behavioural changes and sustaining them could be the single greatest way to power our way to stroke prevention.

This is why Professor Feigin's Ageing Well research focused on Health and Wellness Coaching. The coaching is a new, patient-centred strategy aimed at motivating participants to stick to their recommended medical and lifestyle changes to prevent stroke or CVD. In overseas studies, Health and Wellness Coaching has demonstrated its effectiveness for non-stroke and non-cardiovascular disease prevention. However, could the results be replicated for stroke and other cardiovascular diseases in a diverse nation like New Zealand? Professor Feigin and his team wanted to find out.



**C** Though strokes are

preventable, the number of people suffering the disease has skyrocketed since the beginning of the twenty-first century. As a result, scientists and physicians are now in a race against time to stop a looming 'stroke tsunami'.

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Ageing Well Co-Principal Investigator, Associate Professor Rita Krishnamurthi (Auckland University of Technology)

The team embarked on a preliminary scientific trial. Over 300 Māori, Pacific, European, and Asian participants provided an ethnically diverse sample for the investigation. All participants had an elevated 5-year risk of CVD that was greater than 10% above normal. Split into two groups, the participants were either placed in a 'usual care' group (known as a 'control group') or the Health and Wellness Coaching group. For those in the latter, trained coaches provided fifteen coaching sessions that took place both in person and over the phone for six weeks. After measuring participants' stroke risk and various risk factors at the outset of the investigation, the plan was to see if risk factors reduced following completion of the coaching programme (at 3, 6, 9, and 12 months postintervention respectively).

#### COACHING

Health and Wellness Coaching is about giving people the ability and confidence to take control of their own healthcare. "It strives to encourage and motivate people to improve their self-management of their health and wellbeing," Associate Professor Rita Krishnamurthi, a coinvestigator on this project, explained. "It is very much client-centred,".

Coaches, all trained using the gold standard International Coaching Federation's Core Competencies, aimed to assist participants to increase their 'selfawareness' and feel 'empowered' to set goals and reach their targets. For some participants this meant simply becoming more aware of the risks and taking small, steady steps towards improving their health; others joined a gym or started going to the marae; and others changed their diets.

The results were mixed but promising. Although overall stroke risk was not statistically significantly reduced as a result of Health and Wellness Coaching, it did show a trend towards reducing and —crucially — improving overall cardiovascular health risk factors, including blood pressure, which is the biggest single cause of strokes. Essentially, if we can reduce the nation's high blood pressure and improve cardiovascular health we would be well on our way to meaningful stroke and cardiovascular prevention.

Potentially, then, Health and Wellness Coaching may be a practical, motivational and cost-effective way to reduce CVD and stroke risk, especially in people at moderate to high risk. Based upon this project, Associate Professor Krishnamurthi was awarded a further grant co-funded by Ageing Well and Brain Research New Zealand to continue with this investigation, as it is now important to see how the participants in the study track over a longer period of time (3 years).

Initial evidence suggests that the benefits of the coaching are sustained over the long term and, even at this early stage, may lead to a 4-8% reduction in strokes, which equates to a reduction of 300-500 cases a year nationally.

Such a reduction is not only good news for those who avoid stroke, but the economic benefits to the healthcare system arguably make it more palatable than any current alternative. Given the fight we are in against a rampant, ascendant disease such Health and Wellness Coaching may well provide our most promising stroke prevention strategy yet.

### Health and Wellness Coaching may be a practical, motivational and cost-effective way to reduce CVD and



stroke risk, especially in people at moderate to high risk.

### ALL THE LONELY PEOPLE Chronic loneliness and premature entry into residential care



Ageing Well Co-Principal Investigator, Dr Sally Keeling (University of Otago)



Ageing Well Co-Principal Investigator, Dr Hamish Jamieson (University of Otago)

Loneliness is doing unmistakable, if largely unseen, damage to the health and wellbeing of too many older New Zealanders. Everyone is lonely at some point in their lives, but for older adults feelings of loneliness can be hard to keep at bay.

Ageing Well Co-Principal Investigators Dr Sally Keeling and Dr Hamish Jamieson, of the University of Otago, Christchurch, embarked on a project that aimed to measure exactly what impact loneliness and social isolation have on older people's health.

They knew loneliness and social isolation are both problems, but they weren't sure just how big a problem, especially when "compared with other more medical factors," Dr Jamieson, who is also a geriatrician with the Canterbury District Health Board, explains.

One question underpinned this research: are loneliness and social isolation putting people at higher risk of admission into an aged care facility than common medical conditions?

Learning the answer to this question would have big implications for health professionals, service providers, scientists, and policymakers. Measuring loneliness and its effects is not easy. Everyone, after all, experiences feelings of loneliness differently. And loneliness is slippery. It is intangible—it is difficult to pin down and gauge accurately. It is a state of mind and perception.

But, as the researchers realised, New Zealand has a world-leading advantage: the InterRAI database (see also Dr Jamieson's other study, the Drug Burden Index earlier in the book). InterRAI is the world's first standardised, comprehensive record of older people's health needs. Every adult over 65 entering care undergoes an assessment. Drs Keeling and Jamieson and their team are responsible for deciphering its contents, unlocking



its potential and bringing meaning to several other previously underappreciated clinical datasets.

As an early adopter of the InterRAlassessment tool, New Zealand has clinical information dating from 2011. That represents countless interviews with older New Zealanders, all taking place at the point of care, all furnishing nuggets of information on cognition, mood, diet and social engagement. Data aplenty, if it could be put to work.

Taking a huge chunk of these data — researchers retrospectively drew upon almost 72,000 older Kiwis' responses to the clinical assessment over a five year period — Dr Keeling, Dr Jamieson, and their colleagues examined responses to a section that dealt with social engagement.

Computers crunched the interRAI data to provide a statistical report card on older people's loneliness, and researchers then matched it with health outcomes and living arrangements.

What the research team discovered was slightly unexpected. Most older people surveyed (79%) said they did not feel lonely. However, that still meant that one in five older adults (21%) did self-report feeling lonely some or most of the time. That's over 15,000 people essentially feeling "chronically lonely", Dr Jamieson says. Of these, those who lived alone were more at risk of loneliness (29%) than those who lived with family members or in shared living situations (14%). Being lonely affects everyone differently. Different ethnicities were susceptible to different degrees of loneliness (see the research by Professor Gott and the team of Waldegrave, Tamasese, and Professor Cunningham). Amongst those living alone, older Asians reported being the loneliest (23%) compared with Pacific peoples (17%). Nevertheless, provision of support and appropriate help for vulnerable lonely adults should be understood in this context.

Geography and wealth also play a part in loneliness. Rural areas enjoyed lower rates of loneliness, except Pacific peoples in those communities. And loneliness also increased with social deprivation, a finding that concurs with previous New Zealand studies.

If you are socially isolated and lonely, you are more at risk of depression and anxiety, and some chronic conditions, such as pain, can become worse. The information gleaned from the study can be used to improve "individual care planning", and integrated into health and social services provision. Loneliness also contributed to making people feel unwell, the study found. As Dr Jamieson puts it: "If you are socially isolated and lonely, you are more at risk of depression and anxiety, and some chronic conditions, such as pain, can become worse."

### So could interRAI also offer any insights into why older people entered care homes?

It did; and the answers were surprising. Looking specifically at "social factors" that led to care home admission, Jamieson's team found four things spiked the chances of entry dramatically: loneliness; living alone; carer distress; and lack of positive social interactions. Lonely people were almost 20% more likely to enter a facility; those living alone were 43% more likely to enter care; those with stressed carers were 28% more likely; and those who reported negative social interactions were 22% more likely.

Contrast this with a common medical condition that leads to care entry: incontinence. That issue only raises a person's chances of entering care by 11%. Social factors, the researchers realised, often proved more decisive in residential care admission than some medical factors. More interesting still, lonely and isolated older adults were entering care even when they were otherwise physically well, Dr Jamieson said.

Carers, often families or whānau, strive to support their loved ones staying at home. Many carers (particularly spouses) are themselves experiencing age-related health concerns. But this long-term and demanding caring eventually becomes "exhausting" and led to aged care entry Dr Jamieson reports (for a notable exception, see Dr Ofa Dewes' study on Pacific peoples).

Dr Jamieson said it was "sad" that so many older New Zealanders were experiencing extreme loneliness. Part of the explanation for these statistics, he said, was that society is more "fragmented" than in the past. Families are more likely to be geographically dispersed, and few non-Māori and non-Pasifika elders share the same house with younger family members, neighbours are not visiting each other as much, and community hubs (such as dairies and post offices) are no longer the sites of local interaction.

Findings from the study were presented at an interRAI Services event in Wellington. Eighty people attended Dr Jamieson's presentation (in person and remotely), most coming from key government departments, social agencies, and NGOs.



The healthcare sector is beginning to see that older people's health is not just affected by physical or medical factors – social isolation and loneliness are "causing the real problems" for our seniors, Dr Jamieson says.

Indeed, more attention needs to be paid to social factors in supporting older adults to age well. New Zealand also needs to put better social support and service provision in place. Based on ethnic identification and living arrangement information, efforts to reduce the negative impacts of loneliness also need a nuanced, culturally appropriate approach.

Researchers achieved several other novel accomplishments as a result of this project. They contributed to building New Zealand's own older people's evidence base "within the interRAI methodology". And the information gleaned from the study can be used to improve "individual care planning", and integrated into health and social services provision.

There is an old saying: "in God we trust; everyone else bring data." This Ageing Well study has marshalled tens of thousands of people's anonymised data to lay bare the damage and consequences of loneliness and social isolation in New Zealand. Now health professionals and policymakers can begin to act upon these data.

### HEALTHY PACIFIC GRANDPARENTS Understanding older Pacific peoples' views on ageing

Meeting the needs of Aotearoa New Zealand's older Pacific People is a challenge. A raft of barriers exists that prevents them enjoying equitable health and wellbeing. Disadvantage ranks most prominently.

The price of visiting GPs, or of collecting a prescription, for example, can often dissuade older Pacific people from accessing appropriate healthcare. Additionally, cultural and language barriers also contribute. Many older Pacific people do not feel like they will be cared for in a culturally safe manner.

These factors — and many others — have all "contributed to Pacific peoples having poorer health and greater unmet needs", explained Ageing Well Principal Investigator Associate Professor El-Shadan (Dan) Tautolo. Pacific people are the only ethnic group in the nation whose mortality rate has stagnated rather than decreased in recent years.

Associate Professor Tautolo, the Director of the Centre for Pacific Health and Development Research at Auckland University of Technology, has consistently been interested in addressing the needs of Pacific communities in New Zealand.

In this study, Associate Professor Tautolo and his team wanted to understand older Pacific peoples' views on ageing.

What are their needs, what do they consider the barriers and opportunities to accessing healthcare?

And what matters to older Pacific adults when it comes to social participation and healthy ageing?

These questions are particularly apposite because the number of Pacific people over 65 is expected to rise by 70% over the next two decades, according to Statistics New Zealand.



Ageing Well Principal Investigator, Associate Professor El-Shadan (Dan) Tautolo (Auckland University of Technology)

"Our older Pacific adult population is growing faster than our younger population, and they're living longer lives as well," says Associate Professor Tautolo. But research on Pacific people has been relatively limited. The current study sprang out of Associate Professor Tautolo 's directorship of the Pacific Island Families study, a pioneering longitudinal study of 1,400 Pacific children born in Auckland in 2000.

One of that study's most important discoveries centred on the importance of culture. A strong cultural identity, the study showed, was good for Pacific peoples' health. Those who were in sync with their culture had better health outcomes than those who lost their cultural mooring. Some of the grandparents of the children in the longitudinal study agreed to take part in this new study, eager to also make a "contribution" to their community. Other recruits were found by a major stakeholder of the project, Vaka Tautua, a 'by Pacific, for Pacific' social and healthcare services provider.

Three Pacific ethnic groups were involved—Samoan, Tongan and Cook Islands Māori. Admittedly these three groups represent only a few threads in the diverse tapestry of Pacific people. But they do still make up a significant chunk of New Zealand's Pacific population. Nearly 100 Pacific grandparents volunteered, over a period of more than two years.

By design, the Pacific grandparents were not simply participants but also "co-researchers", Associate Professor Tautolo says, leading the charge to fix the very health and wellbeing problems they faced. They were involved in every aspect of the project — design, development, and evaluation. Feeling "empowered", the grandparent-researchers enjoyed the reciprocal nature of the research: participants gained skills; researchers gained knowledge. Participants took ownership to identify and address the biggest challenges they faced; researchers assisted in co-designing potential solutions to these challenges and working with support services. Genuine engagement was a critical part of the project. Fostering trust and communication amongst the different Pacific communities was not easy, as language barriers and small differences did exist: Pacific groups are not a monolithic group after all.

By design, the Pacific grandparents were not simply participants but also "co-researchers"... leading the charge to fix the very health and wellbeing problems they faced.



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"Our primary focus", explains Associate Professor Tautolo, "was to engage and develop a co-researcher relationship with our Pacific older people, to ensure that our project identified and addressed the issues which were directly relevant for them."

The grandparents' health priorities were somewhat unexpected. After much discussion, they wanted to focus on two, achievable areas: foot health and digital literacy. Researchers set about supporting the participants to find ways to address these issues.

The team created a "podiatry assessment action plan", Associate Professor Tautolo notes, which was tailored individually to all the different ethnic groups. "We came up with a foot screening and maintenance programme which was supported by Auckland University of Technology's Podiatry Department and delivered to the different Pacific ethnic groups within their community settings." The study found that this focus on foot care "improved mobility, independence and reduced the likelihood of going to hospital."

Providing the care within the Pacific community proved critical, something the participants advocated for strongly. As Associate Professor Tautolo explains, it "allowed them to be more in control and familiar with the location – and also gave the podiatry staff and students who were part of the initiative, some valuable experience engaging Pacific people within a community setting." A win-win situation.

High demand for podiatry assessments suggests that folding a podiatry check into outpatient healthcare assessments in ethnic-specific community settings could be an effective way to head off more serious complications, Associate Professor Tautolo argues. Older Pacific people appear at a higher risk of feet and lower limb health issues. So this small change could make a big impact to improving their overall health.

Getting to grips with digital technology was also important to the Pacific grandparents. Associate Professor Tautolo's team worked with a local public library in South Auckland to design sessions that allowed the participants to get support and guidance to harness the benefits of computers and software. Staying connected and learning how to access creditable information safely were integral to this guidance.

All of the grandparent-co-researchers were "very happy with the project" and the way their involvement refined and improved services that existed within the community for older Pacific peoples. Several participants spoke of the "empowerment" and "sense of value" that involvement in the project inspired in them. This was achieved because of the participatory nature of the project and would not have occurred in a "more traditional" research study, Associate Professor Tautolo explains.

The lessons from the study have been spread far and wide, and in unconventional ways. During Fijian language week, the research team released a video, narrated in Fijian with English subtitles, summarising the study findings. Associate Professor Tautolo also addressed over 250 stakeholders at the Pasifika Medical Association Conference in Auckland in 2018, and at the International Association for Gerontology and Geriatrics Asia Oceania meeting in Taiwan in 2019.

The Study's collaborative nature has important ramifications for future New Zealand research, especially with minority groups. Associate Professor Tautolo's and their community of participants demonstrate the benefits of collaborative research partnerships, especially among a population that is often isolated and unheard. Associate Professor Tautolo's team co-designed questions and conducted research with Pacific families and their communities in culturally appropriate ways to enhance health outcomes.

Make no doubt about it: Pacific Island grandparents participated in, and co-led, this study. It was their research, their results. It is no wonder that the outcomes were so positive.



Associate Professor Tautolo's team co-designed questions and conducted research with Pacific families and their communities in culturally appropriate ways to enhance health outcomes.



### **BACK TO CLASS: Older Kiwis take cookery** and fitness courses



Ageing Well Principal Investigator, Dr Ruth Teh (University of Auckland)

Becoming frail, it is often thought, is part of growing old. Part of the inevitable decline that happens as we enter the twilight years. Brittle bones are more susceptible to breaks, and atrophying muscles struggle and strain to perform once-simple functions.

Frailty is actually a complex medical condition that is usually a harbinger of poor health. And although frailty affects people of varying ages, it is more common in older adults, who are most suspectable to the knockon effects, especially falls. Frail older adults have higher levels of disability and often need significant healthcare.

### But what if we could stave off frailty? What if we could encourage healthy and active ageing to maintain older people's independence?

Finding novel and meaningful ways to stop the advance of frailty is a top priority for Ageing Well. New Zealand

already boasts programmes designed to prevent frailty, and two such classes have become very popular with seniors. They are Age Concern Otago's Steady As You Go (SAYGO) and the Canterbury District Health Board's Senior Chef.

SAYGO, established in consultation with the University of Otago, is a 10-week peer-led strength and balance exercise programme for people over the age of 65 living independently in the community. Senior Chef is an 8-week cookery course for people over 60, who want to improve their cooking skills. Both courses aim to improve older peoples fitness and nutrition respectively.

How effective are these programmes? And, if they are effective, should they be rolled out more widely or in concert? Ageing Well Principal Investigator, Dr Ruth Teh, wanted to subject these promising programmes to a rigorous scientific evaluation.

First, she assessed what the programmes did to promote health and wellbeing. Then, her research team sought to analyse whether the programmes were costeffective when compared with other interventions-or the cost of doing nothing.

Dr Teh, a Senior Lecturer at Auckland University, credits her grandmothers for her fascination with older people's health: "My maternal grandmother encouraged me to advance my studies, and my late paternal grandmother inspired me to do research with older people."

With her strong role models as a guide and "case studies", Dr Teh developed an interest in finding ways to ensure older adults enjoy a good quality of life: "It is most rewarding to hear how the research we are doing makes an impact in an older person's life; the smiles on their faces [during the courses] are just priceless."

**C** The early results are promising. SAYGO participants demonstrated understanding of food and nutrition.

Undertaking a rigorous scientific experiment, known as a Randomised Controlled Trial, older adults from several sites across New Zealand were randomly selected to participate. All participants were "pre-frail", which means they were not suffering from any of the adverse effects of frailty. They were then placed into one of four groups: SAYGO; Senior Chef; SAYGO and Senior Chef; or a socialising group. After the participants completed their respective programmes, they underwent four follow-up assessments: one immediately after the trial, and the rest at 6, 12, and 24 months respectively.

John participated in the Senior Chef programme The early results are promising. SAYGO participants demonstrated better balance, gait, and strength after their programme; Senior Chef participants displayed improved cooking skills and a better understanding of food and nutrition. An unexpected benefit was that study participants treasured the "camaraderie" and increase in social networks that the courses created. The courses have transformed the lives of many of the study participants.

"It's opened up a whole new world for me," recalls John, a participant in the study's food and nutrition course, Senior Chef. Before the course, John's cooking skills were rather limited. Aside from "mashing potatoes" and "frying fish" most cooking had fallen to his wife.

"I was basically lost in the kitchen", John relates. The Senior Chef course changed all that. Not only was it "enjoyable" but it "made you want to learn." Participants engaged in discussions about nutritious foodvegetables, dairy and protein, as well as food labels, were now all on John's radar. Putting their new found knowledge to use, participants worked together to prepare and share meals, all under the watchful eye of an experienced instructor.

# better balance, gait, and strength after their programme; Senior Chef participants displayed improved cooking skills and a better



In addition to learning how to prepare meals, there were great social benefits too: "I enjoyed mixing with everyone" John says. Two or three times a week now John prepares meals. Shopping at his local butcher he's trying new chicken cuts and thinking about pairing food: "I ask them, well if I bought that type of cut, what vegetables would I put with it?"

A recipe book was created by study participants which John describes as "perfect...it's simple, easy to read and takes you through all the steps you need in each recipe". He has now gone well beyond the lessons he learned on the course. On one occasion, with the help of the Google search engine, he bought some King Prawns "and I cooked them with a mixture of butter, oil, garlic and chilies and they were divine". Not bad for a man whose previous specialty was mashed potatoes.

Armed with his new nutritional knowledge, John is not looking back: "I guess I can say that all the information, all that I've learned at Senior Chef is in my head now and it's not going to go away". Beverly was part of the SAYGO course. As a keen gardener, she came into the course with an overinflated sense of her own fitness, she recalls. "I thought I was too fit to do exercise. It had never occurred to me to do anything more than gardening, which I do quite a bit of. I didn't go to a gym or anything like that."

After starting the balance and strength classes, Beverly learned that "my balance was so poor" and that she lacked muscle strength. The unexpected revelations spurred her to put in the hard yards. Not only did she attend all 10 sessions of the SAYGO programme, she also started practicing exercises at home.

With a new exercise regimen, Beverly noticed amazing improvements. At the beginning of her programme, for instance, she could complete six sit-to-stand repetition exercises. By the end, she could do 20. She also learnt to walk with confidence. A course facilitator "taught us how to walk properly, telling us to place our heels down first so we don't trip or shuffle and I'm really conscious





of that now." Friends had suffered falls, Beverly said, so to get these "hints" was "very helpful". And walking has now become a big part of her life. Prior to SAYGO, she didn't walk much because of arthritis in her feet. But "now that I'm walking properly I find I can walk a lot further and I enjoy it; I try and go out three or four times a week. I walk down to the beach and back. It's 700 metres down to the beach from here". She has even introduced another friend to a different SAYGO course. Beverly is continuing to do her exercises with gusto. "I'm more conscious now of doing it because I know it's been of such a benefit to me."

Fighting frailty is an important way to ensure older New Zealanders age well. The SUPER study completed data collection in September 2020 (delayed by 3 months due to the pandemic). Preliminary results show that actively engaging seniors in cookery and fitness courses stalls frailty. Detailed analysis is ongoing and final results will be released starting in 2021. For participants like John and Beverly, however, the courses and the social connection have already changed lives. Celebrating Ageing Well

I'm more conscious now of doing it [my exercises] because I know it's been of such a benefit to me. - Beverly, SAYGO participant

### **TE WHAKAHAUMITANGA** Unlocking the potential of māturanga to support Māori women to age well within whānau

What do we know about how well older Māori women — kuia — are ageing in Aotearoa New Zealand? Not enough, it turns out, and certainly not enough from the voices that need to be heard: Māori women.

Dr Kirsten Gabel (Ngati Kahu, Te Paatu, Te Rarawa), a postdoctoral research fellow at the University of Waikato, undertook an Ageing Well project investigating the cultural context of ageing well for kuia (Māori women 55 and over), with specific reference to the value and esteem that kuia are held in, and the essential roles that they have in facilitating whānau and hapū wellbeing.

Adopting a kaupapa Māori approach, Dr Gabel aimed to unlock the potential of mātauranga Māori — Māori knowledge, especially knowledge of the ancestors that predates colonialisation — to inform, innovate, and strengthen approaches to positive ageing for Māori women: "Kia eke kairangi ki te tai kuiatanga", as Dr Gabel relates in te reo.

Māori, Dr Gabel believes, should draw upon their own knowledge and customs to rediscover ways to age well. "This project worked from the premise that mātauranga Māori has something significant to contribute to ageing and wellbeing outcomes," she explained. "In particular, our traditional mātauranga provide Māori women with a valid and effective framework of wellbeing from which to create foundational strategies for ageing well."

Dr Gabel set about understanding that framework. To do so, she focused firstly on reviewing historical literature related to ideas about ageing, and on the effect that colonisation has had on these ideas and particularly on the perceptions and understanding of the role of kuia in society.



Ageing Well Principal Investigator, Dr Kirsten Gabel (University of Waikato)

She envisages that her framework would ultimately "inform health providers and policymakers in their approach to supporting successful ageing for Māori women." The research also seeks to trumpet the positive aspects of ageing for older Māori women. Focusing on their strengths, the research "deemphasises the disability of kuiatanga, and centralises kuia mana motuhake: potential, capacity and ability."

### OUTCOMES

Dr Gabel explains that adopting a mataora (lifecourse) approach helps to establish how Māori women understand ageing. Māori tupuna (ancestors) had a strong approach to lifecourse wellbeing and there were key identified points in life when specific tikanga, karakia and ceremony applied to keep wāhine (women) in a state of wellbeing.

Another crucial lesson to understand about kuia ageing, Dr Gabel continued, is that ageing transitions occur not just on a physical level but on a spiritual and emotional level, too. This concept is known as He tauwhirowhiro ā wairua, ā hinengaro, ā tinana.

A different theme that emerges when ageing is viewed from a mātauranga Māori approach is rangatiratanga (self-determination): Women have integral roles within whānau, hapū, and iwi that evolve as they transition through their lifecourse.

Te Tamitanga (oppression) also features heavily in Māori women's relationship to ageing. Māori knowledge about ageing has been impacted by, has evolved and continues to evolve in the face of (ongoing) colonisation.

Kuia play a central role in the wellbeing of the whānau. If the women are well, so will the whānau be: He oranga wāhine, he oranga whānau. In a contemporary sense, Māori women continue to have a key role to play in the wellbeing of their whānau. Therefore, their wellbeing throughout their lifecourse is of vital importance.

Te Ao Hurihuri. Ageing well for Māori women involves reasserting/reclaiming their mātauranga where possible or practicable in the contemporary world.

### CONCLUSION

Kuia are held in high regard by their whānau, hapū and iwi. They play an essential role in "facilitating whānau and hapū wellbeing", Dr Gabel concluded. But they are not passive and selfless: being a kuia brings significant authority and responsibility.

They enjoy "an active role" in the raising of mokopuna (grandchildren), especially as they are a conduit for passing on key values, morals, and life-messages, Dr Gabel said. This is an empowering role as they are entrusted with the acculturation of the next generation. They are also on the front lines of raising the children in a way that is "culturally and spiritually relevant", especially in withstanding the constant interventions and impositions of the state. Being allowed to play this traditional role, Dr Gabel believes, is one of the chief factors empowering kuia to age well.





# **AGEING WELL** - BRNZ PROJECTS

Long-term effectiveness of health and wellness Coaching



Ageing Well Principal Investigator, Associate Professor Rita Krishnamurthi (Auckland University of Technology)

#### Stemming the tidal wave of strokes washing over our society is one of the biggest challenges facing scientists today. It is an urgent task, but one well within New Zealand's reach.

That's because existing evidence has laid bare a damning statistic: as many as 80% of strokes are preventable, with "adequate control of modifiable risk factors" Associate Professor Rita Krishnamurthi, of Auckland University of Technology, explains.

As described elsewhere in this book, Ageing Well funded Professor Valery Feigin and Associate Professor Krishnamurthi to undertake a trial examining the effectiveness of Health and Wellness Coaching. Trained coaches worked with groups particularly at risk of stroke, including Asians, Māori, and Pacific peoples.

The initial results were promising; Health and Wellness Coaching did appear to decrease levels of high blood pressure, one of the chief risk factors for stroke. But

pressure, one of the chief risk factors for stroke. But Associate Professor Krishnamurthi wanted to see if these gains were sustained over a 3 year period. She was awarded a grant co-funded by Ageing Well and Brain Research New Zealand to continue the investigation.

The outcome of her study suggests that Health and Wellness Coaching has the potential to improve lifestyle risk factors in those at increased risk of cardiovascular disease. As high blood pressure is the most significant modifiable risk factor for stroke, the study showed that implementing health and wellness coaching in primary healthcare has the potential to reduce the incidence of strokes.

By adopting a preventative approach to addressing risk factors for cardiovascular disease, Associate Professor Krishnamurthi's research suggests that it can help to reduce the number of people affected by stroke incidents (and by extension, those suffering permanent disability as a result of a stroke), as well as to reduce the stress on our healthcare system. With Aotearoa New Zealand's population over 65 years set to double by 2036, the effect that Health and Wellness Coaching could greatly improve the quality-of-life for those at risk of CVD as well as result in potentially sizable economic benefits for our healthcare and rehabilitation sectors.

Health and Wellness Coaching may not be a cure-all for cardiovascular disease, but early results indicate that we can make significant inroads in addressing the cardiovascular disease before it leads to stroke.

# **AGEING WELL** - BRNZ PROJECTS Adapting cognitive stimulation therapy for Māori and Pacific people



Ageing Well Principal Investigator, Dr Gary Cheung, (University of Auckland)

Dementia casts a pall over the later life of many New Zealanders, including a growing number of our Māori and Pacific peoples. Currently irreversible, no silver bullet has emerged to treat dementia-related illnesses, despite significant efforts from a large stable of global researchers.

For clinicians like Dr Gary Cheung, at the University of Auckland, focus has partly shifted instead to helping people with dementia to live well with their conditions. Cognitive Stimulation Therapy (CST), an evidencedbased psychosocial group treatment option, has buoyed scientists' and families' hopes. CST helps people with mild to moderate dementia cope with the loss of normal brain function. "It offers a way for people to live well with dementia. It helps to improve their quality of life", explains Dr Cheung.

How does it work? As the name implies, it's stimulation rather than medication. Trained facilitators meet people with dementia in small groups twice weekly as part of a seven-week programme. Sessions include activities, discussions and social interactions that aim to engage and stimulate. Clinical trials have shown that CST improves participants' lucidity and communications skills - and therefore their quality of life.

As part of his co-funded research, Dr Cheung wanted to adapt CST, which was originally developed in the UK, for a Māori and Pacific audience. "It lacked Māori and Pasific cultural content and values", he explains.

So his research team created a Māori CST manual to train facilitators to deliver the therapy in a meaningful way to Māori with dementia. With help from pioneering health professional Amohaere Tangitu (Ngāti Awa), a strong advocate for culturally aware patient care, every one of CST's key principles is now "embedded in kaupapa Māori", which gives the therapy a true cultural richness. "This is a huge step forward in ensuring the treatments work as well as it possibly can for everyone," says Dr Cheung.

Similar work is occurring to adapt CST to Pacific needs. Whilst Dr Cheung's team has not yet reviewed all the study's results, feedback from facilitators has been positive and encouraging. Dementia is becoming a greater threat to older Māori and Pacific peoples; hopefully these new culturally-tailored therapies can offer a brighter quality of life in the long shadow of dementia.

### AGEING WELL - BRNZ PROJECTS Exploring the needs of Pacific families affected by age-related cognitive impairment



Ageing Well Principal Investigator Professor Pauline Norris (University of Otago)

### What do you do when a family member is diagnosed with dementia? This is a question more Pacific families are having to face.

Though they remain a youthful group—almost half of Aotearoa's Pacific people are under 20—its population is also ageing at a relatively fast clip too. Not only will more Pacific people suffer from dementia in the next few decades, but there is also the suggestion that they may be experiencing cognitive impairments at younger ages than New Zealand Europeans.

This project, co-funded by Ageing Well and Brain Research New Zealand, sought to examine the services available to support Pacific families looking after a loved one with dementia.

Principal Investigator Professor Pauline Norris, of the University of Otago, wanted to know what are Pacific families' "unmet needs"—that is, when health and social service assistance is inadequate or absent— when dealing with the fallout of dementia.

Looking at what information and services are currently available to Pacific peoples, this project worked with stakeholders across Aotearoa New Zealand dementia services, medical centres, in-home services, volunteer organisations and NGOs — to identify what steps could be taken to improve support.

Pacific peoples in NZ have identified clear aspirations for thriving communities who are resilient, healthy and with strong ties to identity, language and culture. Older Pacific people play a key role as leaders in language and culture for their extended family and beyond, but healthcare providers and support services indicated the needs of older Pacific people experiencing cognitive decline were often not being met.

Three areas of particular concern were identified by all of the participants. Access to services, getting a diagnosis, and communication and language.

What the study discovered was that many Pacific people experienced a lack of information and therefore access to services. Diagnosis was often made difficult by inconsistent access to general practitioners in lower socio-economic areas and long wait times. Lack of information in Pacific languages that incorporated a Pacific world view made communication more difficult. There was also a lack of health workers across all sectors who spoke Pacific languages, and understood Pacific peoples' cultural needs.

By identifying the challenges facing Pacific peoples navigating the health care sector, changes can be made to ensure greater accessibility, communication, and support as they help their loved ones navigate life with dementia. Older Pacific people play a key role as leaders in language and culture for their extended family and beyond, but healthcare providers and support services indicated the needs of aged Pacific people experiencing cognitive decline were often not being met.



### THE WAY AHEAD The future of Ageing Well



Our aim is to undertake ground-breaking science with life-changing results. And, as the preceding pages have shown, Ageing Well is more than on the way to achieving this.

Though do not just take our word for it. Pleasingly, our progress has been independently reviewed and approved. In 2018, after a review of all National Science Challenges, the Honourable Dr Megan Woods, then Minister for Science and Innovation, announced that Ageing Well would receive funding to continue our research for another five-year period until 2024 (and hopefully beyond). This vote of confidence, and the additional funding (\$20.3M), empowers us to continue our vital work.

So now we are turning our attention to the future. Whereas our initial research was broad in scope and sought to tackle a number of challenges facing older New Zealanders, our current work is deliberately more focussed, and builds on the firm foundation established by our previous research and stakeholder engagement.

Ageing Well currently has two focus areas where we are directing our scientific investigation, decision making, and resources. The first area, *Ageing and Māori*, seeks to address the specific challenges and opportunities faced by Māori; the second area, *Health and Wellbeing in Ageing*, looks at building social connections amongst older New Zealanders, staving off social isolation and deterioration, and encouraging healthy, active lives. In addition, a *Strategic Investment Initiatives* fund has earmarked money for potential collaborations with other research funders where our visions and research missions overlap.

Our organisation aspires to make ageing well more equitable for all New Zealanders. That is why we have invested 50% of new funding into research on Māori and ageing, as Māori are disproportionately disadvantaged ageing, as Māori are disproportionately disadvantaged in their later years. In this vein, we have also embedded Vision Mātauranga not only into our research, but across our whole organisation. We recognise the importance of mātauranga alongside western methods, of engaging in Māori-led research, and of establishing enduring relationships with iwi. We are proud of the steps we are taking, but are clear-eyed about the work we still have to do.

Since our inception, Ageing Well has grown and evolved as an organisation, as we have adapted to the needs of our communities. We will continue to respond to the needs of the communities we serve and the challenges they face. As we embark on our next chapter of research, we also seek to reframe how Government and the broader public think about older New Zealanders. Far too often, the public discourse about New Zealand's older residents is framed in terms of "burden".





Ageing Well is acutely aware of the biggest challenges facing older people. As we continue our work over the next few years, we are striving to turn these challenges—social isolation, frailty and deteriorating brain health, inadequate housing, insufficient retirement savings, and systemic ageism—into opportunities and solutions.

We seek an Aotearoa in which all older New Zealanders play a vital role in our society, as experts, knowledge holders, and mentors; a society in which all older people lead healthy and connected lives; in which housing is built or adapted to their needs, and retirement planning ensures that the fewest end up in poverty; and a nation in which older people are valued for their amazing contributions. **That is a nation in which all older New Zealanders can age well — a nation that Ageing Well is on a mission to make reality.** 

# WITH THANKS

Ageing Well National Science Challenge would like to acknowledge the work of the following people who have helped shape our organisation.

#### **GOVERNANCE GROUP**

Ms Norah Barlow Mr Garrick Cooper Professor Peter Crampton Dr Will Edwards Ms Catherine Fyfe Ms Traci Houpapa Dr Di McCarthy Professor Helen Nicholson Dr Debbie Ryan Dr David Schaaf Ms Robyn Scott Mr Barry Smith (in memoriam) Ms Adrienne von Tunzelmann

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- Dr Moana Theodore
- Professor Debra Waters
- Professor Dave Baxter
- Associate Professor Louise Parr-Brownlie
- Mr Hata Temo



## AGEING WELL PUBLICATIONS

Even though impact is our primary focus, Ageing Well researchers have also published these papers that will benefit future researchers and policymakers.

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