The University of Auckland

Health, Independence and Caregiving in Advanced Age

Findings from LiLACS NZ

LILACS NZ

THE UNIVERSITY
OF AUCKLAND
NEW ZEALAND
Te Whare Wānanga o Tāmaki Makaurau

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> **'Breathing and enjoying life to the fullest of what twilight years I have left ahead of me. Life in general has its ups and downs, joy and sadness, but I'm hanging in there.'**
>
> **'Kia kaha, kia kaha e kete kia kaha.'**

… from a participant in LiLACS NZ,
Drawn from the Wave 3 questionnaire, in answer to "What are some of the highlights of this time of life for you"?

Increasing numbers as well as an increased proportion of people of advanced age is an international trend across developed and developing countries. Governments worldwide have been concerned about the economic and health care impacts of population ageing and research on this trend is urgently needed to support policy making. Research is also required on the experiences, needs, health and wellbeing of people of advanced age. New Zealand research is lacking, particularly research into the needs of the increasing numbers of Māori in advanced age.

Changing demographics will have major policy, funding and planning implications and the Ministry of Health needs to ensure that services are in a good position to meet the needs of older people. The Ministry and the sector requires evidence to prepare for increased demand for services, but there is an even greater imperative to focus on what keeps people well and healthy into old age. To make best use of information and improve our understanding of aging well, the Ministry commissioned this report based on insights from this advanced age cohort and their carers. This study is also the first and only research to provide information on the health of very old Maori, aged 80 plus, over time, essential for health and social sectors planning.

The LiLACS NZ research

Te Puāwaitanga O Ngā Tapuwae Kia Ora Tonu/ Life and Living in Advanced Age, a Cohort Study in New Zealand (LiLACS NZ) is a longitudinal cohort study of New Zealanders living in advanced age and has important linkages internationally with other longitudinal studies (see https://www.fmhs.auckland.ac.nz/en/faculty/lilacs/community.html). It is also the first such study in the world of an indigenous population. The goals of LiLACS NZ are to help people plan better for their own health and wellbeing in advanced age, allow older New Zealanders to share their wisdom with future generations and inform the development of local and national policies to benefit older people.

The knowledge, information and the investment in and outcomes of the research will inform policy development and service improvement. A number of short reports from this cohort are already published on https://www.fmhs.auckland.ac.nz/en/faculty/lilacs.html. These reports inform health service planners and providers in the aged care sector about the health and wellbeing of Māori and non-Māori people living in advanced age.

The aims of this report are to provide a longitudinal analysis of health, independence and care given and received by Māori and non-Māori living in advanced age. These aims are achieved through a focus on the study participants' contributions to others (Section Two), functional status and receipt of care (Section Three), relationships with carers (Section Four) and health-related outcomes (Section Five). **This executive summary outlines key findings of the LiLACS NZ cohort study in relation to these aims.**

The study was approved by the Northern Regional Ethics Committee (NXT09/09/088) in 2009.

Key Findings of LiLACS NZ

Who are the LiLACS NZ participants?

Table 1-1: Enrolment in LiLACS NZ

Enrolment		Data collection	
Maori – 421 people aged 80-90 years (42% men)*	Non-Maori – 516 people aged 85 years (46% men)*±	Six years annual collection (Waves 1-6)	
Carers of LiLACS NZ participants – 286 people		Wave 3 onwards	
Selected demographic data			
	Widowed	74% Maori women 42% Maori men	67% non-Maori women 31% non-Maori men
	Living alone	51% Maori women 27% Maori men	63% non-Maori women 32% non-Maori men
	Living in residential care	7% Maori	9% non-Maori

*The ratio of men to women matched the general population in their age groups
±For non-Māori, more men and fewer women were enrolled than expected (only 42 percent of this age group in the general population are men, owing to men's shorter life expectancy)

The LiLACS NZ Māori cohort is of unprecedented size and constitutes nearly one in ten Māori New Zealanders aged 80 years and over, providing far greater breadth of data and statistical power than any previous surveys or studies of older Māori. Of the Māori participants, 98% had been to a marae in the last year, around half could have an everyday conversation in Māori and three-quarters understood tikanga moderately or completely. Around half said their contacts were mainly with other Māori.

Overall, participant retention in LiLACS NZ compares favourably with similar international work and was aided by kaupapa Māori methodology, age-sensitive data collection methods and ongoing engagement with participants and their carers. The details of enrolment and data collection methods can be found in Section One of this report.

Contributions in advanced age

People of advanced age engaged in LiLACS NZ are mostly independent and living in the community.

They make contributions to whānau and family, communities and society.

They hold heritage, knowledge and tikanga, volunteer and sometimes still engage in paid work, and may be caregivers as well as recipients of care.

Volunteering and paid work

LiLACS NZ participants continued to volunteer as they grew older and a small number continued to engage in paid work. Voluntary work included:

- professional and leadership roles
- roles in Māori cultural activities and organisations
- contributing to a range of other voluntary organisations (health-related, religious, community projects)
- working in opportunity shops (mainly women)

Volunteering or paid work was associated with higher physical health-related quality of life (HRQOL).

Grand-parenting

Nearly all LiLACS NZ participants contributed to the upbringing of their grandchildren and great-grandchildren.

Maori grandparents were more likely to make specific contributions than non-Maori, including:

- providing occasional support (68% vs 50%)
- financial contributions (47% vs 30%)
- teaching their language (36% vs 17%)
- bringing up grandchildren as a parent (14% vs 1%)
- shared parenting (40% vs 7%).

Contributions to grandchildren did not lessen over time in the study.

Providing care or assistance to others

Around one third of participants gave some type of care or assistance to others at least occasionally. They were more likely to be:

- Māori (Māori were more likely to live with other family members than non-Māori)
- men (men were much less likely to be widowed than women).

The types of assistance provided included:

- transport
- financial help
- shopping
- child care
- personal care.

Personal care for others was provided by less than 10 percent of participants, with no significant differences between women and men nor between Māori and non-Māori.

Contributions to others continued at much the same level as the cohorts aged.

Giving care or assistance was associated with higher physical HRQOL.

Functional change

Change in functional status was examined over time:

- Most participants maintained function from one year to the next.
- Around 60% declined in function (more likely to be non-Māori men).
- Improved function was not at all uncommon (15%-18%).

Māori and women were more likely to stay the same or improve between waves of the study.

Participants with low function in Wave 1 were more likely to have died by Wave 4. Mortality was also predicted by older age, being Māori or being male but, interestingly, was not predicted by socioeconomic deprivation.

Neither physical nor mental HRQOL decreased as functional status decreased.

Support services

Support services were more likely to be received by women (55%, compared to 44% for men).

Māori who received support services had lower functional status than Māori who did not, as one might expect. Surprisingly, this was not the case for non-Māori.

Key points

Contributing to the welfare of others continues into advanced age.

The ability to give care or assistance may stem from better health and functional ability, but giving may also contribute to maintaining physical health and function.

Receiving assistance in advanced age

The predicted increase in the number of New Zealanders of advanced age means that demand for health and care services in New Zealand will grow. Prior research suggests that living longer will mean living longer with disability as well as more years of good health.

Supports for independent living ('ageing in place') have successfully slowed demand for institutional care. Physical decline is not inevitable following periods of ill health in advanced age.

Key point

Quality of life in advanced age may not be affected by changes in functional status

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Informal care is unpaid care, usually provided by family or whanau.

Formal care is paid care

Carers for people in advanced age

This section aimed to increase our understanding about carer contributions, health and wellbeing, and the economic value of care, but also provide another source of information on the care given to our LiLACS NZ participants.

Participants receiving support services maintained physical HRQOL whereas physical HRQOL declined for those not receiving services.

Informal care

Year by year in the study, the proportion of participants receiving informal care increased and by the fourth wave 67 percent of Māori and 57 percent of non-Māori were receiving informal care.

Women with the same functional status as men received more informal care.

The majority of LiLACS NZ participants with a low level of function received informal care (85%). They were more likely to receive both formal support services and informal care than higher functioning participants.

Participants who received both support services and informal care improved over time in physical HRQOL, whereas those who received no services showed decreases in physical HRQOL.

Who were the carers?

Carers overall were more likely to be women than men (81% vs 19%).

Informal carers were older than formal carers and were more likely to be:

- a child or a child's spouse (over 50%), or the person's own spouse (around 30%)
- living close to the person they cared for
- employed full or part time in other jobs
- of the same ethnic group as the person they cared for.

Carers of men had started caring earlier than carers of women. Māori men received the most hours of care per week from informal carers (more than 25 hours) and non-Māori women received the least (less than 15 hours). Spouses gave the most care.

Types of care

Virtually all informal carers said that they provided social and emotional support to the person they cared for. Ethnic and sex differences were also observed:

- Māori men were more likely to receive daily household assistance, help with food-related activities and personal care than women.
- Non-Māori women were least likely to receive personal care (they were also more likely to live alone).

The impact of care

Amongst those who were employed, caring affected their working lives: for example, having to take time off to provide care.

Employment also affected their caring: for example, having to make arrangements for others to provide care if they had to work.

Scores on the COPE Index (a measure of carer support and stress) were not affected by the carer's relationship to the LiLACS NZ participant. However:

- providing personal care was associated with a less negative impact of care for the carer
- spouse carers, despite their age, rated their health more positively than did other informal carers, although they had lower HRQOL.

Carers for the different LiLACS NZ groupings (Māori women and men, non-Māori women and men) did not differ in their assessment of the positive value of their caring or in how they rated the quality of support they gave.

The economic value of the informal carers was estimated at $4.3 million annually, based on a mid-range estimate of costs.

Average informal care costs were higher for Māori than for non-Māori. But it should be noted that how carer earnings are calculated makes a big difference to cost estimates.

Key point

While caring carries positive value for the carer, the impact of unpaid care provision on employment productivity and on health spending are potential costs to society.

Health, health service use and common health conditions in advanced age

This section examined how depression, in combination with common physical health conditions, impacted on functional status, frailty, quality of life and health service use.

Depressive symptoms were present in 35 percent of participants at any one time throughout the study, although many individuals improved or worsened over time.

Depression did not differ by ethnic group, sex or socioeconomic deprivation.

Depression was associated with:

- lower functional status
- higher frailty (more so for men than for women)
- poorer HRQOL
- higher health service use and cost.

Forty percent of participants had cardiovascular disease (CVD).

- Twenty-five percent had both depression and CVD.
- There were no significant ethnic differences.

Thirty percent of participants had chronic lung disease (CLD).

- More Māori had CLD than non-Māori.
- Thirteen percent had both depression and CLD.

Twenty-two percent of participants had diabetes mellitus (DM).

- Thirty percent of Māori had DM.
- Sixteen percent of non-Māori had DM.
- Nine percent had both depression and DM.

Depression increased the negative impact of all three physical conditions on functional status, frailty and quality of life and increased health service use and costs. There were no differences in these patterns of association between Māori and non-Māori.

Since CVD was the most prevalent condition, depression in association with CVD contributed the most to negative outcomes.

Key point

Effective treatments for depression in advanced age may lead to improved health and less health service use amongst those with chronic physical conditions, as well as lessening the burden of depression itself.

Section One: Introduction and Methods

1.1 Background

Te Puāwaitanga O Ngā Tapuwae Kia Ora Tonu/ Life and Living in Advanced Age, a Cohort Study in New Zealand, otherwise known as LiLACS NZ, is a longitudinal cohort study of New Zealanders living in advanced age. It aims to determine the predictors of successful advanced ageing and understand the trajectories of health and wellbeing in advanced age in a Māori and non-Māori New Zealand population.

This world-first research programme comes from the University of Auckland's School of Population Health. After a successful feasibility study,[1, 2] all Māori aged 80 to 90 years and all non-Māori aged 85 years within the Bay of Plenty and Lakes DHB areas (excluding the Taupō area) were identified and invited to participate in a detailed interview and physical assessment, and to give a blood sample.[3] Those who agreed to participate (421 Māori and 516 non-Māori) constituted the two inception cohorts of LiLACS NZ, and interviews with these participants began in 2010.[4] In the five years since that time there have been annual follow-up interviews making six data collection waves in total.[5]

A particular strength of LiLACS NZ as a longitudinal study is its high number of Māori participants of advanced age. The study design and recruitment strategies have resulted in nearly equal numbers in the Māori and non-Māori cohorts, allowing for meaningful comparisons between the two groups. The LiLACS NZ study is the first longitudinal study in the world of an indigenous population in advanced age.

1.1.1 The need for research on advanced ageing

What is advanced ageing? Older populations are usually defined as aged 65 years and over, yet people in their 60s are different to people aged over 80. As older populations grow in size, research literature now distinguishes between the 'youngest old' and the 'oldest old', that is, people in their 80s and beyond. Our study population is a group of people in advanced age, including Māori who were aged 80 to 90 years (born between 1920 and 1930) and non-Māori who were aged 85 years (born 1925) at the beginning of the data collection phase of this study (2010).

People of advanced age are the fastest growing population group in New Zealand. The 2013 census found that there were 73,317 people aged 85 and over, making up 12.1 percent of the population over 65. Population projections are that by 2038, only 25 years from the 2013 census, the 85+ age group will have tripled in size to 218,800 and will comprise 17 percent of the population over 65 (which will have doubled in size) and 4 percent of the total population.[6] 'Population ageing', a worldwide phenomenon, refers to these increasing numbers in older age groups. It has come about with increased life expectancy, as well as lower birth rates which mean that younger age groups do not make up the same proportion of the population as in earlier decades.[7]

Life expectancy increases have been dramatic in recent years. In earlier decades, these increases were driven by improvements in the health of infants; now they are driven largely by reduced mortality in older age. People who reach 80 years in New Zealand today can expect to live a further 8.4 years if they are men and 9.8 years if they are women. For Māori aged 80, men can expect to live a further 7.4 years and women 8.5 years. Māori life expectancy at birth is seven years lower than for non-Māori, a gap that has narrowed somewhat from previous years owing to lower death rates in older age groups.[8]

The increase in the numbers, as well as the proportion, of people of advanced age is an international trend across developed and developing countries.[9] The increased lifespan of human populations can be considered a triumph in the history of humanity. It has been made possible by transformations throughout the 20th and into the 21st century which have seen vastly improved public health, advances in medical treatment and health care, healthier environments, improved nutrition, better education and increased wealth overall. Disparities between richer and poorer countries remain a concern, and within countries, social and ethnic inequalities impact on people's likelihood of living into advanced age.

Governments worldwide have been concerned about the economic and health care impacts of population ageing and research is urgently needed to support policy making.[9] As well as investigating the needs of older people and of those who provide services for them, governments pose policy questions about retirement age, the future costs of superannuation schemes and the impact on national budgets of future costs of health care and dependency. In New Zealand, policy development for people of advanced age occurs mainly through the Ministry of Health (the Ministry), which has a Health of Older People team, which in 2002 released the *Health of Older People Strategy,*[10] currently undergoing a refresh. There is also the Office for Senior Citizens, which leads on the *Positive Ageing Strategy* and reports annually on progress; and the Ministry of Social Development, which has produced relevant reports, such as *The Business of Ageing.*[11, 12]

The health of older Māori has also been a focus, with the release of *He Korowai Oranga*, New Zealand's Māori health strategy in 2002. The strategy is regularly updated and supplemented by reports such as *Tatau Kahukura: Māori Health Chart Book* which enable progress to be tracked through its various editions.[13] There is also a Māori health action plan, *Whakatātaka Tuarua: The Māori Health Action Plan*, released in 2006.[14] In relation to older Māori, the Ministry of Health and Te Puni Kokiri in 1997 published *Oranga Kaumātua: the Health and Wellbeing of Older Māori People,*[15] a research study from Te Pūmanawa Hauora, Massey University. The Ministry has also since supported the publication of reports from LiLACS NZ on Māori of advanced age (see LiLACS NZ website www.fmhs.auckland.ac.nz/en/faculty/lilacs.html).

Ageing research in New Zealand has recently received a substantial boost through the National Science Challenges (http://www.msi.govt.nz/update-me/major-projects/national-science-challenges/). The Ministry of Business, Innovation and Employment has funded a nationwide consortium, led from the University of Otago and including the University of Auckland as a partner, to address the Ageing Well Research Challenge/Kia eke kairangi ki te taikaumātuatanga. Research focusing on Māori and Pacific peoples has been prioritised.

Further research is needed, not just into population ageing itself, but into its impact on health and social systems and on the experiences, needs, health and wellbeing of people of advanced age. New Zealand research is sorely needed, particularly research into the needs of the increasing numbers of Māori in advanced age.

1.1.2 Ageing well

'Ageing well' is a phrase often used in policy documents and research reports on ageing. With increased longevity there have been international debates around whether quality of life for these extra years has also been extended, particularly for the rapidly expanding group of people in advanced age. Policy documents and research groups now emphasise 'ageing well' as a core aim for work with older populations. 'Ageing well' is the title of New Zealand's National

Science Challenge on ageing. The concept of 'ageing well' asserts the value of older people's lives and their right to quality of life, even as some become frail and live with increased disability and dependency. It is expressed in other phrases such as 'positive ageing', 'successful ageing' and 'add life to years'. From a research perspective, it involves 'harnessing science to sustain health and wellbeing into the later years of life'.[16] The aims of the LiLACS NZ research programme are entirely consistent with this approach.

1.1.3 Aims of LiLACS NZ

LiLACS NZ aims to determine the predictors of successful advanced ageing and understand the trajectories of health and wellbeing in advanced age.

The goals of the research are to help people plan better for their own health and wellbeing in advanced age, to allow older New Zealanders to share their wisdom with future generations, and to inform the development of local and national policies to benefit older people.

More specifically, the aims of LiLACS NZ are to:

- establish the health status of people in advanced age
- establish predictors of successful advanced ageing for older Māori and non-Māori
- describe trajectories in function and transitions in care for those in advanced age
- establish the relative importance of health, frailty, cultural, social and economic and other factors in predicting relevant outcomes.

1.1.4 LiLACS NZ team

The LiLACS NZ team, led by Professor Ngaire Kerse, consists of Māori and non-Māori investigators based at the University of Auckland collaborating with investigators from Massey University, Auckland University of Technology and the University of Otago. Community partners in Tauranga, Rotorua, Whakatāne, Opotiki and Te Kaha were contracted to recruit participants to LiLACS NZ and to collect the data. They provide links to their communities and have helped ensure that recruitment and retention rates are high. They also enable sharing of findings with local communities as well as participants. LiLACS NZ has a Māori kaitiaki (guardianship) group from the community, Te Rōpū Kaitiaki o Ngā Tikanga Māori, providing cultural and ethical guidance.

1.1.5 LiLACS NZ Māori cohort

The LiLACS NZ Māori cohort is of unprecedented size and constitutes nearly one in ten Māori New Zealanders aged 80 years and over.[17] This cohort study, therefore, provides far greater breadth of data and statistical power than any previous surveys or studies of older Māori and explanatory power equal to the non-Māori cohort. LiLACS NZ used kaupapa Māori methods (Māori approaches to research)[18, 19] to engage with Māori, including Māori researchers, iwi, Māori provider groups and older Māori advisors from the communities selected for the research.

1.1.6 Value of LiLACS NZ data

LiLACS NZ is an increasingly valuable collection of data. Starting with the first data collection wave in 2010/11, data has been collected from cohort participants on an annual basis. The sixth

wave of data collection began in March 2015. Funding for the first three waves of data collection and dissemination costs came from the Health Research Council, Ngā Pae o te Māramatanga, the National Heart Foundation, the Auckland Medical Research Foundation, the Rotorua Energy Charitable Trust and Oakley Mental Health Foundation, with the Ministry of Health funding the fourth to sixth waves. The substantial financial investment in LiLACS NZ reflects confidence from funders in the unique value of LiLACS NZ data for contributing to research and policy development in New Zealand.

LiLACS NZ data also has much value to the international research effort on people in advanced age. Internationally, LiLACS NZ collaborates with a number of longitudinal studies of advanced ageing, particularly studies of people 85 years and over. The TULIP (Towards Understanding of Longitudinal Investigations of Older People) consortium, consisting of LiLACS NZ, the Newcastle 85+ study, the Leiden (Netherlands) 85-plus study, and the Tokyo Oldest Old Survey on Total Health (TOOTH) study from Japan, has been formed to facilitate international collective and comparative research.[5]

1.1.7 How this report came about

This research report was commissioned by the Ministry of Health in order to communicate further findings from LiLACS NZ to appropriate Ministers and policy and planning teams across the health sector. Its information and analysis should underpin more effective policy and service delivery to people of advanced age and their carers. This will, in turn, lead to improved health outcomes for Māori and non-Māori in advanced age. However, its usage is not limited to the Ministry and DHBs but may inform policy across a number of public policy areas such as housing, social welfare, transport and planning.

1.2 Aims of this research report

This research report aims to provide a longitudinal analysis of health, independence and care given and received by Māori and non-Māori living in advanced age. This includes care given by the older person's closest support person. The report aims to:

- describe the giving and receiving of care by Māori and non-Māori in advanced age and outline its impact on quality of life and functional status over time

- identify the contribution of carers to the successful ageing of Māori and non-Māori

- establish how the presence of depression affects people particularly when they also have the most common physical health conditions of advanced age (namely cardiovascular disease, chronic lung disease and diabetes mellitus).

These aims were derived from topic areas identified but not developed further in previous short reports to the Ministry. The topics are central concerns for LiLACS NZ as a longitudinal study of successful ageing.

1.3 Research questions and research topics

The above aims of this report have been developed into specific research questions which are described in the appropriate sections in this report. A preliminary report specifying indicators to be used in this research report and prepared by LiLACS NZ was agreed to in consultation with the Ministry.

1.4 Previous reports

The Ministry has already commissioned a number of short reports from LiLACS NZ, which have been published on https://www.fmhs.auckland.ac.nz/en/faculty/lilacs.html. The Ministry's 'Health of Older People' team has also referenced these reports at http://www.health.govt.nz/our-work/life-stages/health-older-people/lilacs-nz-research-programme. The reports cover oral health, alcohol use, falls, medication use, perceptions of GP care, hospital visits, income, relationships and emotional support, independence in daily activities, primary care, participation in Māori society and extra help in daily activities.

Academic publications by the LiLACS NZ team are also available on the University of Auckland's website https://www.fmhs.auckland.ac.nz/en/faculty/lilacs.html. These include study protocols,[3,5] further detail on engagement and recruitment of the cohort, details of the cohort study overall and publications reporting early findings from LiLACS NZ, including Māori data and health findings.[3,5,20] An increasing number of academic publications use LiLACS NZ data and many of these are listed on the same webpage.

1.5 Sources of data

For the most part, data sources are from the LiLACS NZ cohorts Waves 1 to 4. Data collection was annual, with Wave 1 conducted over 2010 to 2011, Wave 2 over 2011 to 2012, Wave 3 over 2012 to 2013 and Wave 4 over 2013 to 2014. Most participants completed full questionnaires, while a smaller number completed core questionnaires only (there is further information on the core and full questionnaires in 1.6.6 'Gathering the data'). In addition, the LiLACS NZ study of kaiāwhina/carers was introduced to the research in Wave 3. At the time of writing, Waves 5 and 6 are in the process of completion of data collection and collation.

Additional data sources are from the Ministry's statistical information, including the National Minimum Dataset (NMDS), a national collection of hospital discharge information.

Table 1-1 details the key sources of data used in this report, the time period and waves involved, and the number of Māori and non-Māori in the data set.

Table 1-2: Key sources of data for health and care indicators

Source	Data	Duration	Numbers
LiLACS NZ	LiLACS NZ core and full questionnaires: work/volunteering, receiving care and assistance, QOL, health/diagnoses, functional status.	Waves 1–4, 2010–2014	421 Māori aged 80–90 years in 2010, 267 completed all measures 516 non-Māori aged 85 years in 2010, 404 completed all measures
	LiLACS NZ Kaiāwhina questionnaire: amount and views of care.	Wave 3, 2012–2013	337 carers
Ministry of Health	Hospitalisation dates and diagnoses, dates of death.	1988–present	379 Māori, 498 non-Māori (877 participants who gave consent)
Department of Internal Affairs	Births, deaths and marriages: cross-check for mortality.	2010–present	421 Māori, 516 non-Māori

1.6 Demographics and recruitment

1.6.1 Determining eligibility for LiLACS NZ

Participants in LiLACS NZ were recruited from a defined geographic region of two contiguous DHB areas of New Zealand, Bay of Plenty and Lakes DHBs, but excluding the Taupō area of the Lakes DHB after advice on tribal areas from the Rōpū Kaitiaki, the LiLACS NZ kaitiaki Māori guardianship group.

In determining age eligibility for participation in LiLACS NZ, the intention was to achieve two cohorts of approximately equal size. This led to setting the age eligibility at 80 to 90 years old for Māori and at 85 years old for non-Māori. There are fewer Māori than non-Māori living in the region and Māori have lower life expectancy (there is a seven year disparity in life expectancy at birth), meaning that there are proportionally fewer Māori of advanced age in the region. Thus, a one-year birth cohort for non-Māori and an eleven-year birth cohort for Māori was predicted to lead to equivalent cohorts, providing that recruitment rates were similar across the two groups.

The formal criteria for eligibility for LiLACS NZ were non-Māori born between 1 January and 31 December 1925 (aged 85 in 2010), and Māori born between 1 January 1920 and 31 December 1930 (aged 80 to 90 in 2010). Those meeting the age criteria needed to have been living within the Lakes (excluding Taupō area) or Bay of Plenty DHB areas during the 2010 enrolment year.

Within the geographical areas chosen, recruitment strategies aimed to include all eligible participants, in other words, to achieve a total population sample of eligible people.

1.6.2 Demographics of the chosen region

Bay of Plenty DHB and part of Lakes DHB (which excludes Taupō) were chosen as areas having a stable population base and Māori communities. LiLACS NZ's geographical boundaries are located within the Bay of Plenty Regional Council area. The main centres of Tauranga and Rotorua provide the highest numbers of participants, with the surrounding rural areas and regional towns providing a range of contexts and settings in which people of advanced age live. Of New Zealand's regional council areas, the Bay of Plenty has the fourth highest proportion of people aged 65 years and over (at 17.5%). Of territorial authority areas, Tauranga city has the fifth highest proportion (at 19.3%) of people aged 65 and over.[6]

The Bay of Plenty region, which includes Tauranga and Rotorua, has 11.5 percent of the total Māori population of New Zealand, making it the third most populous region for Māori in New Zealand. Māori participants in LiLACS NZ came from Te Arawa, Ngāti Pūkenga, Ngāiterangi, Ngāti Ranginui, Ngāti Awa, Ngāti Manawa, Ngāi Tai, Tūhoe, Whakatōhea, Whānau-a-Apanui and Ngāti Whare. Some Māori participants came from other regions of New Zealand.

The rural areas in the LiLACS NZ study, including Kawerau and Opōtiki, are some of the most socioeconomically deprived in New Zealand, having lower median incomes than the rest of New Zealand. By contrast, in Tauranga and Rotorua median incomes are higher. Overall, the median income for people in the Bay of Plenty region is slightly lower than for New Zealand as a whole.[21]

1.6.3 Recruitment to LiLACS NZ

A feasibility study tested out recruitment procedures and the acceptability and comprehensibility of proposed questions and assessments.[1, 2] After extensive consultation and regional meetings with local tribal leaders and older people, seven local organisations were subcontracted by the University of Auckland to contact, recruit and enrol participants and to conduct the interviews and physical assessments. They comprised three primary health organisations (PHOs; organisations that manage data and distribute funds for groups of general practitioners), and four rūnanga (iwi authority). Four organisations enrolled both Māori and non-Māori participants; two, working under a joint subcontract, enrolled only Māori and one enrolled only non-Māori.

A comprehensive attempt was made to contact all eligible people, including people with disabilities and those who were independent and not well known to social and health agencies. Several sources were used to compile a full list of eligible people. These included the New Zealand General and Māori electoral rolls and primary care databases accessed through PHOs and general practices, whānau and community networks, word of mouth and publicity.

Publicising the study involved speaking on local radio stations and at meetings of older people, such as kaumātua groups, community service agencies and at rest homes, preparing newspaper articles and placing posters and pamphlets in public places such as doctors' surgeries, residential care facilities, pharmacies, bowling clubs and shopping malls.

The Rōpū Kaitiaki group was responsible for leading the research team into the areas to introduce the research, giving advice on translation of questions and ensuring that practices to engage with and interview Māori participants were appropriate.[2, 22]

Participant ethnicity was by self-identification, confirmed at interview using the 2001 NZ census question which asks which ethnic group(s) someone belongs to.[23]

From the electoral rolls there were 766 Māori and 873 non-Māori age-eligible for the study. An additional 72 people were located from other sources and 75 were found to be ineligible, thus 1,636 people were eligible: 766 Māori and 870 non-Māori.

All potential participants or whānau or family were able to be contacted, with the exception of one research site, where contact could not be achieved with the full list of potential participants. Fifty-five percent of eligible Māori and 59 percent of eligible non-Māori were recruited over 14 months. The main reason people declined to participate was that they 'didn't want to'. Other reasons for not participating included refusing due to poor health, being too busy, moving or a potential participant dying before contact.

1.6.4 Who are LiLACS NZ participants?

The first wave enrolled into LiLACS NZ consisted of 937 people, 421 Māori and 516 non-Māori. There were 244 Māori women and 177 Māori men (42% of Māori participants were men); 279 non-Māori women and 237 non-Māori men (46% of non-Māori were men). Figure 1-1 gives further details about participant numbers in the first four waves of the study. Of the 516 non-Māori participants, 89 percent were of New Zealand European descent, 10 percent identified as other European (10%) and 1 percent identified as Pacific, Asian or Middle Eastern. In this report, non-Māori data includes all participants of non-Māori descent.

In terms of marital status, Wave 1 data shows that 32 percent of Māori and 40 percent of non-Māori were married or partnered, 60 percent of Māori and 50 percent of non-Māori were widowed and 8 percent of Māori and 9 percent of non-Māori had never married, or were separated or divorced. More women than men were widowed (74% of Māori women and 67% of non-Māori women).

In the first wave, 72 percent of Māori and 69 percent of non-Māori owned their homes, 41 percent of Māori and 48 percent of non-Māori were living alone, and 7 percent of Māori and 9 percent of non-Māori were living in residential care. Women were more likely than men to be living alone, with 51 percent of Māori women and 63 percent of non-Māori women in this situation.

Sixty percent of Māori in the study and 34 percent of non-Māori lived within meshblocks in the three deciles of highest socioeconomic deprivation.[24]

1.6.5 Information and informed consent

The study was approved by the Northern Regional Ethics Committee (NXT 09/09/088) in 2009. Written informed consent was obtained from participants before data collection proceeded. Sufficient time for discussion was allowed and potential participants were encouraged to invite family members to be present when research staff came to discuss the study. Where the potential participant had significant cognitive impairment, the study was discussed with them and whānau or family members. Families were then asked to provide a statement of agreement to participate in the study.

Attention was given to discussing the taking and storage of blood samples, which is recognised to be of particular cultural importance for Māori. The consent process asked for separate permission for each phase of the study; that is, questionnaire, physical assessment, blood sampling, storing any unanalysed blood for future studies, medical record review from the GP, access to administrative health data from the DHB, and to hospitalisation and mortality data from the Ministry. In subsequent years, consent was obtained anew for all phases.

1.6.6 Gathering the data

Study measures were collected in phases.

- The questionnaires were administered face-to-face by trained interviewers employed by the contracted local organisations. All participants completed a short (core) questionnaire and most completed the full 72-page questionnaire.

- Standardised physical assessments were undertaken by research-trained nurses.

- Blood samples were obtained by pathology lab staff or LiLACS NZ research nurses.

- General practitioners' records were reviewed for medical diagnosis information by practice or LiLACS NZ research staff.

- Participants' National Health Index (NHI) numbers were matched with nationally held hospitalisation data from the National Minimum Dataset and mortality data held by the Ministry.

Questionnaires and physical assessments were offered as home visits or at another site that the participant chose. A koha (gift) was given on completion of interviews, in acknowledgement of the participant's time.

In the first wave, 671 (72% of participants) completed a full questionnaire and 261 (28%) completed the briefer core questionnaire only (4 withdrew before the first interview and 1 questionnaire was lost, making a total of 932 completions out of the 937 enrolments). Physical assessments were completed by 631 (68%), and 570 (61%) participants contributed a blood sample for analysis. Permission for New Zealand Health Information Service (NZHIS) medical record access was given by 877 (94%) participants.

During Wave 3, at the 24 months follow-up, a Kaiāwhina interview was added. Carers, informal and formal, nominated by participants, were asked a range of questions about the type and amount of care they gave to LiLACS NZ participants and for their opinions on that care.

Quotes from participants, like the ones in this section, are drawn from the Wave 3 questionnaire where we asked what the highlights of this stage of life were for the participants. These are included in this report to add a personal voice to the data.

1.6.7 Follow-up of LiLACS NZ

For the purposes of this report, data from Waves 1 to 4 are used. Figure 1-1 shows the retention figures across Waves 1 to 4 and the data collected.

Wave 2, the first annual follow-up in 2011, retained, interviewed and assessed 66 percent of Māori and 78 percent of non-Māori participants. When Wave 3 was finished, assessments on 74 percent of Wave 2 Māori and 87 percent of Wave 2 non-Māori were completed. At the finish of Wave 4, assessments on 83 percent of Wave 3 Māori and 82 percent of Wave 3 non-Māori were completed. Appendix Table 1.1 (Appendix 1.1) shows the retention success and reasons for drop-out. The most common reasons for dropping out were death (20% of the original cohort), or preferring not to continue (29%, including for reasons of ill health or frailty). Overall, the retention rate between Wave 1 and Wave 4 was 47 percent.

1.6.8 How representative is the sample?

The overall response rate in recruiting the cohort for LiLACS NZ was 57 percent, which is in line with other longitudinal studies of ageing.

Comparing the LiLACS NZ cohorts with the general population, using 2006 NZ census data with projections to 2010, sex and age distribution for Māori matched the general population, and for non-Māori, more men and fewer women were recruited than expected (LiLACS NZ 48% vs NZ census 42%).[4]

Fifty-two percent of LiLACS NZ Māori participants were able to have an everyday conversation in te reo Māori.[25] In comparison, the 2013 NZ census showed that 44 percent of Māori aged 80 years and over could speak te reo Māori.[26]

In terms of health measures, 7 percent of LiLACS NZ participants were regular smokers; this is similar to the 7 percent of the Lakes DHB population aged 75+ and 5 percent of the New Zealand population aged 75+ who smoke, as reported in the 2013 New Zealand census. Forty-seven percent of LiLACS NZ participants were ex-smokers, similar to the 52 percent ex-

smokers of the Lakes DHB census population and more than the 36 percent of the New Zealand population aged 75+ reported to be ex-smokers in the 2013 census.

The Older Persons' Ability Level (OPAL) study examined the prevalence of residential care placement from a population census of all facilities in the greater Auckland region. In 2010 there were 13 percent of non-Māori aged 85 years and over in residential care and 6 percent of Māori aged 80 to 90 years in residential care.[27] Similar data are not available for the rest of New Zealand. Of those recruited in 2010 to 2011 to LiLACS NZ, 9 percent of non-Māori and 7 percent of Māori were in residential care. Although all age-eligible people were sought and invited, there were lower enrolments than expected from non-Māori in residential care facilities. This factor may limit generalisability, particularly for estimates of prevalence for frailer participants.
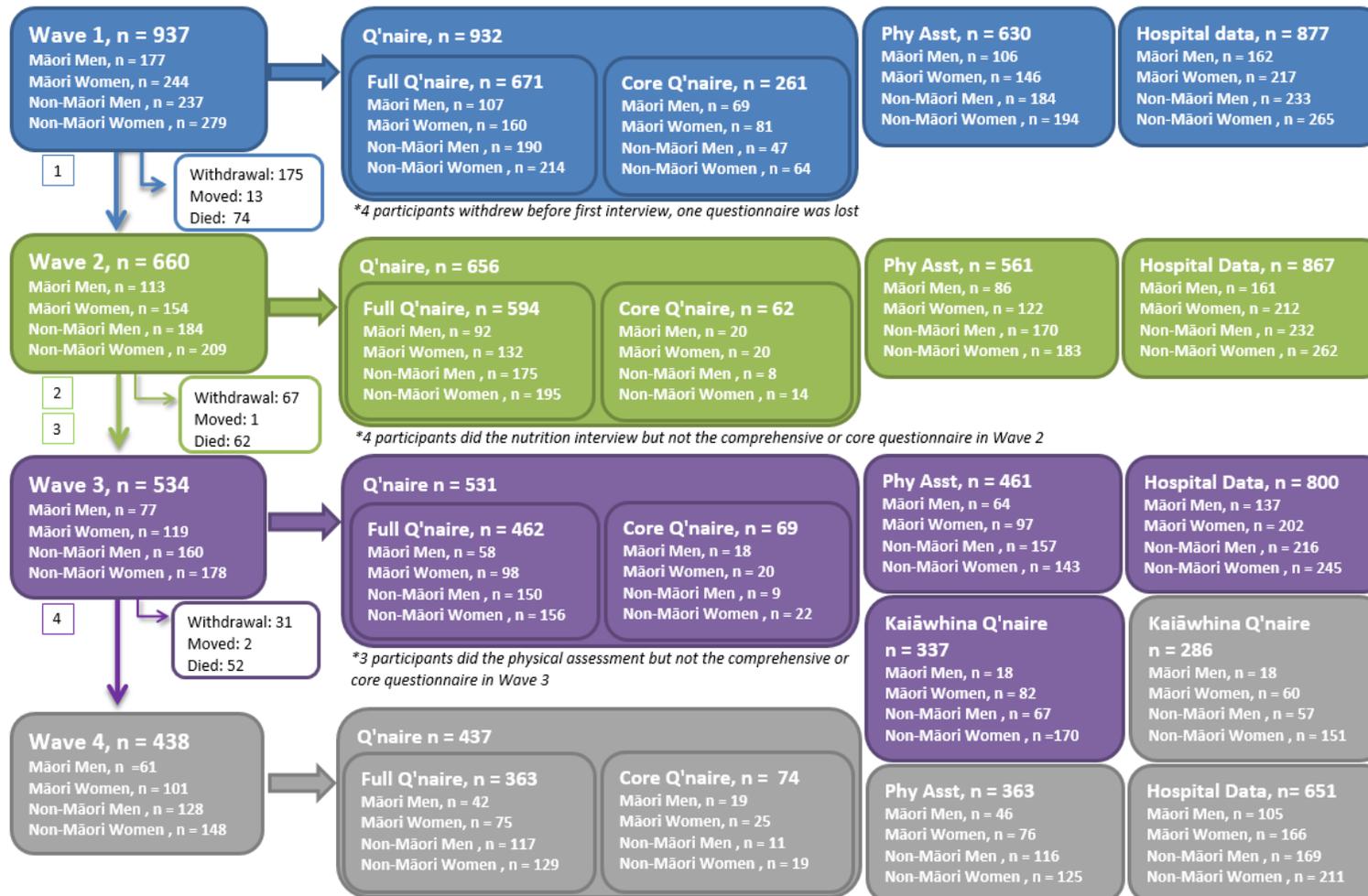
It should also be noted that, within the sample, there were differences in functionality between those who completed the full questionnaire and those who completed only the core questions. Participants who completed the full questionnaire were more functionally able, on average, than those completing only core questions.

In summary, LiLACS NZ potentially under-represents those in residential care for non-Māori and over-represents non-Māori men. More of the Māori participants were able to speak te reo Māori than expected. Otherwise, sociodemographically, the sample is comparable to the regional and national spread. Some caution, of course, should be exercised in generalising the findings beyond the Bay of Plenty and Lakes DHB areas. For Māori, issues in generalising across iwi should be kept in mind.

'It was a most pleasant surprise when I found that I had been asked to take part in the LiLACS NZ Study – at the age of 85 years it gave me a lift and made me feel useful at this late stage of my life.

When I attended my first appointment with the research staff…I was made to feel at ease, welcome and contributing something worthwhile.'

Figure 1-1: Participants with data available in LiLACS NZ (absolute numbers, Waves 1 to 4)

Wave 1, n = 937
Māori Men, n = 177
Māori Women, n = 244
Non-Māori Men , n = 237
Non-Māori Women , n = 279

Q'naire, n = 932

Full Q'naire, n = 671
Māori Men, n = 107
Māori Women, n = 160
Non-Māori Men , n = 190
Non-Māori Women , n = 214

Core Q'naire, n = 261
Māori Men, n = 69
Māori Women, n = 81
Non-Māori Men , n = 47
Non-Māori Women , n = 64

Phy Asst, n = 630
Māori Men, n = 106
Māori Women, n = 146
Non-Māori Men , n = 184
Non-Māori Women , n = 194

Hospital data, n = 877
Māori Men, n = 162
Māori Women, n = 217
Non-Māori Men , n = 233
Non-Māori Women , n = 265

1
Withdrawal: 175
Moved: 13
Died: 74

4 participants withdrew before first interview, one questionnaire was lost

Wave 2, n = 660
Māori Men, n = 113
Māori Women, n = 154
Non-Māori Men , n = 184
Non-Māori Women , n = 209

Q'naire, n = 656

Full Q'naire, n = 594
Māori Men, n = 92
Māori Women, n = 132
Non-Māori Men , n = 175
Non-Māori Women , n = 195

Core Q'naire, n = 62
Māori Men, n = 20
Māori Women, n = 20
Non-Māori Men , n = 8
Non-Māori Women , n = 14

Phy Asst, n = 561
Māori Men, n = 86
Māori Women, n = 122
Non-Māori Men , n = 170
Non-Māori Women , n = 183

Hospital Data, n = 867
Māori Men, n = 161
Māori Women, n = 212
Non-Māori Men , n = 232
Non-Māori Women , n = 262

2
3
Withdrawal: 67
Moved: 1
Died: 62

4 participants did the nutrition interview but not the comprehensive or core questionnaire in Wave 2

Wave 3, n = 534
Māori Men, n = 77
Māori Women, n = 119
Non-Māori Men , n = 160
Non-Māori Women , n = 178

Q'naire n = 531

Full Q'naire, n = 462
Māori Men, n = 58
Māori Women, n = 98
Non-Māori Men , n = 150
Non-Māori Women , n = 156

Core Q'naire, n = 69
Māori Men, n = 18
Māori Women, n = 20
Non-Māori Men , n = 9
Non-Māori Women , n = 22

Phy Asst, n = 461
Māori Men, n = 64
Māori Women, n = 97
Non-Māori Men , n = 157
Non-Māori Women , n = 143

Hospital Data, n = 800
Māori Men, n = 137
Māori Women, n = 202
Non-Māori Men , n = 216
Non-Māori Women , n = 245

Kaiāwhina Q'naire n = 337
Māori Men, n = 18
Māori Women, n = 82
Non-Māori Men , n = 67
Non-Māori Women , n =170

Kaiāwhina Q'naire n = 286
Māori Men, n = 18
Māori Women, n = 60
Non-Māori Men , n = 57
Non-Māori Women , n = 151

4
Withdrawal: 31
Moved: 2
Died: 52

3 participants did the physical assessment but not the comprehensive or core questionnaire in Wave 3

Wave 4, n = 438
Māori Men, n =61
Māori Women, n = 101
Non-Māori Men , n = 128
Non-Māori Women , n = 148

Q'naire n = 437

Full Q'naire, n = 363
Māori Men, n = 42
Māori Women, n = 75
Non-Māori Men , n = 117
Non-Māori Women , n = 129

Core Q'naire, n = 74
Māori Men, n = 19
Māori Women, n = 25
Non-Māori Men , n = 11
Non-Māori Women , n = 19

Phy Asst, n = 363
Māori Men, n = 46
Māori Women, n = 76
Non-Māori Men , n = 116
Non-Māori Women , n = 125

Hospital Data, n= 651
Māori Men, n = 105
Māori Women, n = 166
Non-Māori Men , n = 169
Non-Māori Women , n = 211

1. 15 not interviewed in Wave 2 but not withdrawn
2. 13 of the 15 were re-interviewed at Wave 3
3. 9 were interviewed in Wave 2, not interviewed in Wave 3 but not withdrawn
4. 11 interviewed in Wave 3, not interviewed in Wave 4 but not withdrawn

1.7 Measures used in this report

This section is a brief description of the information gathered from participants that is used in this report. Further detail of the questionnaire, tests and measures is given in Appendix 1.2 and in a recently published cohort profile.[5]

Table 1-2 gives an overview of measures used with the LiLACS NZ cohorts and their carers that are used in this report.

Table 1-3: Measures included in LiLACS NZ and used in this report

Predictor variables	W1	W2	W3	W4
Demographics (incl. iwi, hapū, Māori ancestry, family size & longevity)	√			
Socioeconomic status (incl. occupation, education, home ownership)	√			
Marital status, living arrangement, perceived income	√	√	√	√
Health and function				
CVD status*	√	√	√	√
Functional status; Nottingham Extended Activities of Daily Living (NEADL)[28]	√	√	√	√
Depression, Geriatric Depression Scale, GDS-15[29]	√	√	√	√
Frailty: Fried frailty assessment scale[30]	√	√	√	√
Mental Health Related Quality of Life (HRQOL) SF-12® summary score[31]	√	√	√	√
Physical HRQOL SF-12® summary score[31]	√	√	√	√
Carers identified, care amount and type described			√	√
Carers' perceptions and experience (Kaiāwhina interview)			√	√
GP record review and diagnoses	√			

Notes: W1: Wave 1 (baseline 2010/11), W2: Wave 2 (1 year follow-up 2011/12), W3: Wave 3 (2 year follow-up 2012/13), W4: Wave 4 (3 year follow-up 2013/14).
* CVD-cardiovascular disease defined according to self-report diagnoses, GP medical record review (Wave 1), physical examination for blood pressure, lying and standing, and electrocardiogram (ECG), hospitalisation data established at Wave 1,[32] self-report CVD status asked at every wave.

The wording of LiLACS NZ questions for the data used in this report is shown in Appendix 1.2, Box 1 to Box 5.

1.7.1 Core questionnaire schedule

The core questionnaire schedule included measures of demographics, iwi affiliation (for Māori), living arrangement and cardiovascular diagnoses.

Eight items from the 22-item Nottingham Extended Activities of Daily Living Scale (NEADL) were included in the core questionnaire, asking about feeding self, mobility outside, food preparation, carrying a hot drink from one room to another, clothes washing, telephone use, shopping and housework. Further items assessing Basic Activities of Daily Living function were added, including personal care, toileting and getting in and out of bed.

Other items in the core questionnaire included smoking, hospital admissions, major health and psychological stress events, falls and current health problems.

1.7.2 Full interview schedule

The full interview schedule, 72 pages in length, comprised:

- sociodemographic and personal history, including marital status, living arrangement, income, previous occupation, education, iwi affiliation for Māori and participation in cultural practices

- physical and psychological health status, using validated research tools

- health behaviours, including smoking, alcohol use and nutrition risk

- environmental data, type of housing and attachment to neighbourhood

- social network structures and social support exchanges.

Measures used in each wave of data collection (unless noted otherwise) and of key importance to this report are described below.

- Functional status and transitions in function were assessed, predominantly using the items of the Nottingham Extended Activities of Daily Living Scale (NEADL).[28] This scale has 22 items and a higher score represents better function. Basic ADL items were added, which contributed to assessment of functional status.

- Health-related quality of life (HRQOL) was assessed using the SF-12®, a short-form HRQOL questionnaire, providing summary scores for mental and physical HRQOL.[31] The scale has 14 items and focuses on limitation in function due to physical or emotional health problems. The scale gives a standardised score out of 100 with 50 being an average score. The higher the score, the higher the quality of life.

- Depression was assessed using the 15-question version of the Geriatric Depression Scale (GDS-15). This gives a score out of 15 with a higher score indicating more depressive symptoms.[29]

- Frailty score: Fried frailty assessments were used, where one point is assigned for each of five markers of frailty: unintentional weight loss of more than 5 kg in the last year, being in the lowest quintile for strength, lowest quintile for speed, lowest quintile for physical activity, and self-reported exhaustion.[30]

Section 2 of this report uses questions from the full questionnaire about voluntary and paid work outside the household, contributions to grandchildren, and providing care and assistance to other people. Data from Wave 1 recorded the range of care and support activities and the amount of time spent on these.

Section 3 focuses on transitions in functional status and uses the abbreviated list of functional status items completed by all participants in the core questionnaire. These are used to show the proportion of the sample who transitioned between functional categories over time. Receipt of care and support, from questions in the full questionnaire, are then described in relation to functional status.

Section 4 focuses on carers and reports the responses to a specially designed interview schedule for those who were the main providers of care and support to participants.

Section 5 focuses on specific health conditions and outcomes. The outcomes of hospitalisation, mortality and HRQOL over time are described for those with depression, chronic lung disease, cardiovascular disease and diabetes mellitus. These diagnoses were ascertained using

established algorithms[32] from data from the GP record review, self-report and hospital International Classification of Disease (ICD) coding in the Ministry's hospitalisation database from hospitalisations prior to enrolment in LiLACS NZ. Depression was assessed from scores on the GDS-15. Outcomes are reported on associations with combinations of depression and each of the three chronic physical conditions.

1.7.3 Physical assessment

Physical assessment was completed by a trained research nurse. This report draws on electrocardiography assessments, which contributed to the diagnosis of cardiovascular disease.

1.7.4 GP records

Existing medical diagnoses and procedures were accessed from the participant's general practice patient records using their NHI number. Study nurses or general practice staff recorded the presence of specified medical conditions and diagnostic or medical procedures and, where possible, the date they were first noted. These diagnoses included asthma, osteoporosis, chronic lung disease, stroke, diabetes mellitus, high blood pressure, heart attack, congestive heart failure, epilepsy, Parkinson's disease and dementia. Total hip and knee joint replacements were recorded, as were cancer diagnoses with type, details of cardiovascular procedures and events, and bone density tests.

1.7.5 National and DHB data

Hospital admissions and length of stay, ICD-9 and ICD-10 diagnosis and mortality were ascertained from Ministry of Health data by matching of participants' NHI identifiers.

1.7.6 Kaiāwhina interview

LiLACS NZ participants were asked if they would agree to interviews with the main person giving them care and support, either an informal (unpaid) or formal (paid) carer. Carers who agreed to take part were engaged in Waves 3 and 4 with a face-to-face interview, using the Kaiāwhina questionnaire. The aim of this questionnaire was to investigate the contributions carers make to the wellbeing of participants. The data used in this report is from Wave 4, which contained the most extensive questioning. By the end of Wave 4, 286 interviews with carers had been completed and could be matched with LiLACS NZ participants. These 286 dyads represent about 60 percent of LiLACS NZ participants at Wave 4. Carer interviews have continued through the study since then. Most of the participants who did not nominate a carer said they did not need one.

The Kaiāwhina questionnaire for informal carers asked about the age, ethnic group, sex, occupational and beneficiary status of the carer. Carers were also asked about their relationship and residential proximity to the LiLACS NZ participant.

In terms of delivering care, the carers were asked about the types of care they gave, as well as how often they delivered that care and the amount of time in a typical week caring took place. They were also asked about providing assistance in a crisis.

The length of time that they had contributed care was established and they were also asked how much responsibility they felt towards the LiLACS NZ participant. They were asked if they had engaged in planning any future care arrangements, if caregiving had impacted on their own

paid work and finances, and whether others were also involved in the care of the LiLACS NZ participant.

Finally, the carer was asked to complete the EQ-5D-3L, a health status questionnaire, designed to measure health-related quality of life,[33] and the Carers of Older People in Europe (COPE) index, a measure of carer support and carer stress.[34]

The questionnaire for formal carers (13% of the carers interviewed) was brief, focusing on the amount of help given, the carer role and the relationship with the LiLACS NZ participant. Therefore it did not include the EQ-5D-3L or the COPE index.

1.8 Statistical analyses

Longitudinal data on LiLACS NZ participants are derived from annual data collection from all remaining participants from the inception cohort. Waves 1 to 4 (baseline and three years of follow-up, conducted over 2010 to 2014) are analysed in this report in Sections 2 and 4. Longitudinal analysis of observational data can show associations between predictors and outcomes, and can be used to support inferences of causality, but nevertheless poses analytical challenges. These challenges are minimised by adjusting for potentially confounding variables such as sex or differential age criteria in any comparisons between Māori and non-Māori.

Analyses of change over time may also be influenced by differential drop-out rates, where people with greater disability are less likely to continue in a study. Bias in attrition was expected and is tested for. A technical appendix for each section gives a more detailed account of statistical analyses used in this report.

Findings in this report are normally presented separately for Māori and non-Māori, keeping in mind that these are two separate cohorts within LiLACS NZ. These cohorts are roughly equal in size, meaning that when the two are taken together, the proportion of Māori considerably exceeds their proportion in the New Zealand population. Where there are significant differences between Māori and non-Māori, these are highlighted. P-values and confidence intervals are provided for each test of significance and are reported in the appropriate tables in the appendices. Appendix 1.3 contains a technical explanation of p-values and confidence intervals.

Section Two: Contributions in Advanced Age

2.1 Introduction

News media often publish items on positive ageing but they also publish items that focus on the impact of the ageing population that can stoke fears.[35] People in advanced age may be portrayed as placing a burden on caregivers, health and social services, and the economy because of their rapidly increasing numbers. The Government's *Positive Ageing Strategy* has taken a lead in reducing stigma arising from negative attitudes towards older people.[11] Although concerns about the impact of an ageing society are very real, they should not be fuelled by incorrect assumptions or encourage stigma and discrimination towards the ageing population. The evidence being collected and disseminated through this LiLACS NZ study can provide robust evidence to help overcome these biases.

People of advanced age are mostly independent and living in the community. They make contributions to whānau and family, communities and society. They are holders of cultural heritage, knowledge and tikanga (Māori cultural practice).[25] They may be caregivers as well as recipients of care, looking after their partners, their grandchildren and providing care to other family members with illness or disability. As well as working in and around the house, they undertake voluntary and occasionally paid work.[12, 36, 37] A strengths-based approach to older people emphasises these valued contributions.[25, 38-42]

Making meaningful contributions is important to the wellbeing of people in advanced age, as well as to the people who benefit from their activities. The ability to contribute is considered a hallmark of successful and active ageing.[36]

Productive activities engaged in by people in advanced age mostly take place outside the paid workforce. This means that their contributions are less likely to be counted, although New Zealand's *Time Use Surveys* provide some information. The latest survey, conducted in 2009/10 and including information on Māori time use, shows, for example, that people over the age of 65 do more hours of unpaid work than any other life stage group.[43] Describing and quantifying the contributions of people in advanced age through research is one way of re-evaluating the 'longevity dividend'. Investing in ways to enhance their contributions will support their capacity to enrich our worlds.[36,44,45]

This section presents findings from LiLACS NZ about the contributions made by people of advanced age to others. It describes the giving of care by Māori and non-Māori in advanced age. It reports on LiLACS NZ participants' work outside the household, with a focus on volunteering, involvement with grandchildren and caregiving activities. Some data on paid work is also presented. Associations between participants' contributions and their quality of life and functional status over time are also considered.

Appendix Table 2.1 (in Appendix 2.1) shows the number of participants who answered each of the questions for which data are presented in this section. Other tables in Appendix 2.1 give full details of data used in text and figures in this section.

2.2 Working as a volunteer or for pay outside the household

2.2.1 LiLACS NZ participants continued to volunteer as they grew older

LiLACS NZ participants were asked if they had worked as a volunteer or for pay outside the household during the past seven days (Appendix Table 2.2).

Wave 1 of the study found that 14 percent of Māori women and 13 percent of Māori men volunteered; this compared with 20 percent of non-Māori women and 17 percent of non-Māori men. This difference was not statistically significant for sex or for ethnic group. This proportion of people involved compares favourably with QuickFacts from the latest census which shows that 21 percent of people over 65 participate in helping or voluntary work.

Figure 2-1: Top five activities/skills involved in volunteering for LiLACS NZ participants

Source: LiLACS NZ
Note: 188 LiLACS NZ participants responded to an invitation to describe their unpaid/voluntary work. The responses were analysed in terms of the activities or skills involved. The above illustration shows the top five categories, along with the number of LiLACS NZ respondents in each category.

Figure 2-2: Top five beneficiaries from LiLACS NZ volunteering

Source: LiLACS NZ
Note: 188 LiLACS NZ participants responded to an invitation to describe their unpaid/voluntary work. The responses were analysed in terms of who benefited from volunteering. The above illustration shows the top five categories, along with the number of LiLACS NZ respondents in each category.

Health, Independence and Caregiving in Advanced Age: Findings from LiLACS NZ
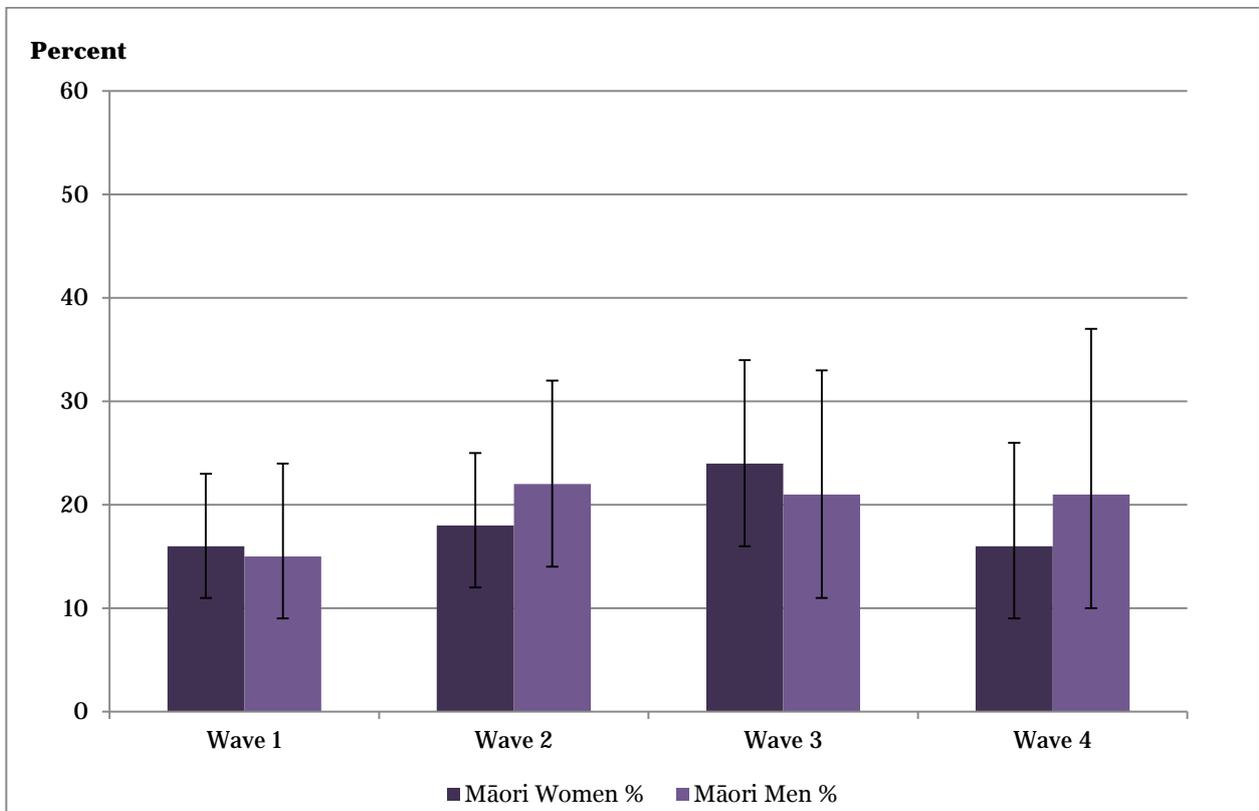
Paid work by people in advanced age was uncommon, with only 3 percent of Māori women, 6 percent of Māori men, 1 percent of non-Māori women and 2 percent of non-Māori men involved in paid work.

Sixteen percent of Māori women, 15 percent of Māori men, 21 percent of non-Māori women and 18 percent of non-Māori men contributed either through volunteering or paid work.

There were *no significant differences* by ethnic group, sex or socioeconomic deprivation in undertaking volunteering or paid work (Appendix Table 2.3).
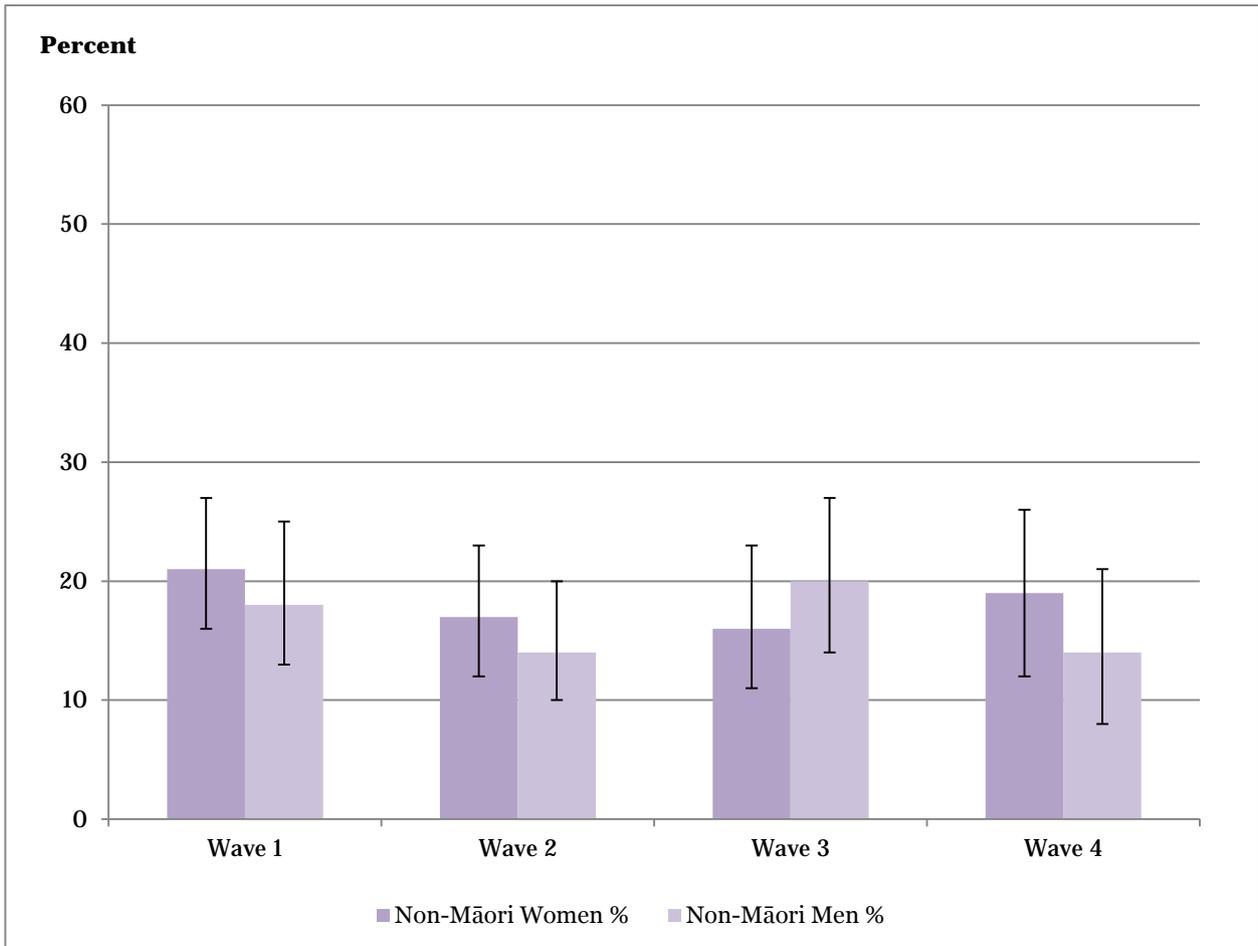
Over time there was no drop-off in rates of participation in voluntary activity or paid work amongst LiLACS NZ participants remaining in the study. The following figures show participation in voluntary activity or work over Waves 1 to 4 by ethnic group and sex (Figure 2-3, Figure 2-4, see Appendix Table 2.1 to Appendix Table 2.3 for data and significance testing).

Figure 2-3: Māori participation in voluntary activity or work over time, Waves 1 to 4

Source: LiLACS NZ

Figure 2-4: Non-Māori participation in voluntary activity or work over time, Waves 1 to 4

Percent

Source: LiLACS NZ
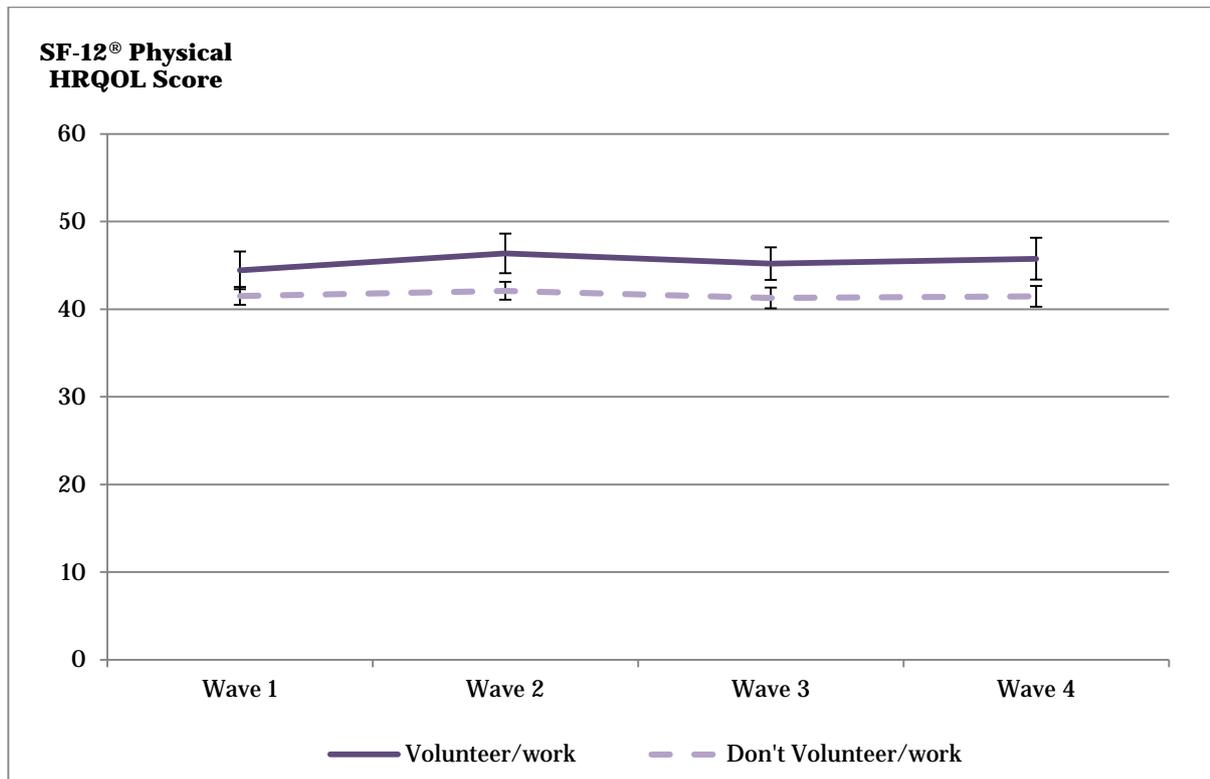
'**To have the time to participate as a volunteer in activities which one enjoys, has skills in and which benefit and contribute to a community which has provided much for us.**'

2.2.2 Volunteering or paid work was associated with higher physical but not mental health-related quality of life

Is participation in work (either voluntary or paid) associated with higher quality of life amongst LiLACS NZ participants? This question was examined in relation to physical and mental HRQOL. The investigation looked at whether there were differences between those who undertook any work and those who did not; it did not examine relationships between hours of work and quality of life.

Those who undertook any work (volunteering or paid) had *significantly higher* physical HRQOL scores (mean score 43.3), compared with those who did not (mean score 41.6), adjusting for age, ethnic group, sex, socioeconomic deprivation, functional status and time in the study (Figure 2-5, Appendix Table 2.4). The direction of causality cannot be determined. It is possible that those who are more physically healthy are able to do more, and also that doing more keeps people in better health.
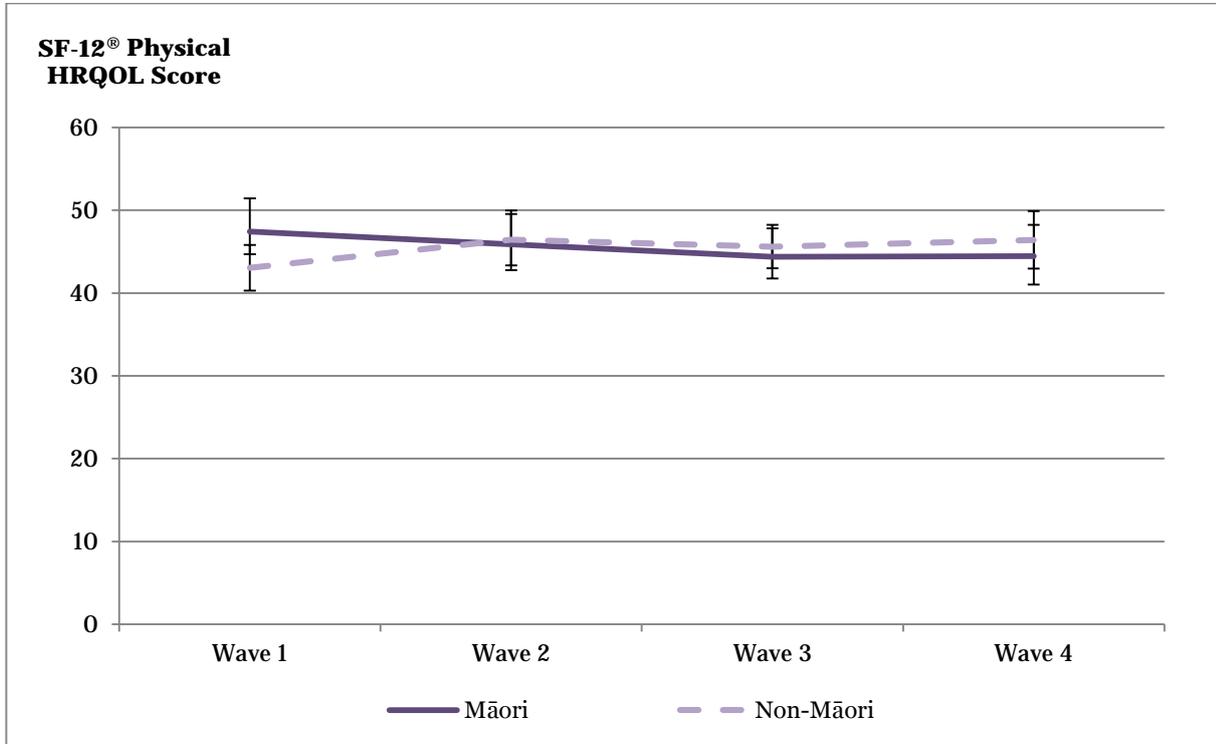
Figure 2-5: Physical HRQOL for LiLACS NZ participants involved or not involved in volunteering and/or paid work, Waves 1 to 4

Source: LiLACS NZ

Physical HRQOL for those who undertook volunteering and/or paid work was not markedly different comparing Māori and non-Māori at each wave (Figure 2-6).
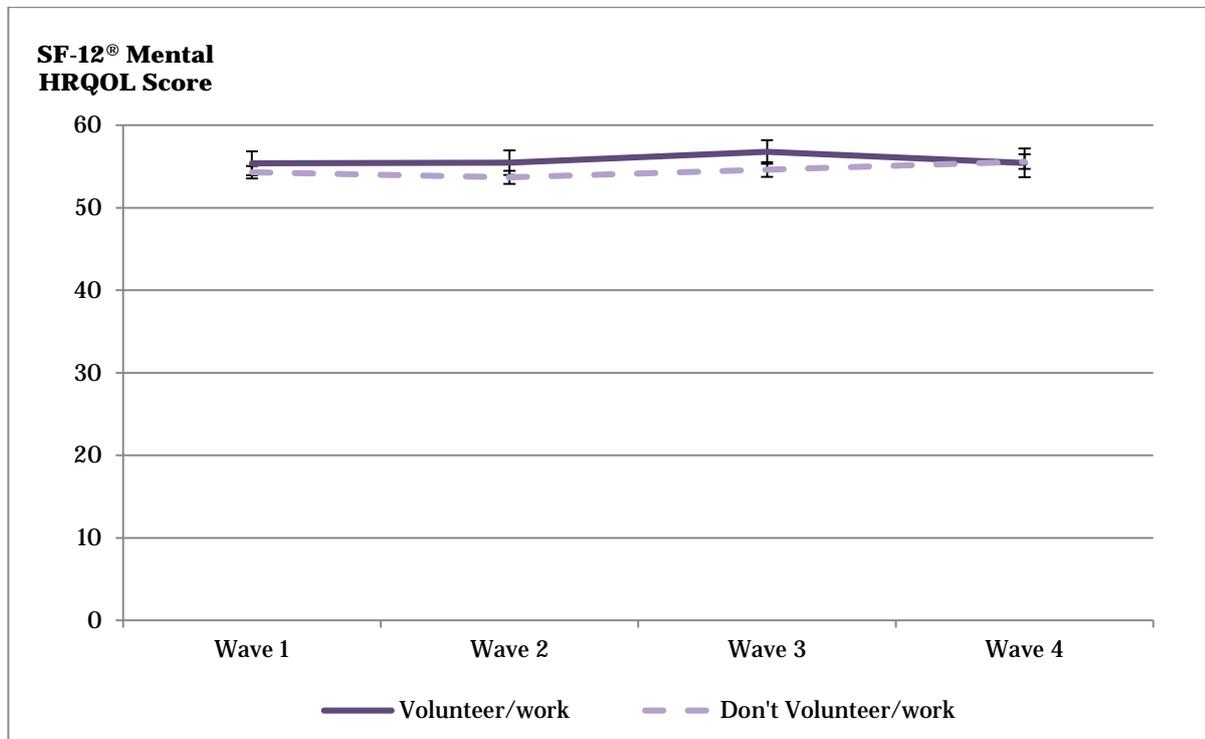
Figure 2-6: Physical HRQOL for LiLACS NZ participants involved in volunteering and/or paid work by ethnic group, Waves 1 to 4

Source: LiLACS NZ

Mental HRQOL was *not significantly different* between those LiLACS NZ participants who reported doing any work as a volunteer or for pay (mental HRQOL mean score 55.1) and those who did not (mental HRQOL mean score 54.3), adjusting for age, ethnic group, sex, functional status and socioeconomic deprivation and time in the study. (Figure 2-7, Table 2.5).

Figure 2-7: Mental HRQOL by involvement in volunteering and/or paid work, Waves 1 to 4

Source: LiLACS NZ

2.3 Grandchildren contributions

Grandparents and great-grandparents play a significant role in the lives of many New Zealand families. Provision of childcare, whether regular or irregular, helps parents remain in paid work, allows them time for other activities such as study or gives them a break from the demands of family life. Financial contributions are another way of supporting grandchildren and their families.

Currently older Māori have more mokopuna, on average, than other New Zealanders and become grandparents at younger ages (more than half of Māori are grandparents by the age of 45 years).[46] In the future Māori may have children later, however at present it is traditional for older Māori to care for some of their mokopuna or for children to be placed in their care through the practice of whāngai, where children are seen as belonging to the wider whānau rather than just to their biological parents. Māori custom is to pass the language and culture on to grandchildren.

LiLACS NZ provides new findings on grandparenting (including great-grandparenting) in advanced age.
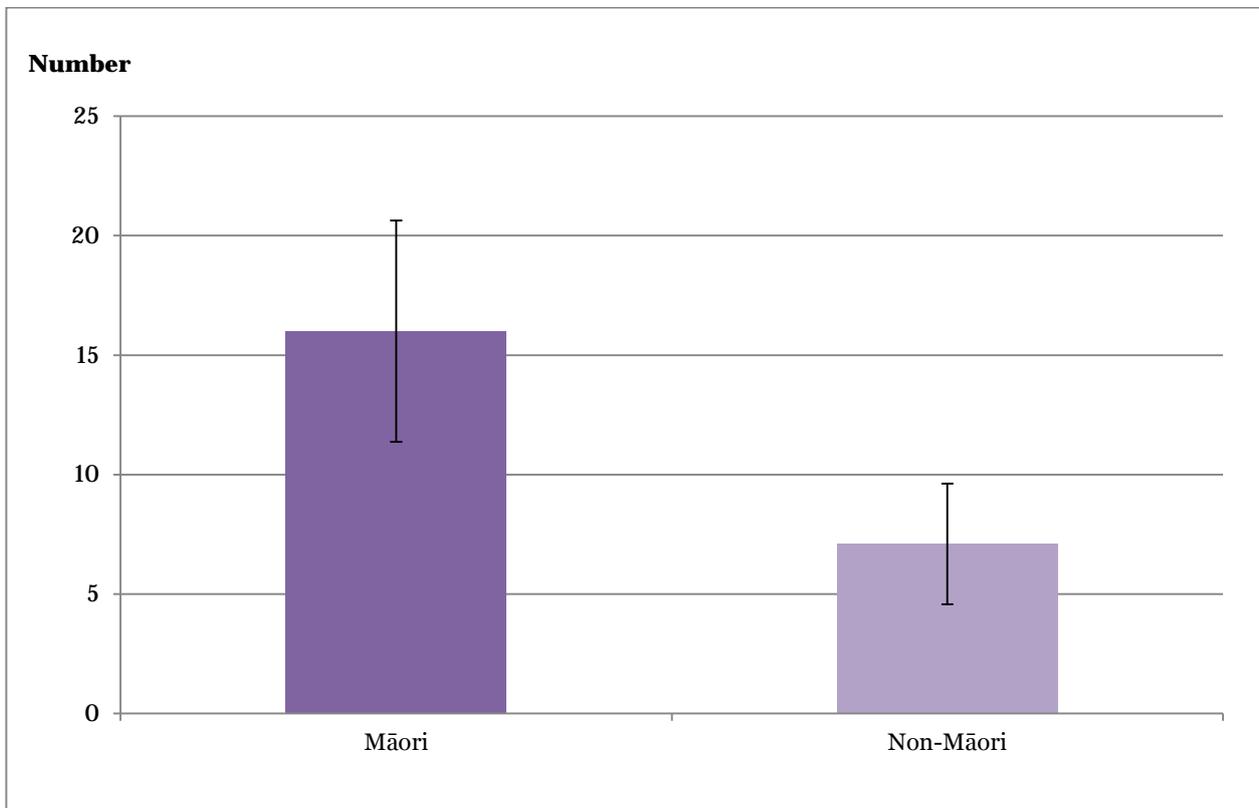
2.3.1 Nearly all LiLACS NZ participants had grandchildren and most had great-grandchildren

Ninety-three percent of LiLACS NZ participants have living children, 95 percent have grandchildren and 72 percent have great-grandchildren. Māori participants have *significantly more* mokopuna than non-Māori, an average of 16 grandchildren, 13 great-grandchildren and one great-great-grandchild each. Non-Māori have an average of seven grandchildren, four great-grandchildren and less than one great-great-grandchild each (Figure 2-8, Table 2.6). This is a consequence of Māori participants having had *significantly more* children, an average of five each compared to three for non-Māori.

Overall men had *significantly more* children than did women. Participants living in areas of lower socioeconomic deprivation, particularly men, had *significantly more* children on average (Appendix Table 2.7).

'When I see my mokopuna and getting to see my fifth generation mokopuna. Helping out and being a part of kohanga reo and kura [is a highlight of this stage of life for me].'

Figure 2-8: Average number of grandchildren, great-grandchildren and great-great-grandchildren by ethnic group, Wave 1

Source: LiLACS NZ
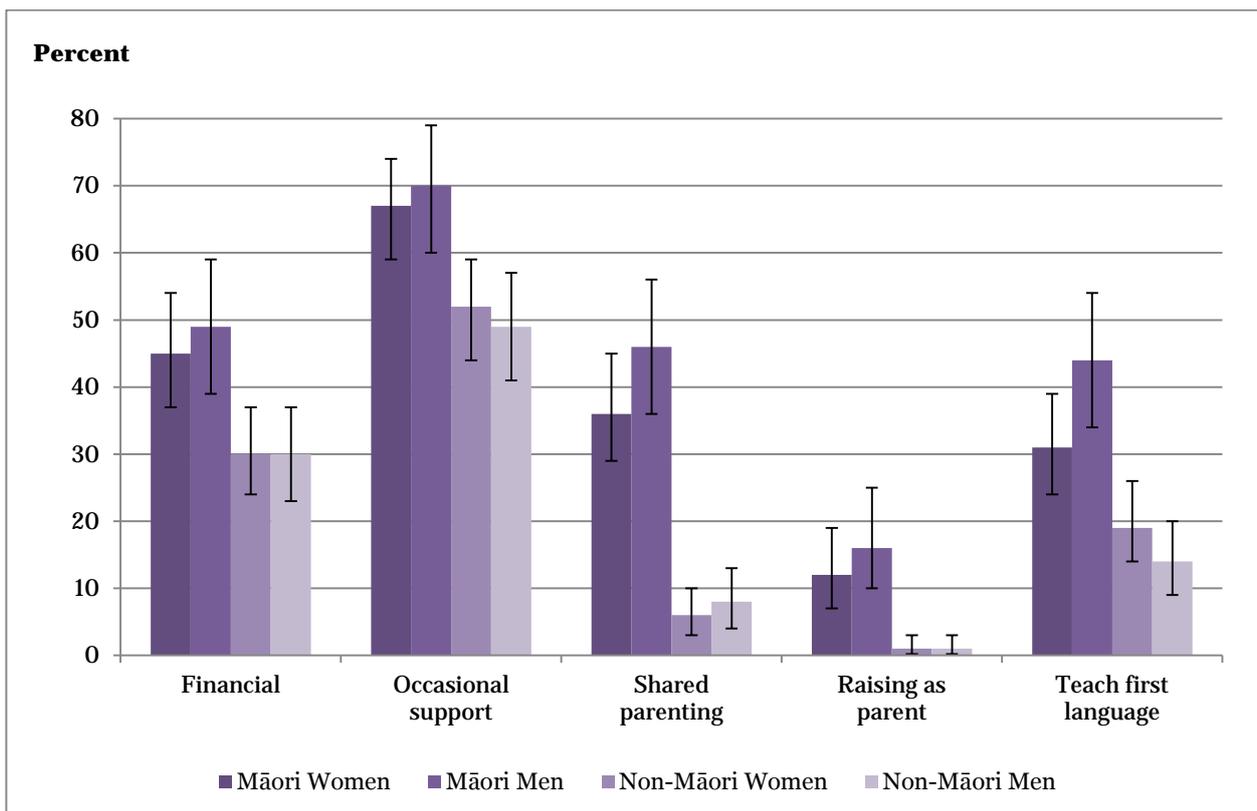
2.3.2 Most LiLACS NZ participants contributed to mokopuna

LiLACS NZ participants with grandchildren were asked how they currently contribute to their development (the question covered great-grandchildren and great-great-grandchildren, too). Almost all in Wave 1 (96.1%) said that they do make contributions (98% of Māori men, 95% of non-Māori men, 95% of Māori women, 96% of non-Māori women). Figure 2-9 (Appendix Table 2.8) shows what type of contributions they made.

The most common form of contribution to grandchildren was giving emotional support and love (94%, not shown in Figure 2-9 as there was a high prevalence in all groups). There were no differences between ethnic groups in relation to giving emotional support and love, although for all other forms of contribution to grandchildren there were differences between Māori and non-Māori.

The next most common kind of contribution was giving occasional support (68% for Māori, 50% for non-Māori). *Significantly more* Māori than non-Māori made financial contributions towards the wellbeing of their grandchildren (47% for Māori, 30% for non-Māori), adjusted for age and sex (Appendix Table 2.9).

Figure 2-9: Type of contribution to grandchildren by ethnic group and sex, Wave 1

Source: LiLACS NZ

Significantly more Māori than non-Māori helped their grandchildren by 'teaching them my first language' (36% for Māori, 17% for non-Māori). This was particularly so for Māori men (44%, compared to 32% of Māori women). It should be noted that 52 percent of Māori said they could carry out an everyday conversation in te reo Māori and only 4 percent said that they did not speak Māori.[25]

Significantly more Māori (14%) than non-Māori (1%) were bringing up grandchildren as a parent. Shared parenting was also *significantly more* common amongst Māori (46% of Māori men, 36% of Māori women) than non-Māori (8% of non-Māori men, 6% of non-Māori women).

Significantly more Māori living in areas of high socioeconomic deprivation reported giving love and support than Māori living in areas of low socioeconomic deprivation.
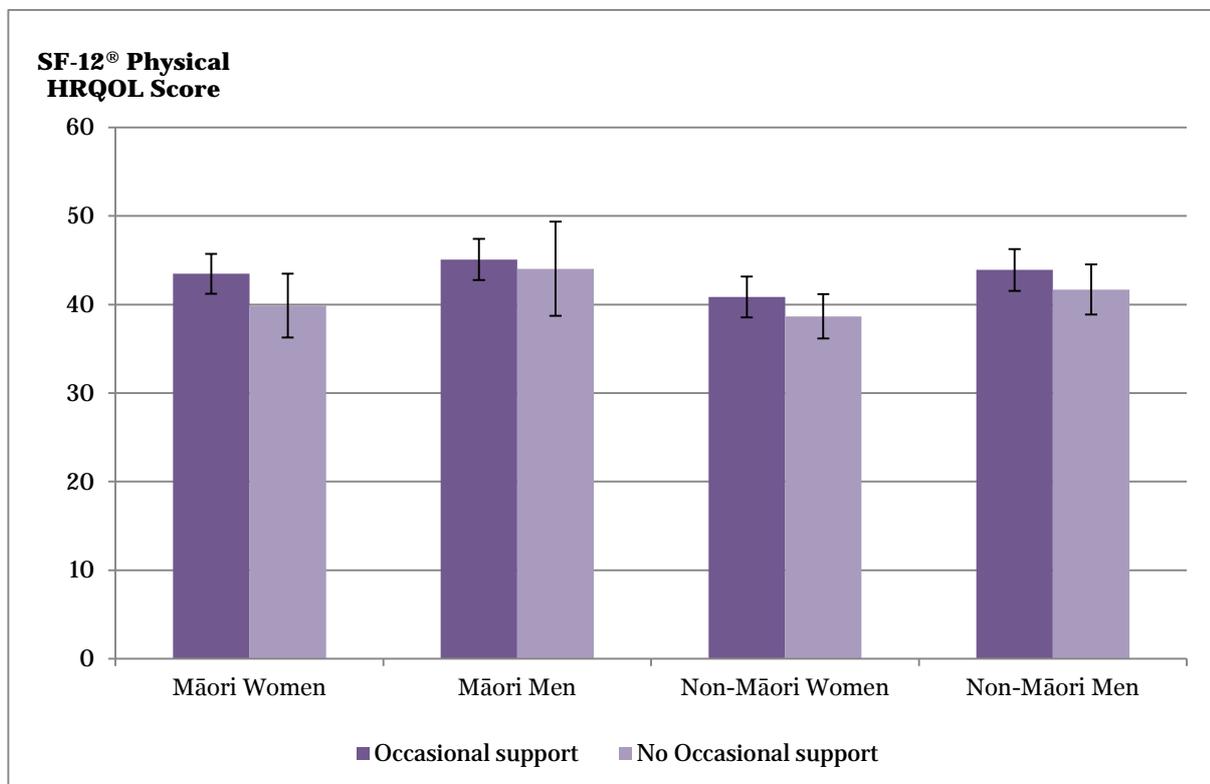
> **'All our extended family [are] very family orientated. Getting a great kick out of our grandchildren who range from 34 to 12 years plus 3 great-grandchildren. We help them with advice and support and sometimes finances. Their appreciation and love is a joy in our lives. A plaque in our kitchen says, "If we had have known grandchildren were so much fun, we would have had them first".'**

2.3.3 Providing occasional support to grandchildren was associated with higher physical health-related quality of life and providing financial support was associated with lower mental health-related quality of life

The association between various forms of contribution to grandchildren and HRQOL for LiLACS NZ participants was investigated using Wave 1 data. Overall there was *no significant* difference in physical HRQOL between those who gave any contribution and those who did not. Several significant differences were found for types of support.

Those who contributed occasional support to grandchildren had *significantly higher* physical HRQOL (mean score 43.0) than those who did not (mean score 41.9), adjusted for age, ethnic group, sex, socioeconomic deprivation and functional status (Figure 2-10, Table 2.10).

Figure 2-10: Physical HRQOL and occasional support, by ethnic group and sex, Wave 1
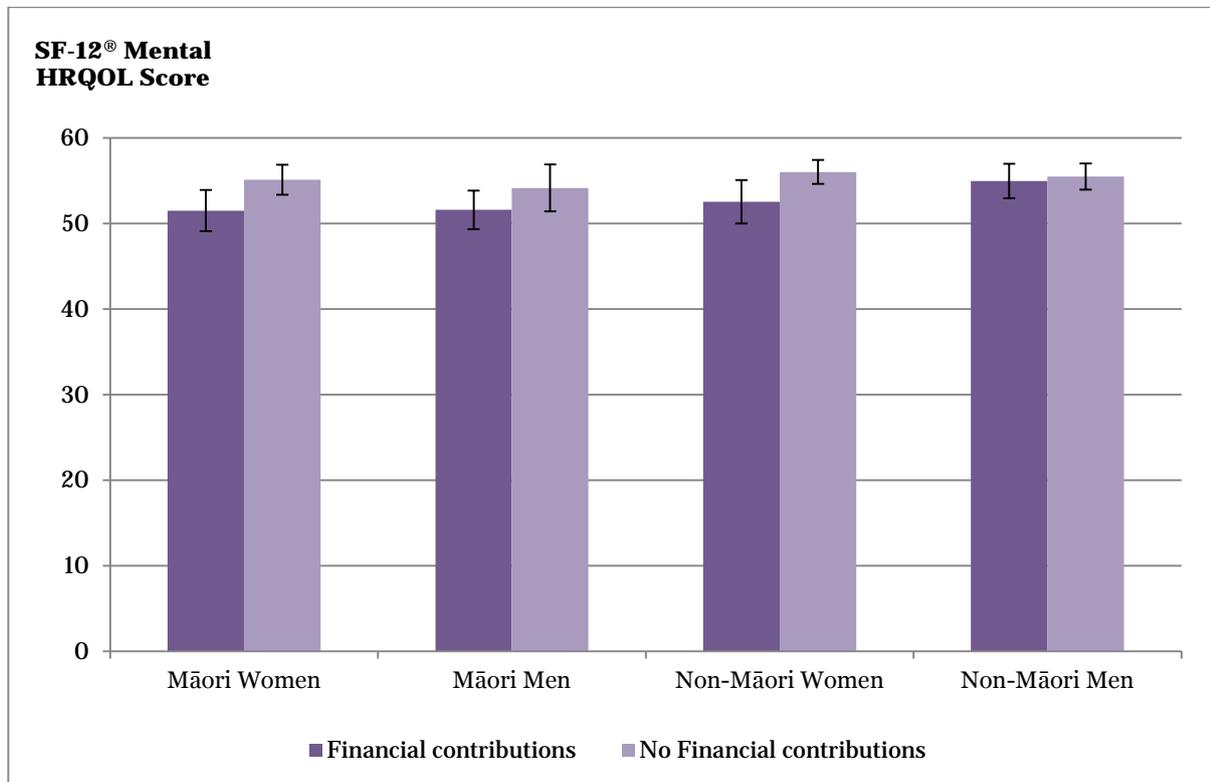
Source: LiLACS NZ

'**The older I get the more experience of life I have and I love that! The highlight of my life is when I have all my mokopuna around me.**'

Raising grandchildren as a parent, shared parenting, teaching first language, financial contributions and providing emotional support were *not significantly* associated with physical HRQOL. Neither was providing emotional support, since this was something nearly all grandparents did.

Those who contributed financially to grandchildren had *significantly lower* mental HRQOL than those who did not contribute financially, adjusting for age, ethnic group, sex, socioeconomic deprivation and functional status (Figure 2-11, Table 2.11). This is a finding that would require further analysis in the future.

Figure 2-11: Mental HRQOL and financial contributions by ethnic group and sex, Wave 1

Source: LiLACS NZ

2.4 Giving care or assistance

Around half a million people in New Zealand provide care for someone ill or disabled,[47] half of whom are living in the same household.[48] Many of these are older people caring for a spouse in ill health. In the research literature and in this report, these care providers are referred to as informal carers. Informal caring is often invisible since the tasks undertaken merge into the normal reciprocity of tasks that spouses undertake for each other.[49] However, providing care for a dependent spouse can be a heavy burden, both physically and emotionally, and many studies show heightened levels of stress in caregivers.[47] When the burden becomes too great, or the person becomes too ill or frail to live at home, the dependent spouse may be moved to residential care and caregiving is continued through visiting, advocacy, providing resources and making arrangements.

Since most people in advanced age live in their own homes, it is likely that many receive informal care from family, spouses in particular. As Alpass, Keeling and Pond say, 'Unpaid family caregiving is an essential part of the health system and saves billions in health care expenditure each year' (p. 4).[47]
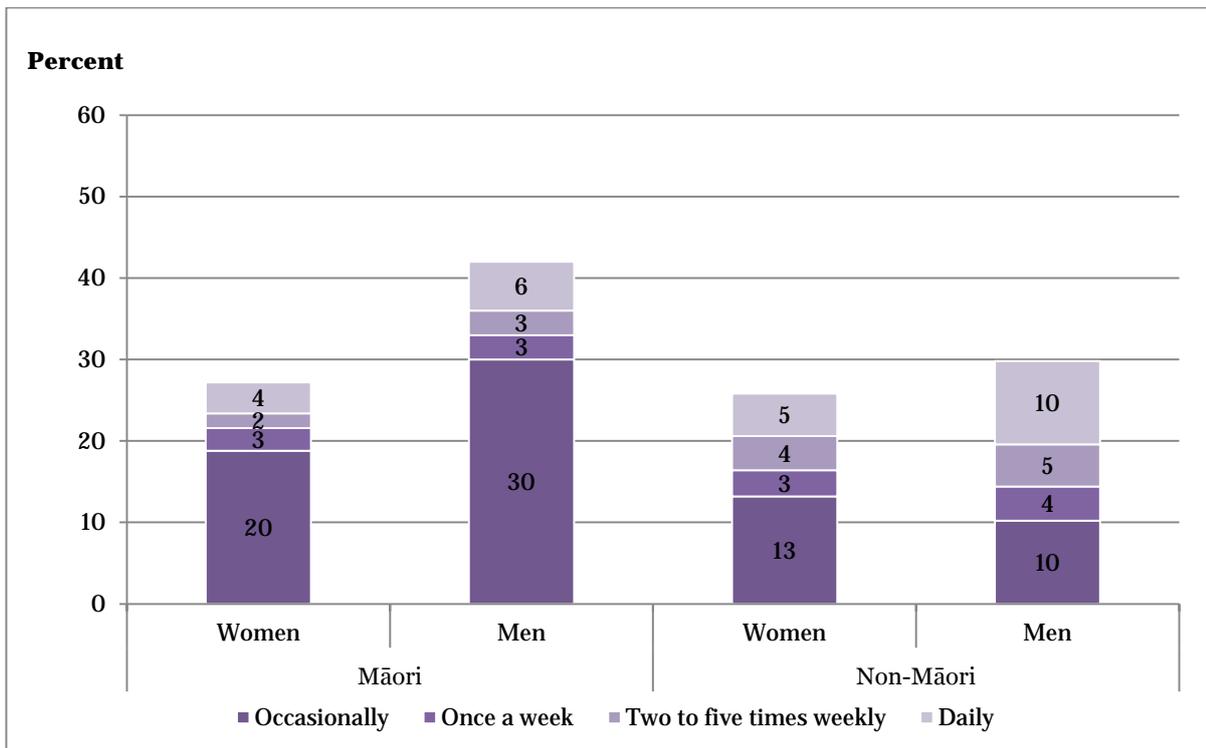
In general, women spend more time as unpaid carers than men, but in advanced age, perhaps surprisingly, men spend as much or more of their time on caring as do women.[50] This is because men in advanced age are far more likely than women to be living as part of a couple rather than alone; therefore, they are more likely than the women in the cohort to be in a situation that calls for caregiving.

2.4.1 LiLACS NZ participants provided care and assistance to others

The questions asked about caregiving were: 'How often do you currently provide care or assistance for other people?' and 'Do you give care or assistance for…?' with the options being financial help, transport, shopping, child care, personal care and 'other'. LiLACS NZ participants were asked if the care or assistance they gave was to someone in the same household, to family in another household or to people in other situations.

Figure 2-12 shows how frequently LiLACS NZ Māori and non-Māori gave care or assistance, ranging from occasionally, once a week, two to five times a week, to daily, by ethnic group and sex (Appendix Tables 2.12, 2.13, 2.14). *Significantly more* men (particularly Māori men) gave care or assistance than other groups. At Wave 1, 45 percent of Māori men, 33 percent of Māori women, 30 percent of non-Māori men and 26 percent of non-Māori women gave some type of care or assistance.

Figure 2-12: Frequency of care or assistance given by ethnic group and sex, Wave 1
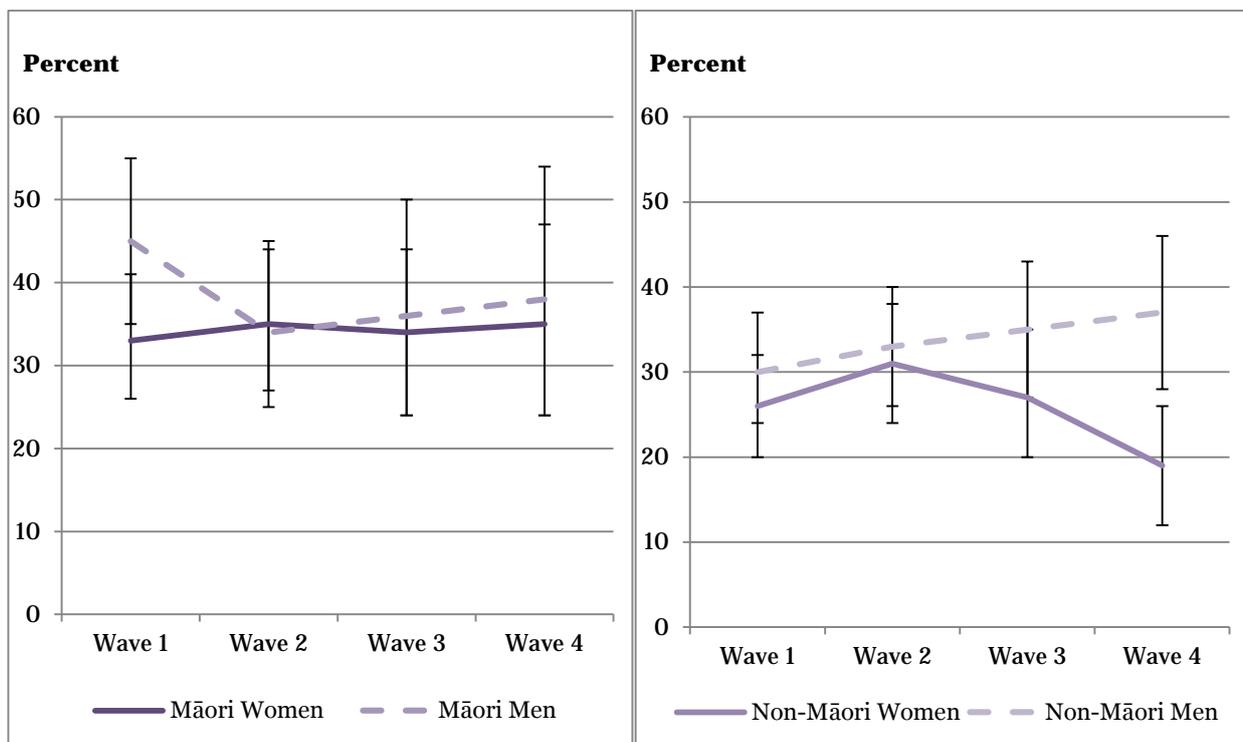
Source: LiLACS NZ

The living situation is important to caregiving. In terms of marital status, as recorded in Wave 1, 32 percent of Māori and 40 percent of non-Māori were married or partnered, 60 percent of Māori and 50 percent of non-Māori were widowed and 8 percent of Māori and 9 percent of non-Māori had never married, or were separated or divorced. More women (74% of Māori women and 67% of non-Māori women) than men (42% of Māori men and 31% of non-Māori men) were widowed.

Significantly more Māori (38%) gave care or assistance than did non-Māori (28%) at Wave 1. At Wave 4, 36 percent of Māori and 27 percent of non-Māori were still giving some sort of care or assistance (Appendix Tables 2.14, 2.15). These differences were driven by the higher percentage of Māori men giving care or assistance in Wave 1 and the lower percentage of non-Māori women at Wave 4 (Figure 2-13). It should be kept in mind that the cohort was smaller by Wave 4, with a number of the original participants having died or withdrawn because of frailty or illness. Nevertheless, it is important to note that as they continue to age, LiLACS NZ participants who are well enough to continue to participate in the study do continue making contributions to others.

Figure 2-13: Giving any care or assistance by sex and ethnic group, Waves 1 to 4
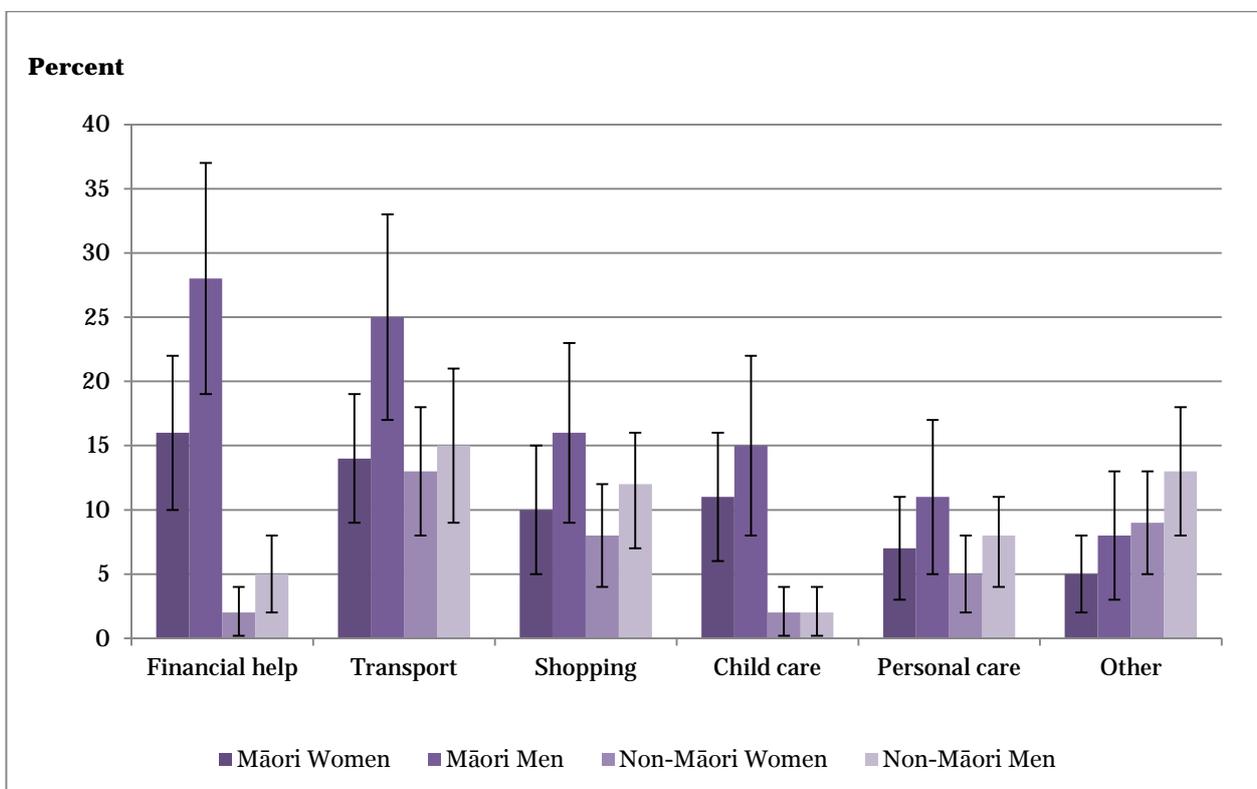
Source: LiLACS NZ

Figure 2-14 (Table 2.15) shows that financial help was a common type of care or assistance (given by 28% of Māori men, 5% of non-Māori men, 16% of Māori women and 2% of non-Māori women). Financial help was given by *significantly more* men than women and by *significantly more* Māori than non-Māori.

The most common type of care or assistance given overall was transport, provided by 25 percent of Māori men, 15 percent of non-Māori men, 14 percent of Māori women and 13 percent of non-Māori women (*significantly more* men than women, no significant difference between Māori and non-Māori).

Shopping for others was done by 16 percent of Māori men, 12 percent of non-Māori men, 10 percent of Māori women and 8 percent of non-Māori women (no significant difference between men and women, no significant difference between Māori and non-Māori).

Figure 2-14: Types of care or assistance by ethnic group and sex, Wave 1

Source: LiLACS NZ

In relation to child care, 15 percent of Māori men, 2 percent of non-Māori men, 11 percent of Māori women and 2 percent of non-Māori women answered that they gave this care (no significant difference between men and women, *significantly more* Māori than non-Māori).

Personal care for others was provided by 11 percent of Māori men, 8 percent of non-Māori men, 7 percent of Māori women and 5 percent of non-Māori women (no significant difference between men and women, no significant difference between Māori and non-Māori).

Other forms of care or assistance were given by 8 percent of Māori men, 13 percent of non-Māori men, 5 percent of Māori women and 9 percent of non-Māori women. These included

emotional support and household chores (no significant difference between men and women, no significant difference between Māori and non-Māori).

Of those who gave assistance, 32 percent gave care or assistance to someone in the same household, 33 percent to family in another household and 44 percent to others (Table 2.16). Māori were *significantly more* likely than non-Māori to give care or assistance to family in another household; and 31 percent of Māori and 55 percent of non-Māori gave care or assistance to 'others' (ie, non-family members), a *significant* difference (Table 2.17).
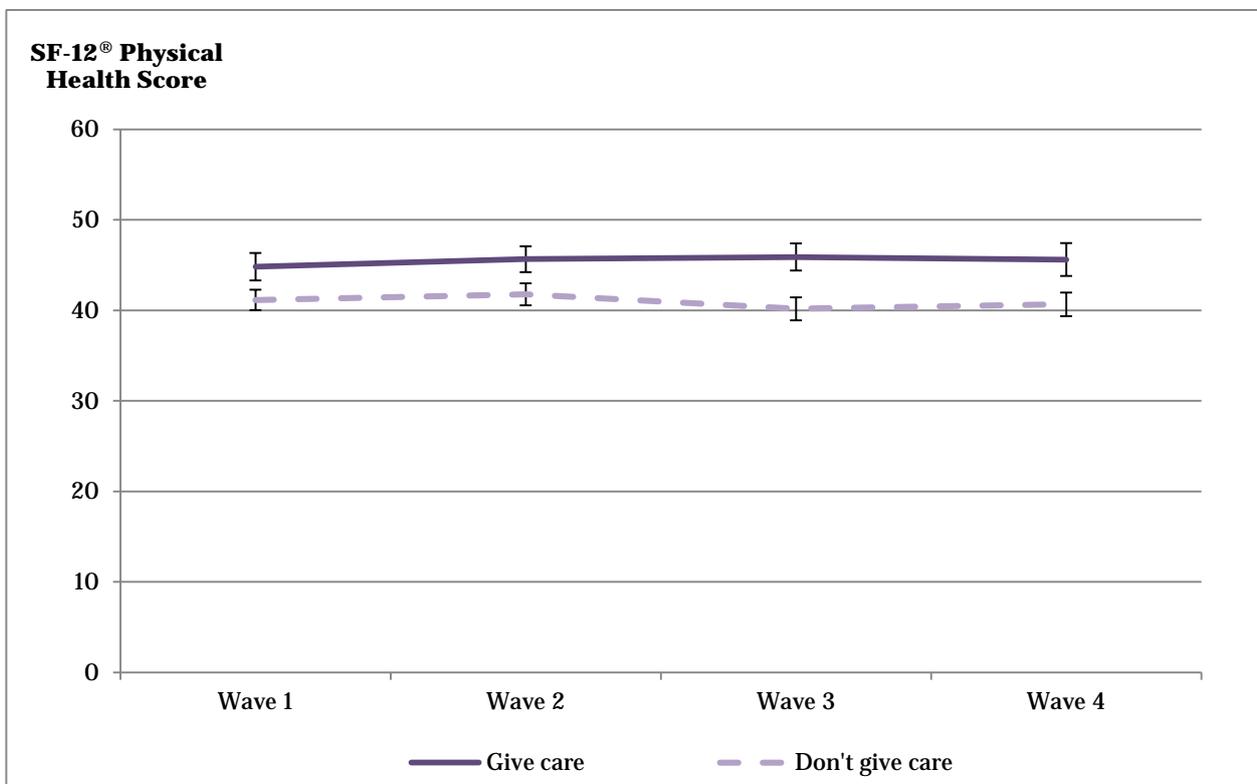
Giving contributions did not vary by socioeconomic deprivation over time, controlling for sex and ethnic group (Table 2.17).

2.4.2 Giving care or assistance was associated with higher physical but not mental health-related quality of life

Giving care or assistance in advanced age may reflect better health and functional ability but it may also be morale-boosting, with giving to others assisting in maintaining health and function. The causal direction of associations in our data cannot be established, but any associations discovered are of interest nonetheless.

Our study found that those who gave care or assistance had *significantly higher* physical HRQOL than those who did not, when adjusted for age, ethnic group, sex, socioeconomic deprivation and functional status in each wave of LiLACS NZ (Figure 2-15, Table 2.18).

Figure 2-15: Physical HRQOL by giving care or assistance, Waves 1 to 4

Source: LiLACS NZ

At each year of follow-up, those who gave care or assistance *did not have a significantly different* level of mental HRQOL as those who did not give care or assistance, adjusted for age, ethnic group, sex, socioeconomic deprivation and functional status (Table 2.19).

There was *no significant difference* in physical or mental HRQOL according to the type of assistance given (Tables 2.18, 2.19).

2.5 Key findings

- LiLACS NZ participants continued to volunteer as they grew older.

- Volunteering or paid work was associated with higher physical but not mental health-related quality of life (HRQOL).

- Nearly all LiLACS NZ participants had grandchildren and most had great-grandchildren.

- Māori LiLACS NZ participants had more grandchildren and great-grandchildren than did non-Māori.

- Most LiLACS NZ participants contributed to grandchildren and great-grandchildren; Māori were more likely to make contributions.

- Providing occasional support to grandchildren was associated with higher physical HRQOL and providing financial support was associated with lower mental HRQOL.

- People of advanced age provided care or assistance to others, with Māori more likely to provide care or assistance than non-Māori and men more likely than women.

- The most common type of care or assistance given was transport, followed by financial help, shopping, child care and personal care.

- Māori were more likely than non-Māori to give care or assistance to family members.

- Giving care or assistance was associated with higher physical but not mental HRQOL.

Section Three: Receiving Assistance in Advanced Age

3.1 Introduction

It is clear that population ageing (increased longevity as well as a substantial increase in the absolute number of people in advanced age) will increase the demand for health and care services in New Zealand in the future. [7,51,52] High utilisation of health and care services and some degree of dependency are common in advanced age. However, the rise in prevalence of disability has been slower than expected, indicating that better health is being maintained for longer. There has been much debate in the research literature around whether increased longevity will be accompanied by more years spent with disability in older age, or whether, conversely, better overall health will mean that, for older populations, illness and disability are compressed into a shorter time period towards the end of life. It seems as if both may be true, that a longer life will give us more healthy years as well as more years with disability. [53]

The emphasis on 'ageing in place', which supports independent living, as well as the expansion of retirement villages in New Zealand, has meant that institutional care is expanding more slowly than might have been expected. The proportion of older people using residential care has fallen, but age and level of frailty amongst residents has increased. [27,54] A recent study suggests that around half of New Zealanders will spend some time in residential care towards the end of their life. [55]

While population ageing will inevitably lead to higher health and social service use, a clearer understanding is needed of the trajectories of disability, dependency and recovery amongst people in advanced age in order to provide adequate preventive health care, community support, social care and treatment for illness and disability. [56] Physical decline is not inevitable following health crises or periods of ill health; some people will recover, others will improve, needing less care than previously. Adjustments may be made by those whose conditions limit some of their everyday activities, minimising the impact of disability and illness on quality of life and independence. Support for recovery, regaining of function and compensation for disability may improve quality of life during and after periods of illness, disability or dependence. Understanding these processes of transition in and out of dependency is important for those who are ageing and those who support older people. It is critical for service planning.

Very little is known about the care and assistance received by Māori of advanced age. A previous LiLACS NZ report noted resilience and wellbeing amongst Māori despite the health conditions commonly present. [32]

Functional status is an important concept in research on people of advanced age. Functional status is different from the diagnosis of disease. It refers to the extent to which people can engage in the activities of daily living and is a measure on the spectrum of ability to disability. Some degree of physical deterioration with ageing is inevitable, but functional status does not have a one-to-one relationship with specific diseases or health conditions. As well as decline over time, recovery and improvement in functional status do occur in people of advanced age and their potential for recovery should not be overlooked.

Functional status, referring to the capacity to engage in activities of daily living (ADLs), is measurable via validated scales such as the Nottingham Extended Activities of Daily Living (NEADL) scale. [28] How individuals score on such scales—in other words, their ADL status—is a strong predictor of mortality, hospitalisations and institutionalisation. This is the case even when disease status and socioeconomic status (other predictors of mortality) are controlled for. [57]

Self-reported functional status and objective performance measures of functional status independently predict health service use, changes in health status and decline in function in primary care patients. The use of both methods of measurement increases predictive power considerably.[58,59] Arguably, changes in functional status, rather than disease status, are the most salient aspects of bodily ageing for clinicians and older people alike.[60–65]

This section explores functional status and how it changes over time in LiLACS NZ Māori and non-Māori participants in advanced age. It also explores the extent to which LiLACS NZ participants receive support services and informal care. The relationship between receiving assistance, functional status and health-related quality of life (HRQOL) is examined.

Appendix Table 3.1 (Appendix 3.1) shows the number of participants who responded to each question or measure used as data in this section.

3.2 Functional change

Change in functional status was examined for all LiLACS NZ participants over each wave of the study. Eleven questions about ADLs (eight from the NEADL scale, with an additional three about basic ADLs) were asked of all participants. In relation to each daily activity, such as doing housework, they were asked whether in the last few weeks they had done it 'not at all', 'with help', 'on your own with difficulty' or 'on your own'. The highest possible score from these items was 11, meaning that the person was 'high functioning', having accomplished all 11 activities independently (on their own with or without difficulty) in the last few weeks. A score of 9 or 10 meant participants were 'medium functioning', needing assistance with one or two activities, and a score of 8 or less meant participants were 'low functioning', meaning personal assistance was needed for at least three of the activities.

With the same questions asked of each participant in each wave of the study, it can be established how many participants improved, how many stayed the same and how many declined in function (Tables 3.2 to 3.4).

For some further analyses, the full NEADL scale was used, completed only by those who undertook the full questionnaire.

'[I'm] still physically able to do maintenance on our property. [I] still play golf although limited by previous hip operations. I particularly get a lot of pleasure in the demands of vegetable gardening, some landscaping and flower care too.'

3.2.1 Most participants maintained function over time and improved function was not uncommon

As Figure 3-1 shows, most of the participants who remained in LiLACS NZ through Waves 1 to 4 maintained function over time and improved function was not uncommon. At Wave 1, 35 percent of participants were high functioning. At Wave 2, 26 percent were high functioning, as were 24 percent at Wave 3 and 23 percent at Wave 4.

Forty percent of participants were medium functioning at Wave 1, 42 percent at Wave 2, 40 percent at Wave 3 and 38 percent at Wave 4.

Low functioning scores were recorded for 24 percent of participants at Wave 1, 32 percent at Wave 2, 36 percent at Wave 3 and 39 percent at Wave 4.

Figure 3-1 shows transitions in function for the participants between each wave of the study, including those who did not remain in the study at each wave. It shows how many participants (and what proportion) improved, stayed the same or declined.

Improvements in function were recorded over time for between 15 and 18 percent of participants who remained in the study across the waves of the study.
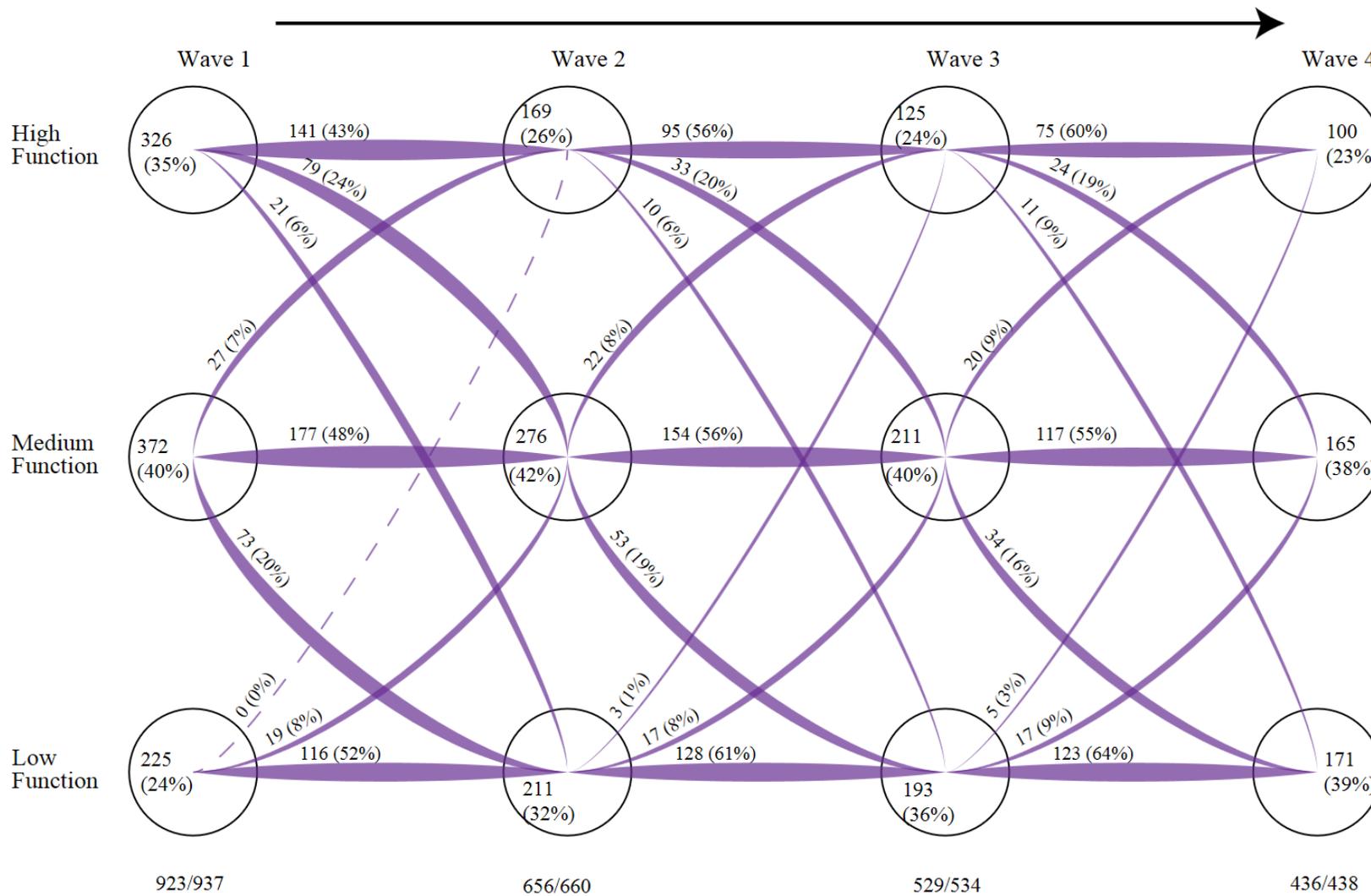
From each wave to the next, the highest proportion of participants *stayed at the same level* of function.

Decreases in function were recorded by 59 percent of participants of varying function levels across the waves of the study.

Some participants died over the three years of the study (Appendix Table 3.3). Of those with high function, only 3 percent died between Waves 1 and 2; 4 percent between Waves 2 and 3; and 4 percent between Waves 3 and 4. For those with medium function, 5 percent died between Waves 1 and 2; 5 percent between Waves 2 and 3; and 7 percent between Waves 3 and 4. *Significantly more* people (3.5 times more) with low function died from one wave to the next, than did those with high or medium function. Between Waves 1 and 2, 19 percent of those with low function died, as did 18 percent between both Waves 2 and 3 and Waves 3 and 4.

Those who were of older age, Māori or male also had *significantly greater* mortality, although these associations were not as strong as for functional status. Socioeconomic status did not make a significant difference to mortality.

Figure 3-1: Transitions in function, Waves 1 to 4
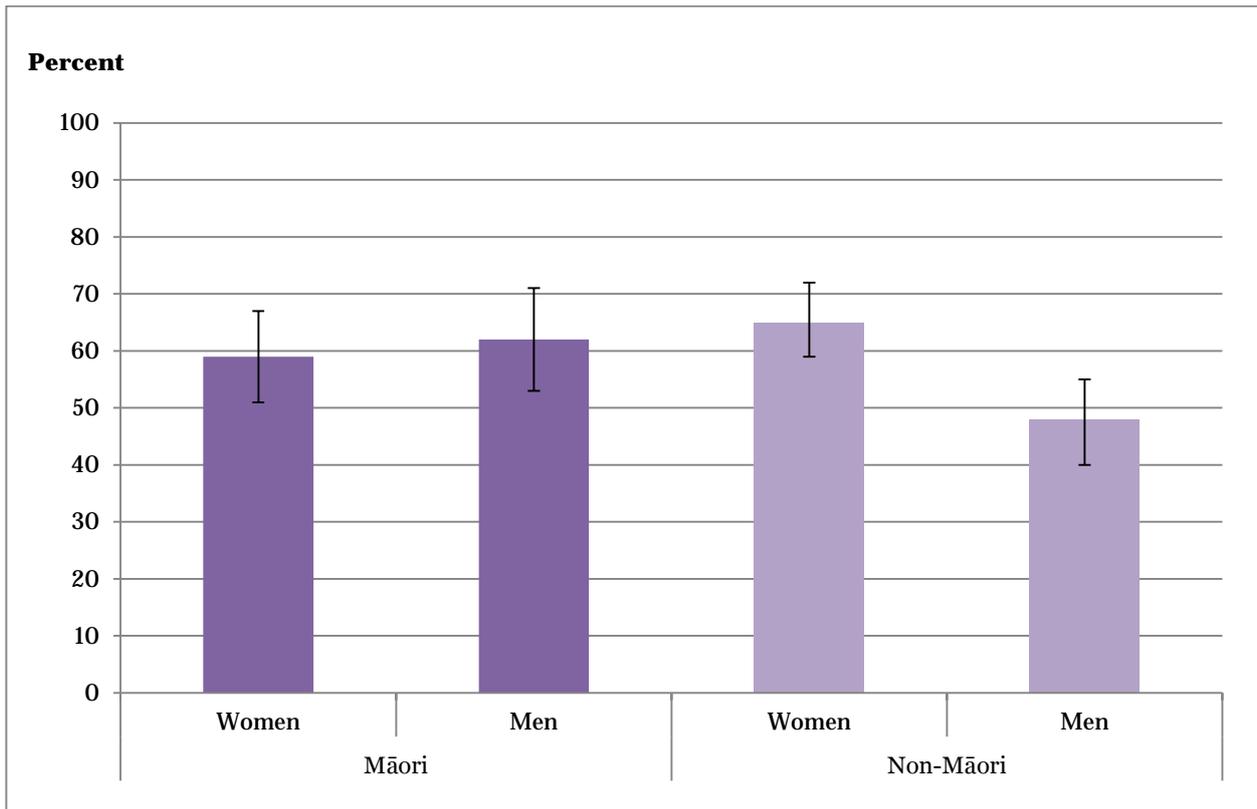
Source: LiLACS NZ

3.2.2 Non-Māori men were more likely to decline in function than other groups

Figure 3-2 (Appendix Table 3.4) demonstrates that the pattern of transitions in function differed for the two ethnic groups and for men and women. Over the course of the study s*ignificantly more* Māori (61%) stayed the same or improved than did non-Māori (57%), adjusting for age, sex, and socioeconomic deprivation.

Figure 3-2: Remaining the same or improving in function, by ethnic group and sex, Waves 1 to 4

Source: LiLACS NZ

Significantly more women (74%) stayed the same or improved than did men (68%), adjusting for age, ethnic group and socioeconomic deprivation.

These differences were driven by the *significantly lower* proportion of non-Māori men who stayed the same or improved.

Did participants' socioeconomic position relate to changes in their functional status? Those living in areas of high socioeconomic deprivation were more likely to maintain or improve function than were those in areas of low socioeconomic deprivation. (A fully adjusted model is available in Appendix Tables 3.5 and 3.6.)

3.2.3 Neither physical nor mental health-related quality of life decreased as function decreased

Interestingly, there were *no significant differences* in physical or mental HRQOL between those who maintained their function and those whose function declined (Appendix Tables 3.7, 3.8). This may suggest that quality of life is not affected by changes in functional status.

3.3 Support services
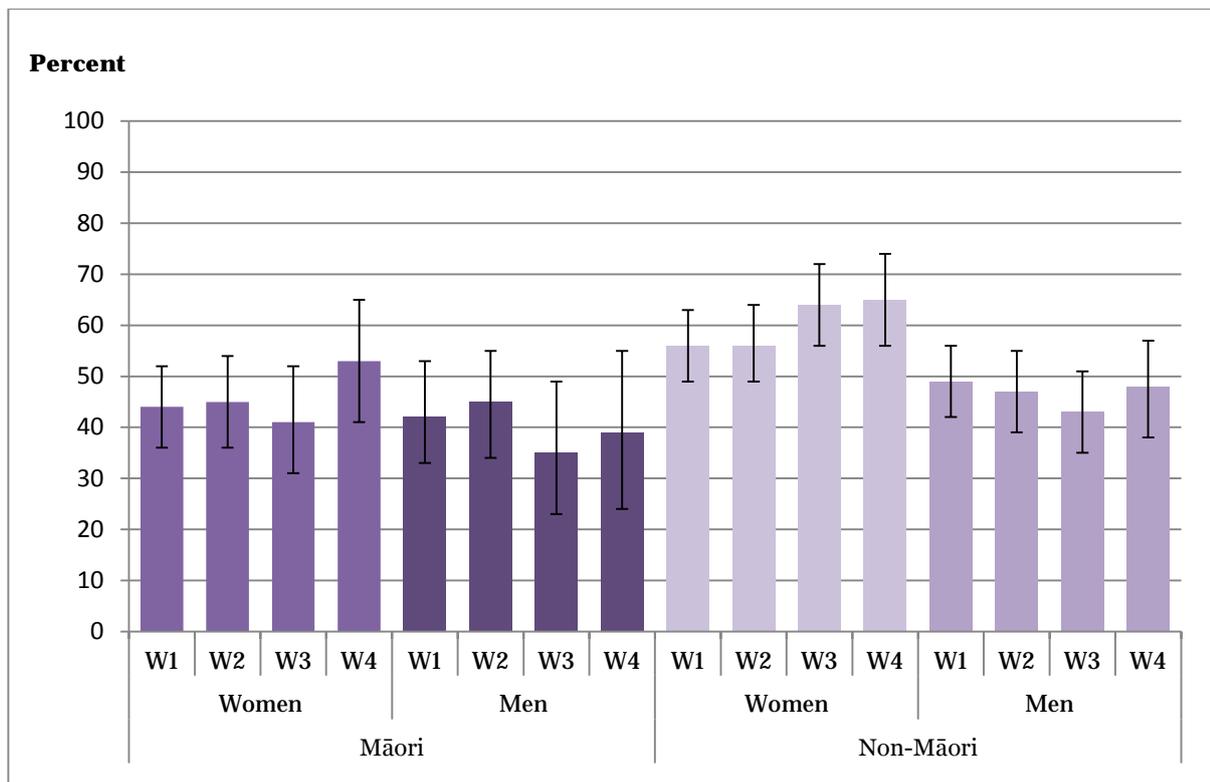
Participants were asked if they received any regular support services. Support services include home help for housework, shopping or gardening, and personal care. These could be funded in full or in part by the public health or social welfare system, the Accident Compensation Corporation or through payment by participants. Low functional status, which involves difficulties with activities of daily living, is clearly a reason for needing support services and so functional status and age were adjusted for when comparisons were made between the ethnic group and sex of recipients.

'**Independence… I live alone. [I] only have home help once a week. [I] still have my driver's licence. My son gave me a mobility scooter, [which is] very handy for short trips. In spite of continuous pain with arthritis and sciatica I still manage running my home and doing my gardening (slowly).'**

3.3.1 More women received support services than men

Forty-three percent of Māori and 53 percent of non-Māori in Wave 1 received support services. In Wave 2, 45 percent of Māori and 52 percent of non-Māori received services, as did 39 percent of Māori and 54 percent of non-Māori in Wave 3, and 48 percent of Māori and 56 percent of non-Māori in Wave 4 (Figure 3-3, Appendix Table 3.9).

Figure 3-3: Receipt of support services by ethnic group and sex, Waves 1 to 4

Source: LiLACS NZ

The receipt of support was *not significantly different* for Māori and non-Māori, controlling for age, sex, functional status and socioeconomic deprivation (Appendix Table 3.10).

Significantly more women (55%) than men (44%) received support services, adjusting for age, ethnic group, functional status, socioeconomic deprivation and time in the study (Appendix Table 3.10). (It should be noted that women were more likely to live alone than men.)

Socioeconomic deprivation made *no significant difference* to receipt of support services, adjusting for age, ethnic group, sex, and functional status (Appendix Table 3.10).

A fully adjusted model is available in Appendix Table 3.11. The older a person was, the more likely they were to receive support services over time.
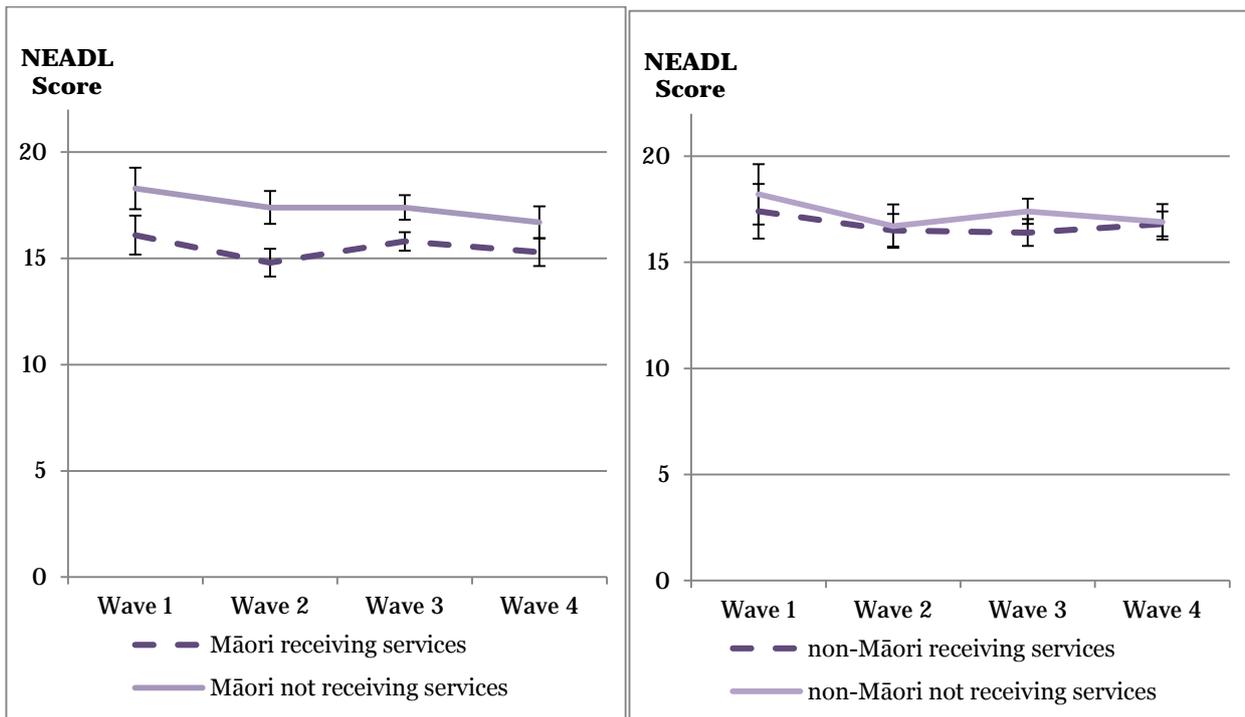
3.3.2 Receipt of support services was related to functional status for Māori, but not for non-Māori

The full NEADL scale, administered to those who completed the full LiLACS NZ questionnaire, asked participants about 22 activities. Those who scored 22 were completely independent and those with lower scores required assistance with at least some activities of daily living.

The relationship between activities of daily living and support services was investigated (Tables 3.12 to 3.14). In Wave 1, the mean NEADL score for Māori who received support services (16.1) was *significantly lower* than for Māori who did not receive support services (18.3). In other words, those who received support services had lower functional status.

This and subsequent waves are illustrated in Figure 3-4, where there is some convergence between the two groups. But for non-Māori, there was *no significant difference* in functional status between those receiving or not receiving services. In other words, for non-Māori, receipt of support services did not appear to be related to the need for assistance with daily living, and there appeared to be a convergence between the two groups over time. These findings suggest that there may be differences in the way support services are used by or allocated to Māori and non-Māori, although this would need further exploration.

Figure 3-4: Functional status by receipt of support services and ethnic group, Waves 1 to 4
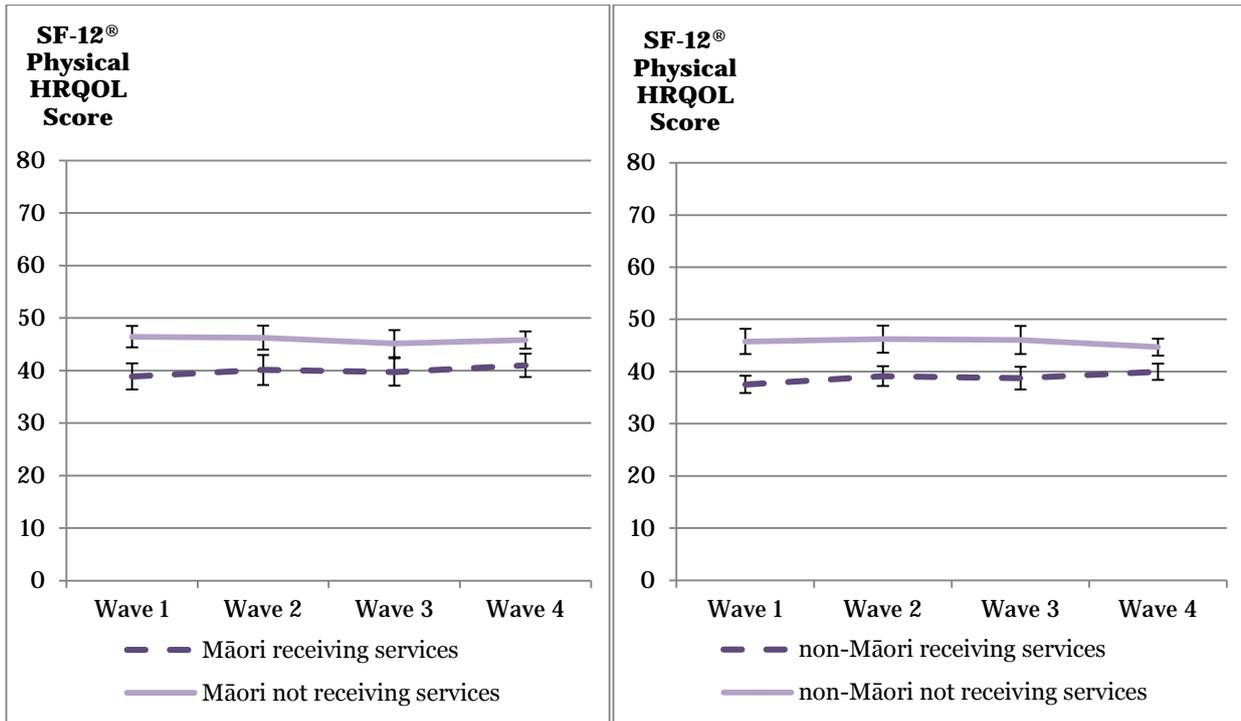
Source: LiLACS NZ
Note: NEADL score error bars represent 95 percent confidence intervals

3.3.3 Those receiving support services maintained their physical health-related quality of life despite functional decline

Those who received support services had overall a *significantly lower* physical HRQOL score, adjusting for functional status, age, sex and socioeconomic deprivation (Figure 3-5, Appendix Table 3.12).
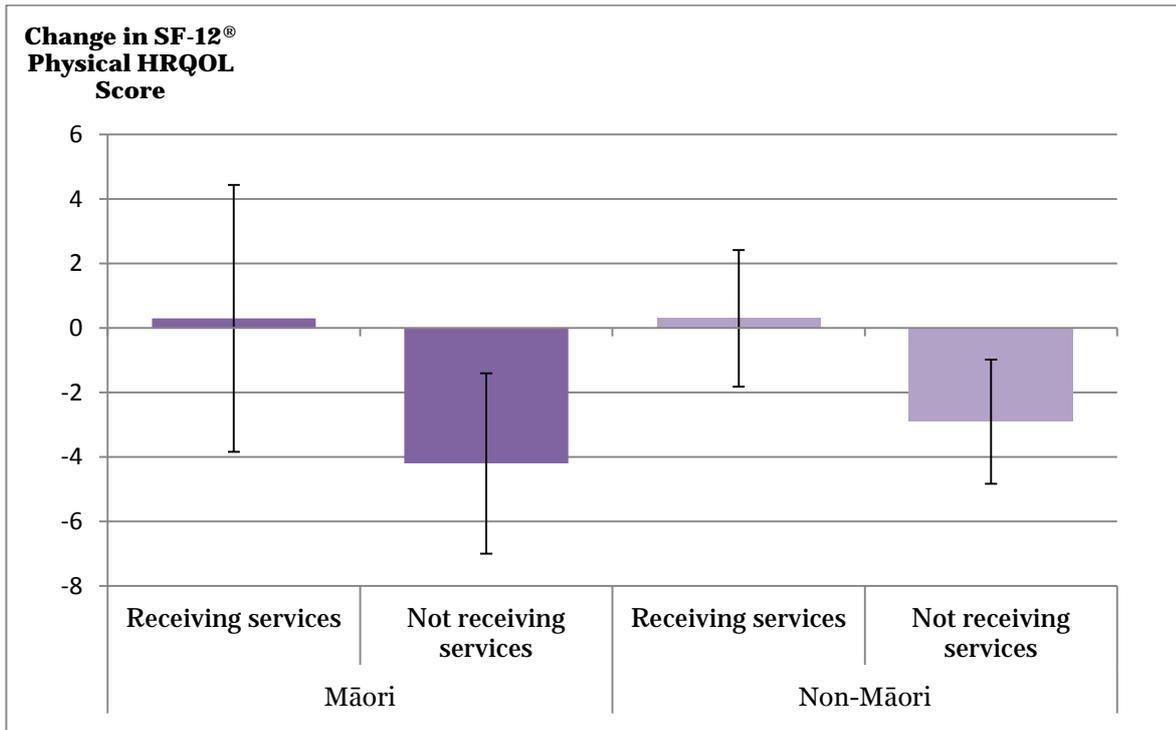
Figure 3-5: Physical HRQOL by receipt of support services and ethnic group, Waves 1 to 4

Source: LiLACS NZ
Note: Error bars represent 95 percent confidence intervals

Over the course of the study, those who did not receive services had a *significant* decrease in physical HRQOL over time, whereas those receiving services maintained physical HRQOL (Figure 3-6, Appendix Table 3.13). The Wave 1 mean physical HRQOL score for those who received services was 39.5. When re-interviewed at Wave 4 the score was 39.8. The mean score for those not receiving services was 48.0 at Wave 1 and 44.7 at Wave 4.

Figure 3-6: Change in physical HRQOL by receiving services & ethnic group, Waves 1 to 4

Source: LiLACS NZ

Mental HRQOL was similar for those who received support services and those who did not (Appendix Table 3.14). Scores were maintained over time with *no significant* change and scores *did not vary significantly* by ethnic group, adjusted for age, sex, socioeconomic deprivation and functional status.

These findings suggest that support services protect and maintain physical HRQOL for people with appropriate levels of need. Mental HRQOL did not change over time despite changes in functional status and whether or not support services were received.
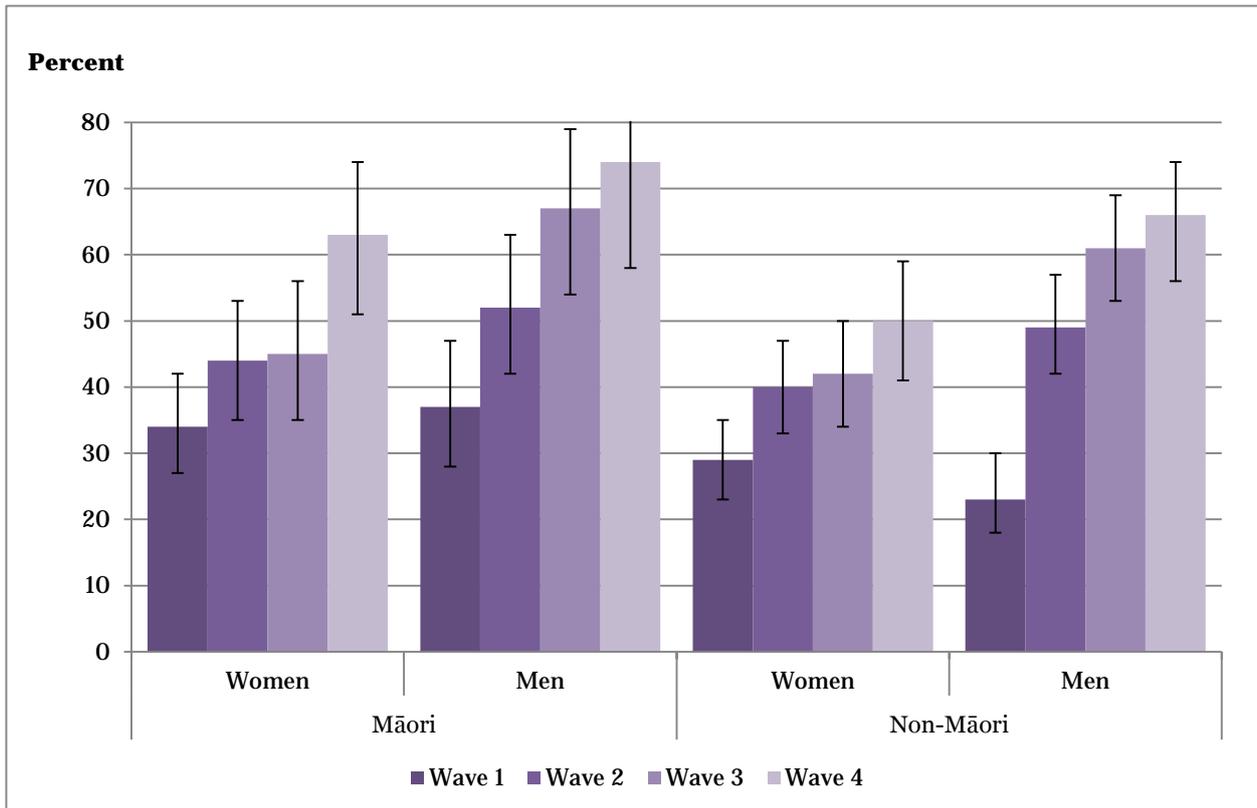
3.4 Informal care

For the purposes of this report, informal care is defined as receiving unfunded help or assistance with activities of daily living from whānau/family in the same household or whānau/family outside the household. Informal care may complement formal care or it may be a substitute for it. Later in the report (Section 4), informal care is described from the perspective of those who provide it and their contributions are costed.

3.4.1 More Māori than non-Māori and more men than women received informal care, which increased over time for all groups

At the beginning of the study, 36 percent of Māori and 26 percent of non-Māori received informal care (Appendix Table 3.15). As the study progressed, *significantly more* participants received informal care each year, whatever their level of function (Figure 3-7). By Wave 4, 67 percent of Māori and 57 percent of non-Māori were receiving informal care.

Figure 3-7: Receipt of informal care by ethnic group and sex, Waves 1 to 4

Source: LiLACS NZ
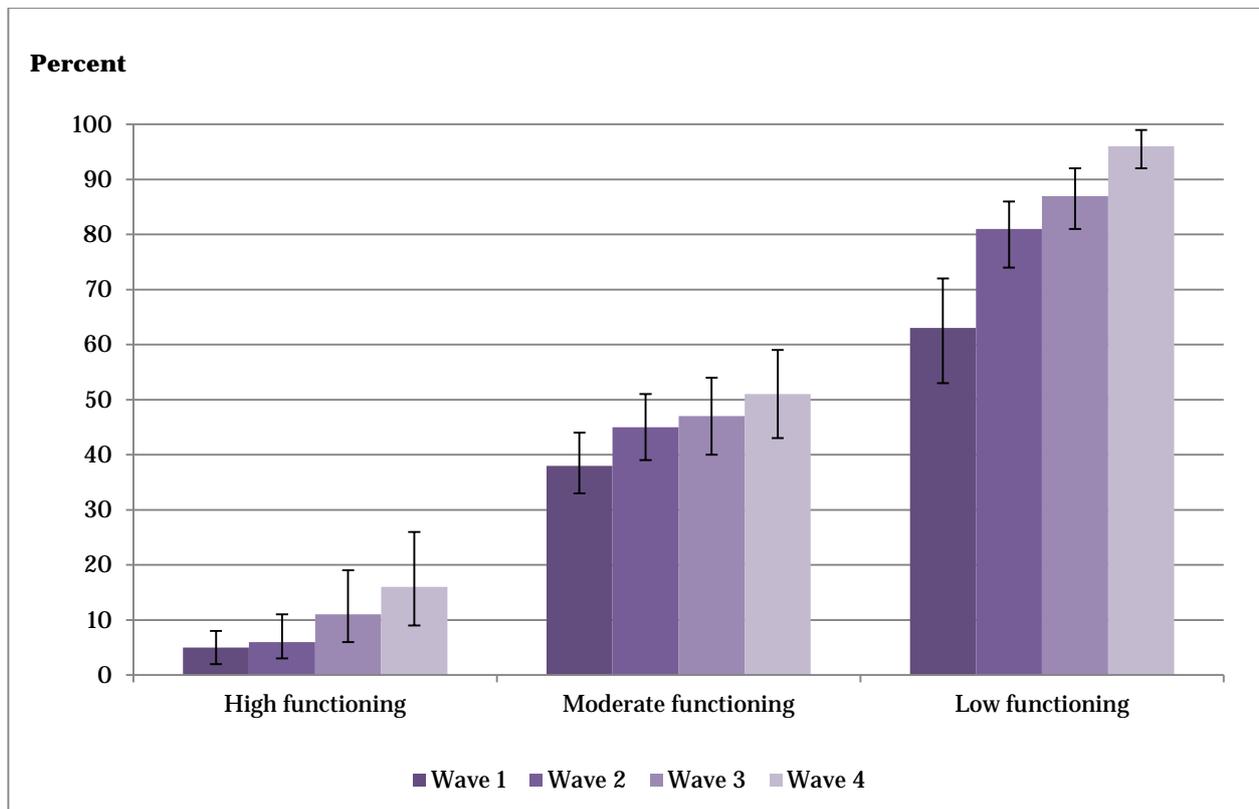
When we adjust for age, socioeconomic deprivation and functional status, we can see that over the course of the study *significantly more* Māori (50%) received informal care than non-Māori (35%) and *significantly more* women (45%) received informal care than men (39%) (Appendix Table 3.16). Note that while men received more informal care than women, once functional status was adjusted for, we showed that women with the same functional status as men received more informal care.

Those in areas of high socioeconomic deprivation received *significantly less* informal support (Appendix Table 3.16); however, when adjusted for age, ethnic group, sex, level of function and time in the study, this difference was *not significant* (Appendix Table 3.17). Functional status was the strongest driver of whether participant received informal care or not. Living alone, which was not adjusted for, may also impact on receipt of care.

3.4.2 Those with a low level of function were more likely to receive informal care

The majority of those with a low level of function received informal care (85%), *significantly more* than those with a medium level of function (47%) or high level of function (7%) (Figure 3-8, Appendix Table 3.18). Figure 3-8 also shows informal care increasing over the time of the study.

Figure 3-8: Receipt of informal care by level of function, Waves 1 to 4

Source: LiLACS NZ

3.4.3 Women receiving informal care had lower physical health-related quality of life than those not receiving care
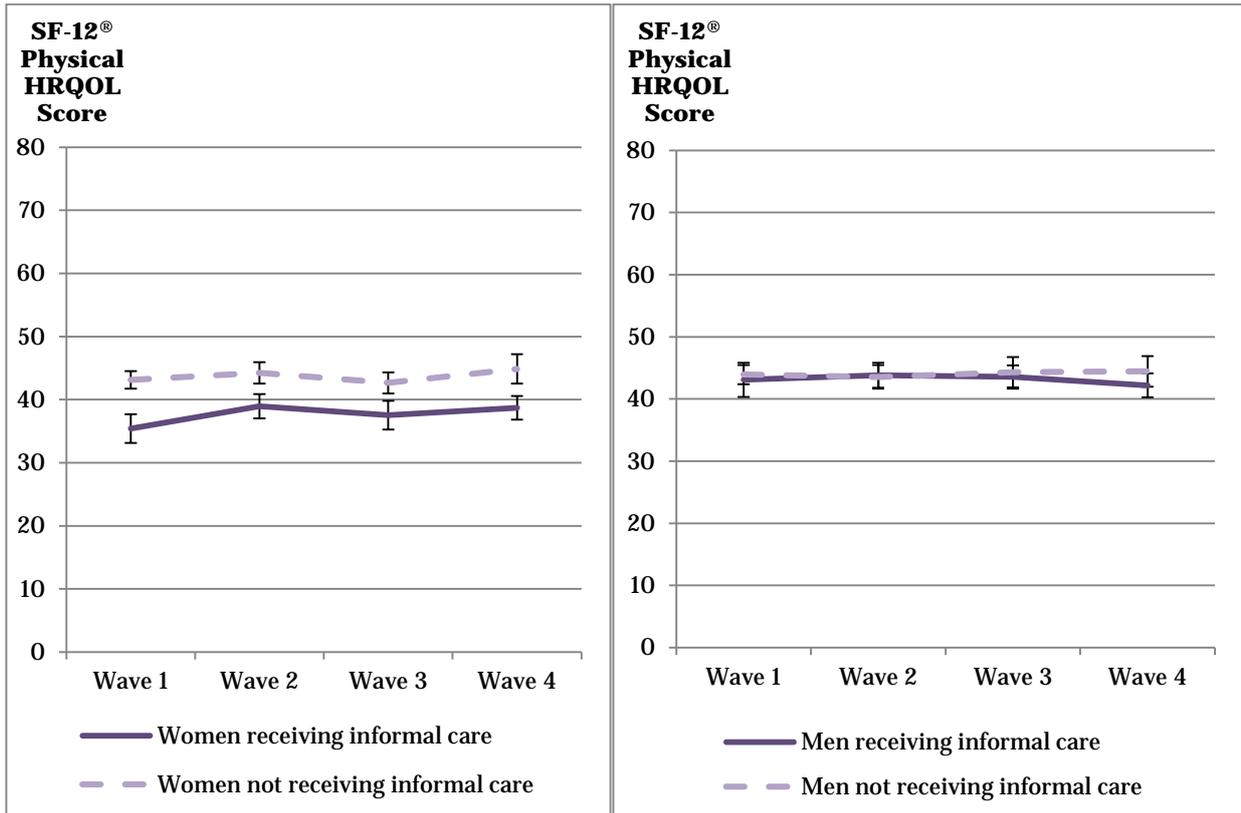
Overall there was *no significant difference* in the physical HRQOL scores between those who received informal care (adjusted mean score of 42.1) and those who did not (adjusted mean score of 42.1) (Appendix Table 3.19). However, the physical HRQOL score for those who received informal care differed *significantly* between the sexes (Tables 3.20, 3.21, 3.22).

Over the course of the study, women receiving informal care had a s*ignificantly lower* physical HRQOL score than women not receiving informal care (adjusted for age, ethnic group, socioeconomic deprivation, function and time in study, adjusted mean scores of 40.0 and 42.5 respectively, Figure 3-9). Receiving support services was much more strongly associated with physical HRQOL than informal care (Appendix Tables 3.22, 3.23). This may be due to assessment requirements in order to qualify for support services.

3.4.4 Men receiving informal care had marginally higher physical health-related quality of life

Overall, men receiving informal care had marginally better physical HRQOL scores than those not receiving informal care (adjusted for age, ethnic group, socioeconomic deprivation, function and time in study, mean HRQOL scores of 43.3 and 41.9 respectively).

Figure 3-9: Receipt of informal care by physical HRQOL by sex and ethnic group, Waves 1 to 4

Source: LiLACS NZ
Note: Error bars represent 95 percent confidence intervals

This difference between the sexes in HRQOL related to receipt of informal care may be because of different attitudes towards receiving care. Informal care was also more likely to be delivered by spouses to men, whereas women were more likely to be living alone.

3.4.5 Those receiving both support services and informal care had higher physical health-related quality of life
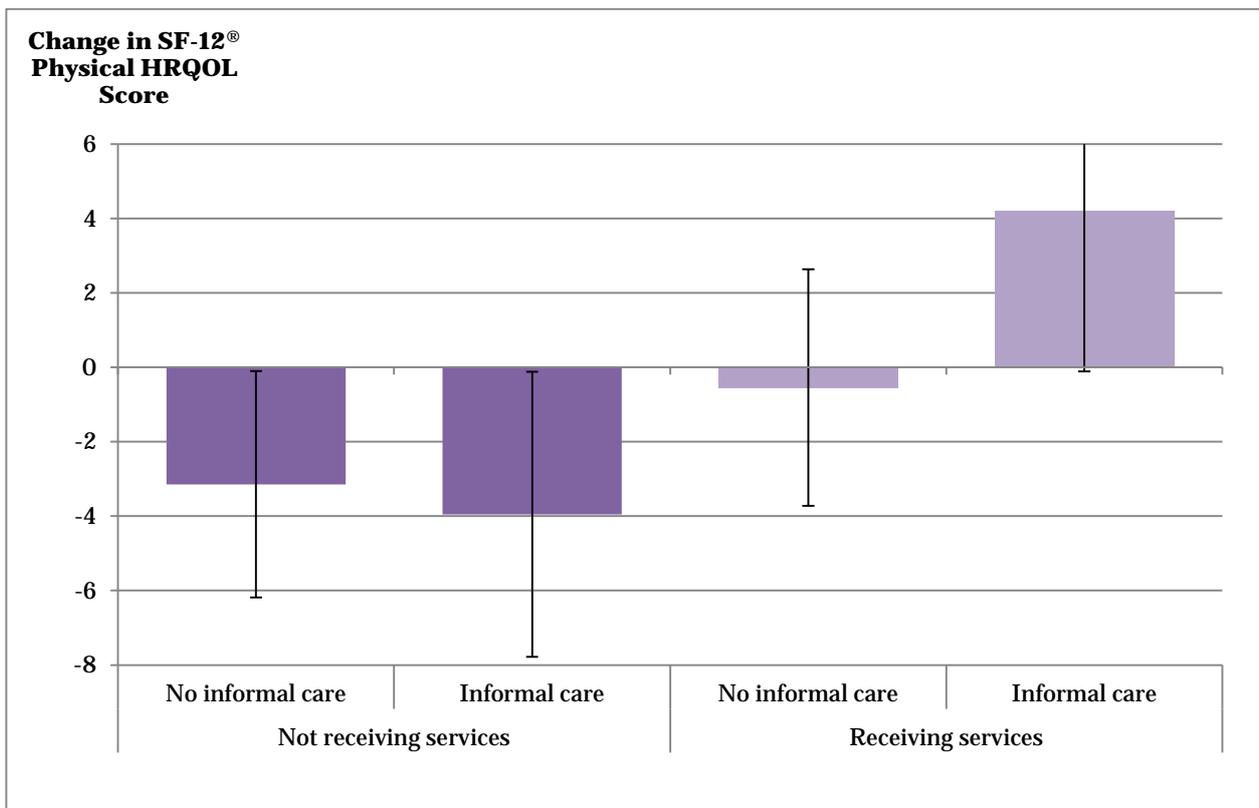
Because those receiving informal care were also likely to be receiving support services, we adjusted for receiving services in a series of analyses.

There was *no significant* difference in change over time for the physical HRQOL scores associated with either receiving informal care (an average decrease of 0.9 points) or not receiving informal care (an average decrease of 1.8 points). However, the change in physical HRQOL relating to receipt of informal care was *significantly different* for those who also received support services compared with those who did not (Figure 3-10, Appendix Table 3.24).

Over time the physical HRQOL score of those who received support services and informal care *significantly increased* (by 4.2 points) compared with those who received only support services (score decreased by 0.5) (Appendix Table 3.25).

In contrast, the physical HRQOL score for those who did not receive services *significantly decreased* over time, regardless of whether they also received informal care (Figure 3-10, Appendix Table 3.26).

Figure 3-10: Change in physical HRQOL, by receipt of services and informal care, Waves 1 to 4

Source: LiLACS NZ
Note: Error bars represent 95 percent confidence intervals

There was *no significant* difference in mental HRQOL score for those who received informal care, when adjusted for age, ethnic group, sex, functional status and socioeconomic deprivation. Nor was there a difference after also adjusting for receipt of support services (Appendix Tables 3.27, 3.28). There was also no difference in the rate of change of mental HRQOL over time by receiving informal care when adjusted for support services (Appendix Table 3.29).

These findings suggest that formal support services and informal care interact in a complex way that is affected by whether the person in advanced age is male or female. Receiving formal support may trigger informal care and vice versa, with receiving both forms of care impacting on physical health-related quality of life.

3.5 Key findings

Functional change

- Most participants remaining in the LiLACS NZ study maintained function over time and improved function was not uncommon.

- Non-Māori men were more likely than other groups to decline in function.

- Neither physical nor mental HRQOL decreased as function decreased.

Support services

- More women received support services than men.

- For Māori, level of function was lower for those that received support services but not for non-Māori.

- Those receiving support services maintained physical health-related quality of life over time whereas physical HRQOL declined for those not receiving support services.

- These findings suggest that support services protect and maintain physical HRQOL for people with appropriate levels of need.

Informal care

- More Māori than non-Māori and more men than women received informal (unpaid) care, which increased over time for all groups.

- Those with a low level of function were more likely to receive formal (paid) support services as well as informal care, suggesting that formal and informal care are complementary.

- Women receiving informal care had lower physical but not mental HRQOL than those who were not receiving care.

- Men receiving informal care had marginally higher physical health-related quality of life.

- Those receiving support services and informal care had higher physical HRQOL, suggesting that the combination of care types is important.

Section Four: Carers for People in Advanced Age

4.1 Introduction

This section presents findings from the LiLACS NZ Kaiāwhina (Love and Support) study of carers for people in advanced age. Carers, also known as kaiāwhina, were nominated by participants in Waves 3 and 4 of the LiLACS NZ study and were then invited to take part in the Kaiāwhina study. This section reports on data gathered during Wave 4 of LiLACS NZ, when the most extensive interviews with carers took place. Carers included some formal (paid) caregivers, but the main emphasis of the Kaiāwhina study was on informal (unpaid) caregivers.

With population ageing and policies to encourage 'ageing in place', there is increased need for caregiving in home settings. Traditionally, families and neighbours have been a source of informal care for people in advanced age who are no longer able to undertake all the usual tasks of personal care and household maintenance. With families now smaller in size, spread across the globe and women in mid-life having high rates of engagement in the paid workforce, the pool of potential informal caregivers has grown smaller, even though the need is greater. Formal caregiving, growing to fill the gap, is a low paid job. With an ageing workforce, suitable carers may become harder to recruit and retain.[66]

Informal caregiving has an economic value since it is work, although unpaid, and in many circumstances it obviates the need for formal care that is often paid for by the state. An American study estimated the worth of informal care to ill and disabled adults was double that of community and residential care together.[67] In New Zealand, older people who need residential care are required to contribute to the cost, subject to means-testing, and so informal caregiving may delay loss or sale of the older person's assets, which could otherwise be passed on to their heirs.

A good definition of informal caregiving is:

> …caring for a friend, family member or neighbour who because of sickness, frailty or disability, can't manage everyday living without help or support…[it] is not usually based on any formal agreement or services specifications. Informal caregiving is characterised by relationships and social expectations.[68]

There is an extensive research literature on informal caregiving, well summarised by Goodhead and McDonald.[49] As the definition above implies, informal caregiving can only be understood in the context of family and close social networks, structures and values. Insofar as Māori whānau, hapū and iwi are structured along different lines from non-Māori family and society, there are likely to be differences in caregiving between Māori and non-Māori. However, little research has been done on contemporary Māori caregiving, particularly in relation to carers for Māori in advanced age.[69]

The tasks undertaken by carers include personal care, giving love and emotional support, shopping, transport, assistance with mobility, housework and other household tasks, and assistance with finances. Carers may assist with health needs, transport to/from appointments, and advocacy and liaison with health and social care systems. One study of Māori caregiving (for people with disabilities rather than for people in advanced age) showed that, as well as these tasks, there was also an emphasis on spiritual guidance, acting as an interpreter and an advocate, and maintaining community links.[70]

Most informal caregivers in New Zealand are female, as are most formal caregivers.[49] As shown in the previous section of this report, people in advanced age themselves may be in caregiving roles, particularly in relation to their spouse. Men of advanced age, who are more likely to be

married, are also more likely to be involved in carer roles than women in this age group. Likewise, carers who live in the same house as the person they care for are likely to spend more time on caregiving than those who live elsewhere. They are particularly likely to be spouses, but may also be other close family members. Caregiving is likely to exact a heavier toll and give less respite to those in such circumstances, than on those who live elsewhere.[49]

Much of the research literature has focused on the 'burden of caregiving' on informal carers, who are shown to have higher rates of physical ill health, medication use, stress and depression. They are more isolated from social contacts than others, participate less in paid work, report lower life satisfaction and may suffer undue financial costs. Negative impacts increase with the length of time spent caregiving.[49]

While research has frequently measured 'caregiver burden', the LiLACS NZ Kaiāwhina study explores both positive and negative impacts on carers of the provision of help, love, support and care, and assesses the amount of contribution of this care and support to people in advanced age.

The Kaiāwhina study aims to describe the carers of LiLACS NZ participants, their relationship to participants, and the amount and type of care they give. For informal carers, the impact this caring has on their lives is investigated, including their health, quality of life and employment.

This research also seeks to understand the economic value of the contributions of informal caregivers. Potentially, there are many ways to analyse the costs of formal and informal care, and this study assesses the sensitivity of various measures of the cost of care. Methodological decisions are involved in deciding how much value should be placed on the time spent caring (eg, valuing time at the average wage or at the current wage the carer receives in other non-caring roles or at the usual price paid for formal care). The impact of caring on carer's employment can also be considered, as well as whether impact on quality of life for participants and/or carers should be monetised, that is, given a monetary value.

4.2 The LiLACS NZ Kaiāwhina study

4.2.1 Selection of carers

In Wave 4, following questions about the help, care and support they received, LiLACS NZ participants were asked to identify up to two people who had provided them with the 'most help, care and support in the last three months'. If they identified someone, they were asked whether they would be comfortable with the researchers contacting their nominated carers and, if so, they were then asked to provide contact details for at least one of the nominated carers. The carers for the LiLACS NZ participant could be a close family member (including their spouse), other family members, friends, neighbours or unpaid helpers provided through organisations such as their church. LiLACS NZ participants could also nominate formal carers, although since the focus of this sub-study was on informal caregivers, if a formal carer was the first person nominated, participants were asked if there was anyone else they would like to nominate as well. If no-one else was nominated, the formal caregiver was chosen for follow-up. By this means, a sample of carers was obtained, with informal carers predominating.

Nominated carers were then approached and interviewed, if they consented. As well as the usual demographic questions, the interviews with informal carers included questions about their relationship to the LiLACS NZ participant, such as how close they lived to them; the duration, amount and type of care they provided; their feelings of responsibility; their occupational and

financial circumstances and whether caring had impacted on these; and how informed they felt about other sources of support available to them. Two standardised scales were administered during the interview: the COPE Index, a measure of carer support and carer stress; and the EQ-5D-3L, a health questionnaire indicating quality of life. The carer interviews during Wave 3 of the Kaiāwhina study did not include the EQ-5D-3L and since carer quality of life is of interest for this report, only interviews from Wave 4 are reported here.

The interviews with formal carers were briefer. Their questionnaire focused on the duration and amount of care they provided, the care they gave in crisis situations, their relationship with the LiLACS NZ participant, their perception of the importance of their role and whether they did unpaid as well as paid tasks. Several demographic questions and one question about carer health were also asked.

Appendix Table 4.1 (Appendix 4.1) shows the questions asked at carer interviews and the numbers of carers who answered each question.

The following bullet points describe the process of identifying and recruiting carers to the Wave 4 LiLACS NZ Kaiāwhina study and give details of the study sample (some data are repeated from Figure 1-1):

- By Wave 4 of LiLACS NZ, 438 participants remained in the Māori and non-Māori LiLACS NZ cohorts (437 participants provided usable questionnaires analysed for this report).

- Of the 437 questionnaires reported, 363 (83%) were full questionnaires and 74 were core questionnaires.

- The Māori cohort included 162 participants (37% of the total of the two cohorts), 62 percent of whom were women. The non-Māori cohort included 276 participants, 54 percent of whom were women.

- Ninety-two percent of LiLACS NZ participants identified at least one person who provided them with the most help, care and support in the last three months.

- Almost three-quarters (74%), that is 319 LiLACS NZ participants, consented to a nominated carer being approached for an interview (Appendix Table 4.2).

- Kaiāwhina interviews were completed with 288 carers, but two were excluded as their participant's main carer had already been interviewed, leaving 286 carer interviews.

- There were 261 informal carers (91% of the interviewees) and 25 formal carers (9%) interviewed.

- Of the 286 LiLACS NZ participants who had carers interviewed, 108 (38%) were Māori (62 women and 46 men) and 178 (62%) were non-Māori (96 women and 82 men).

4.2.2 How representative is the carer sample?

We examined whether the LiLACS NZ participants who nominated carers and gave permission to contact them were representative of all the LiLACS NZ participants in Wave 4.

Overall, there was *no significant difference* between the Māori and non-Māori cohorts in whether they gave consent to contact the carer or not. However, men (77%) were *significantly more likely* to agree to carer contact than were women (71%), with the highest level of consent from Māori men (85%) (Appendix Table 4.2).

In terms of their relationships to LiLACS NZ participants, people with all types of relationships were nominated and recruited in similar proportions, with the exception of other family and non-professional carers who were nominated *significantly more often* than they were recruited (Appendix Table 4.3).

LiLACS NZ participants who did not nominate carers (8% of Wave 4 enrolees) may have been in better health with less disability than those who nominated carers as their physical health-related quality of life was *significantly higher*. Several told the interviewer they did not have a carer because they did not need care.

4.2.3 The Kaiāwhina study carers and the LiLACS NZ participants they cared for

Appendix Table 4.4 shows the characteristics of the 286 Wave 4 Kaiāwhina carers organised according to the LiLACS NZ participants' ethnic group. Data from all 261 informal and 25 formal carers are included in the information on age, sex and ethnic group; and there are also data for informal carers on their employment status, the distance they lived from the participant and their receipt of benefits. Appendix Table 4.5 compares formal and informal carers in terms of age, ethnic group and sex. The main findings on the carers in the Kaiāwhina study in relation to those they cared for are as follows.

Age of carers

The mean age of carers of LiLACS NZ participants was 63.4 years (62.7 years for carers caring for women, 64.4 years for carers caring for men). The LiLACS NZ participants for whom they cared were in their late 80s. Informal carers were *significantly older* (mean age 66 years) than formal carers (mean age 50 years) (Appendix Table 4.5); the main reason for this was that the informal carer group included spouses, many of whom were also in their 80s. One spouse was also a LiLACS NZ participant.

Sex of carers

Seventy-three percent of informal carers and 88 percent of formal carers were women, a *significant difference* (Appendix Table 4.5). In relation to the sex of informal carers, there was *no significant difference* between Māori and non-Māori LiLACS NZ participants, but LiLACS NZ women were less likely than LiLACS NZ men to have a woman as caregiver because of male spouses giving care (Appendix Table 4.6).

Ethnic group of carers

In Wave 1 of LiLACS NZ, the Māori and non-Māori cohorts were similar in size, but by Wave 4 the Māori cohort was smaller. Of all carers, 28 percent were Māori and 72 percent non-Māori, compared with 38 percent of LiLACS NZ Wave 4 participants who were Māori and 62 percent who were non-Māori.

The informal carers for Māori LiLACS NZ participants were mostly Māori. LiLACS NZ Māori participants were *significantly more likely* than non-Māori to have an informal carer who was Māori (74% of Māori women participants, 67% of Māori men) (Appendix Table 4.7). For LiLACS NZ non-Māori there was a Māori informal carer for only 2 percent of women and 1 percent of men (Appendix Table 4.8).

Informal carers for 29 percent of LiLACS NZ Māori participants were non-Māori (these could include family members of a different ethnicity, for example, spouses or daughters-in-law).

Employment status of carers

Forty-seven percent of informal carers were employed full or part time; 41 percent of carers of Māori LiLACS NZ participants and 51 percent of carers of non-Māori LiLACS NZ participants were in paid employment (Appendix Table 4.9 breaks down responses to this question into Māori and non-Māori women and by ethnic group and sex of the carer). Informal carers for Māori LiLACS NZ participants were somewhat less likely to have paid work but this difference was *not significant* (Appendix Table 4.10).

Distance between carer's and participant's residences

Most informal carers lived close to the person they cared for. Forty-seven percent lived either in the same house or on the property, 43 percent lived within a 30 minute drive and only 9 percent lived more than 30 minutes away (Appendix Table 4.11 breaks down responses to this question by the ethnicity and sex of the carer).Those caring for Māori were *significantly more likely* to live in the same house or on the property (62%) and were *significantly less likely* to live more than 30 minutes away (5% lived more than 30 minutes away compared with 11% of carers for non-Māori LiLACS NZ participants) (Appendix Table 4.12). Appendix Table 4.11 shows greater detail about where informal carers lived.

4.2.4 Informal carers characterised by their relationship to LiLACS NZ participants

The Kaiāwhina study included 261 informal carers, whose relationship to their LiLACS NZ participants is shown in Appendix Table 4.13. Of the informal carers interviewed, 91 percent were family members, with 29 percent spouses, 55 percent children and 7 percent other family (including all in-laws, such as daughters-in-law, sons-in-law, brothers- and sisters-in-law).

Appendix Table 4.13 also shows, for each relationship category of carer, their mean age, ethnic group, sex, employment status and the distance they lived from their matched LiLACS NZ participant. The data are arranged by the ethnic group of their LiLACS NZ participant.

Informal carers were not young. Spouses comprised 29 percent (74 people) of the Kaiāwhina study participants, and with an average age of 81.2 years they were the oldest group of carers. Those caring for their parents (that is, children of LiLACS NZ participants) comprised 55 percent of Kaiāwhina participants with an average age of 58 years. Other family carers (7%) also had an average age of 58 years, and non-family informal carers had an average age of 75 years.

Women predominated amongst the informal carers, making up 63 percent of children, 72 percent of the spouses and 82 percent of other carers.
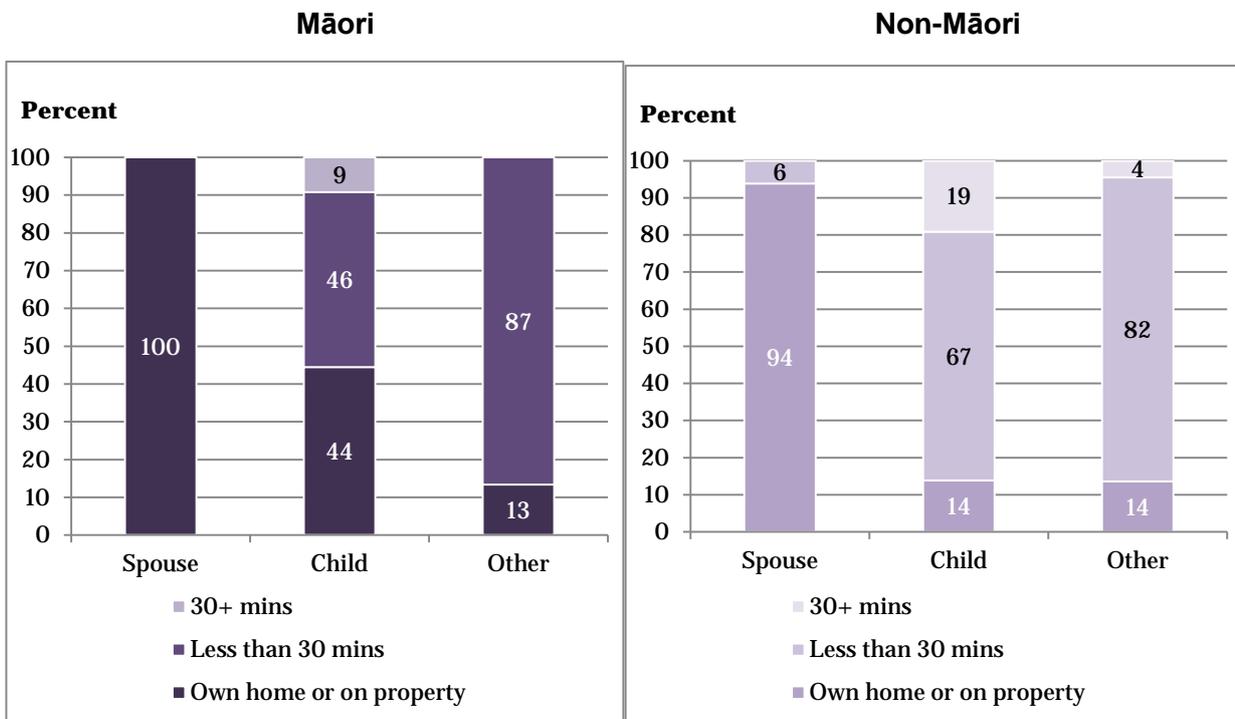
Spouse carers were less likely to be Māori, but in other categories of carer-participant relationship, around one-third of the carers were Māori.

Nearly all spouse carers were not employed. Around half of the child carers (48% of Māori and 50% of non-Māori) worked in full time occupations; more than in any other of the family categories.

'My highlights centre around family. A grandchild rings me from wherever and asks how I am and am I looking after myself. When they visit their parents they find time to pop in and say hello. I have two sons who live reasonably close…and they keep an eye on my home conditions.'

In terms of the distance between the carer and recipient, nearly all (96%) spouse carers lived in the same house, and so did 27 percent of those caring for their parents. Most carers lived within 30 minutes' drive, but 15 percent of those caring for their parents lived more than 30 minutes away. Figure 4-1 shows the distance carers lived from Māori and non-Māori LiLACS NZ participants and shows that children who were carers for Māori parents were *significantly more likely* to live in the same house or on the same property than were children caring for non-Māori parents.

Figure 4-1: Distance informal carers lived from LiLACS NZ participant by type of relationship and ethnic group

Source: LiLACS NZ

4.3 Amount and type of care

Questions in this section relate to the amount of care that carers gave, how long they had been giving care, the amount of time they spent caring in a typical week, and whether they had provided help in a crisis in the last three months. Data are from both formal and informal carers.

Informal carers were also asked about the type of care they gave, distinguishing between personal care and household assistance. The time reported was considered by the informal carer to be time spent in caring. It is possible that, particularly for spouses, this time included some personal activities such as their own meal preparation.
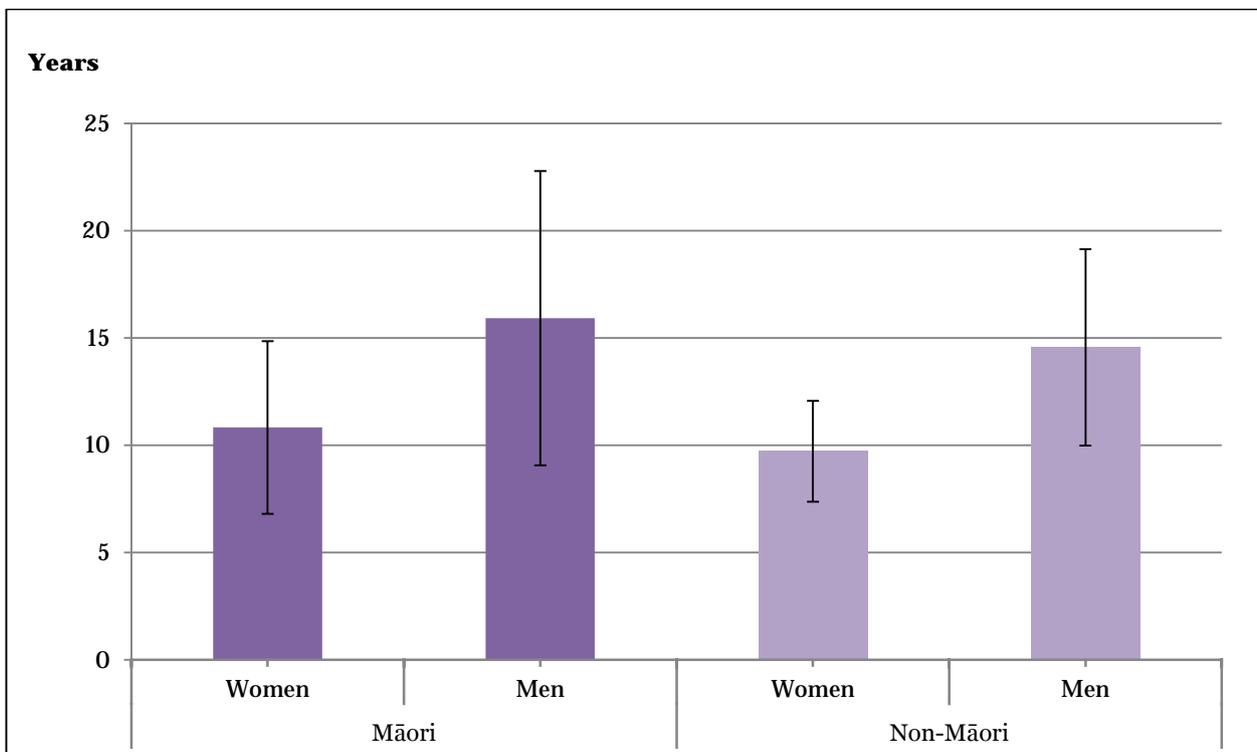
4.3.1 Caring started earlier for men than for women

Carers were asked when they began providing care for the LiLACS NZ participants. Seventy-nine percent had been giving care for more than two years (Appendix Table 4.14). Overall, the average time since caring began was around 12 years. Formal carers started giving care for their LiLACS NZ participant *significantly later*, around four years previously on average (Appendix Table 4.16).

Figure 4-2 shows the length of time carers had been caring for LiLACS NZ participants. LiLACS NZ men, both Māori and non-Māori, had been cared for *significantly longer* than LiLACS NZ women (15 years on average, compared to 10 years) (Appendix Table 4.15).

Formal carers had typically been caring for *significantly fewer* years than informal carers (4.4 years vs. 12.6 years respectively) (Appendix Table 4.16).

Figure 4-2: Mean number of years of giving care by LiLACS NZ participant ethnic group and sex

Source: LiLACS NZ

4.3.2 Māori men were given the most care per week and non-Māori women the least
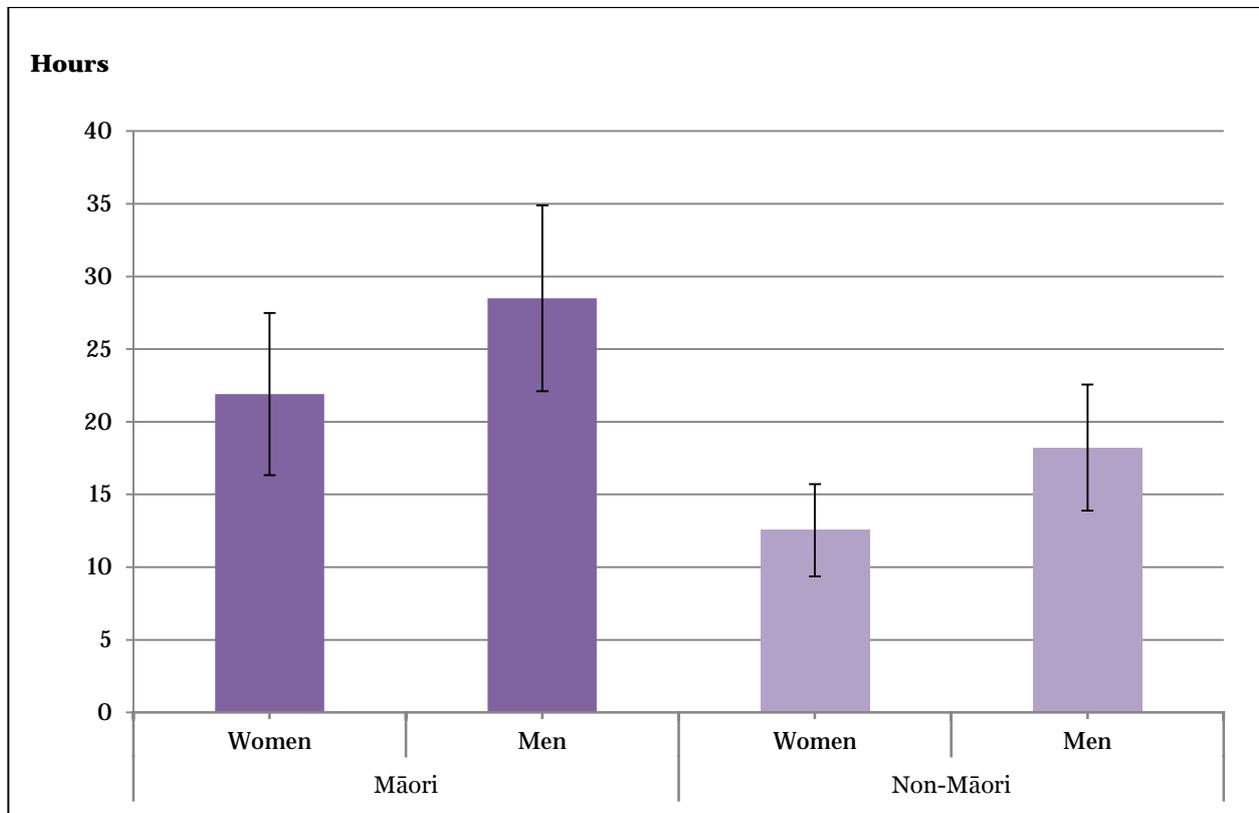
In a typical week, the hours estimated by informal carers were as follows:

- up to 3 hours (27.2%)

- 4–9 hours (23.0%)

- 10–19 hours (16.1%)

- 20–49 hours (22.6%)

- 50+ hours (11.1%)

The average time spent caring is given in Figure 4-3, where the number of hours of care was estimated by taking the mid-point of each response category and assuming 60 hours for those working more than 50 hours a week.

Overall, carers of Māori gave *significantly more* hours of care than carers of non-Māori and carers of men gave *significantly more* hours of care than carers of women. Carers of Māori men gave *significantly more* care than all other groups (28.5 hours per week compared to 16.9 hours). Carers of non-Māori women gave *significantly less* care than other groups (12.5 hours per week compared to 21.6 hours for Māori women) (Appendix Table 4.18). Once again, extended family living arrangements could contribute to an explanation of these differences.

Figure 4-3: Average weekly hours spent caring, by LiLACS NZ participant ethnic group and sex

Source: LiLACS NZ

There were *no significant differences* between formal and informal carers in the weekly hours spent caring (Appendix Table 4.16). Māori received *significantly more* hours of informal care than did non-Māori (Appendix Table 4.18).

Both formal (32%) and informal (39%) carers had helped in a crisis in the last three months (Appendix Table 4.16).
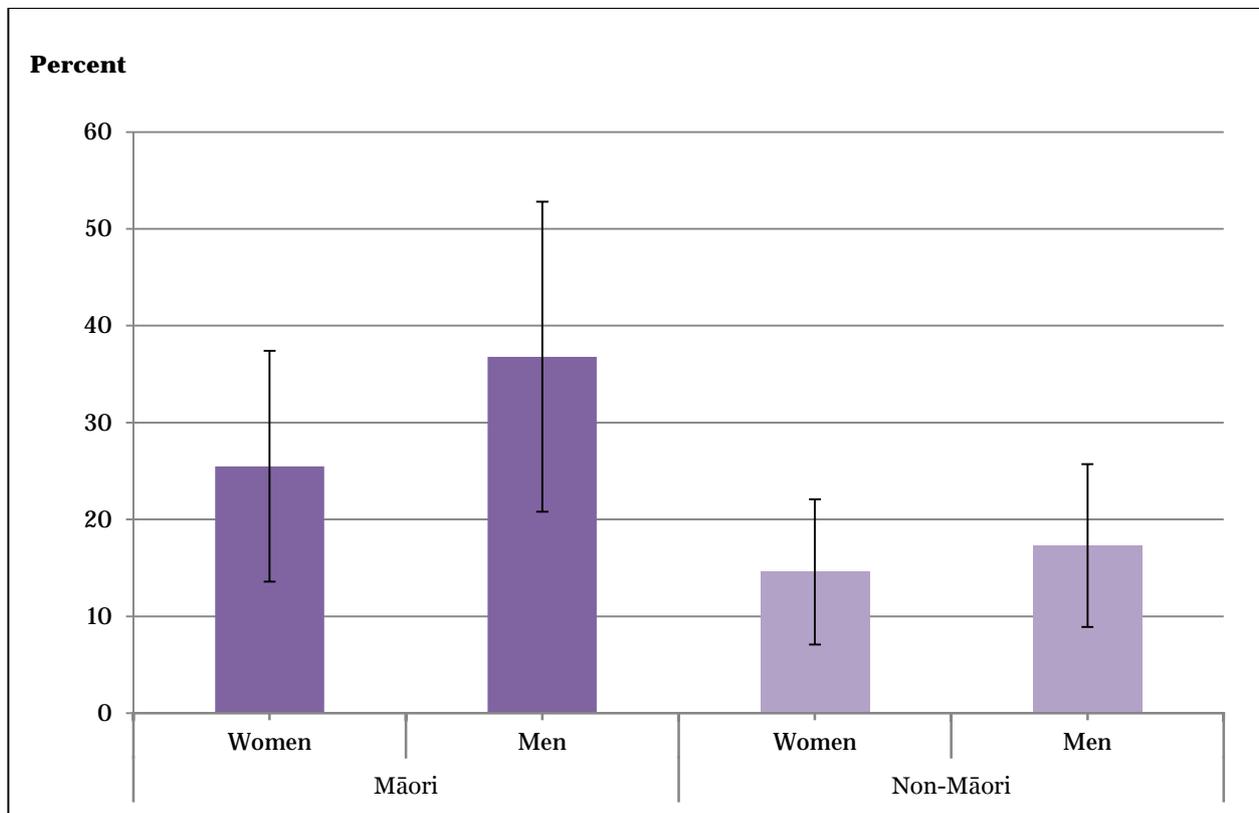
Spouses spent the most time every week giving care; on average 28 and 33 hours were given to Māori women and men respectively, 37 and 34 hours were given to non-Māori women and men respectively. Children gave an average of 24 and 23 hours to Māori women and men, and 9 and 5 hours to non-Māori women and men respectively. Other carers gave 13 and 27 hours per week to Māori women and men respectively and an average of 9 hours to non-Māori LiLACS NZ participants (Appendix Table 4.18). It is difficult to say exactly how much of this time within the care period was spent on meal preparation or personal care.

4.3.3 Spouse carers and carers for Māori men felt the most responsibility for those they cared for

Informal carers were asked how much responsibility they felt for those they cared for. Forty-eight percent said that they had all or most of the responsibility, 43 percent had about half or less than half of the responsibility and 9 percent said that they had hardly any responsibility (Appendix Table 4.19).

Informal carer perceptions of responsibility differed depending on their LiLACS NZ participant's ethnic group and sex. Spouses were *significantly more* likely than children to feel that they had all the responsibility (27% compared to 15%). A *significantly higher* proportion of those caring for Māori men (37%) felt that they had all the responsibility; this compared to 26 percent for those caring for Māori women, 15 percent for those caring for non-Māori women and 17 percent for non-Māori men (Figure 4-4, Appendix Table 4.20).

Figure 4-4: Proportion of carers who felt they had all the responsibility for care by LiLACS NZ participant ethnic group and sex
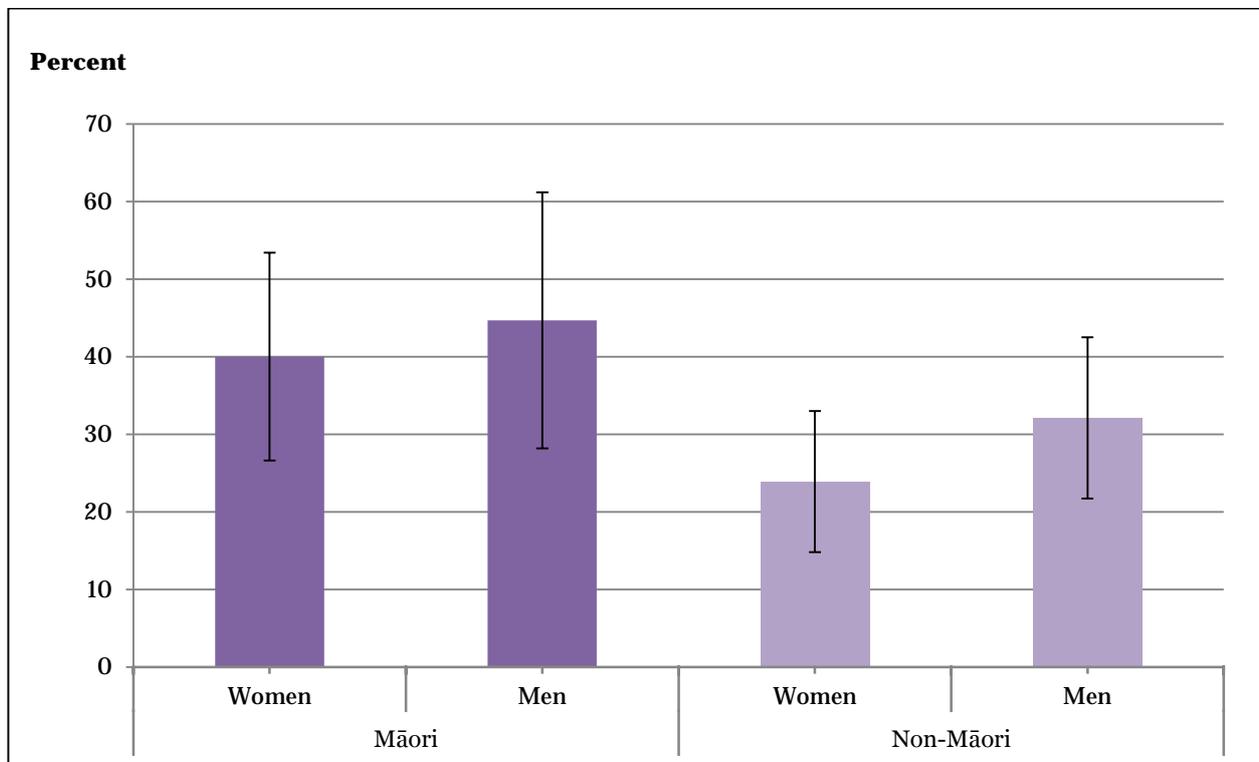
Source: LiLACS NZ

If Māori men were in greater need than other groups, we might expect a difference in their scores on the Nottingham Extended Activities of Daily Living (NEADL) scale. However, there were *no significant differences* between the functional status of Māori men in the LiLACS NZ Wave 4 cohorts compared with the other three groups (Appendix Table 4.21).

4.3.4 Carers for non-Māori women were least likely to provide personal care

The informal carers were asked about how often they had provided different types of care to the LiLACS NZ participant over the last three months. During this period, one-third (33%) had provided at least some personal care, such as help with dressing, washing, eating, taking medication or toileting (Appendix Table 4.22). Carers for non-Māori women were *significantly less likely* to provide any personal care than any other group (24% vs. 37%) (Appendix Table 4.22), as shown in Figure 4-5. Overall, carers of Māori gave *significantly more* personal care than did carers of non-Māori (Appendix Table 4.23).This finding is consistent with those in Section 3 where we showed that overall more Māori receive informal care. Informal care is also more likely to be personal care for Māori than it is for non-Māori.

Figure 4-5: Proportion of carers providing any personal care, by LiLACS NZ participant ethnic group and sex

Source: LiLACS NZ
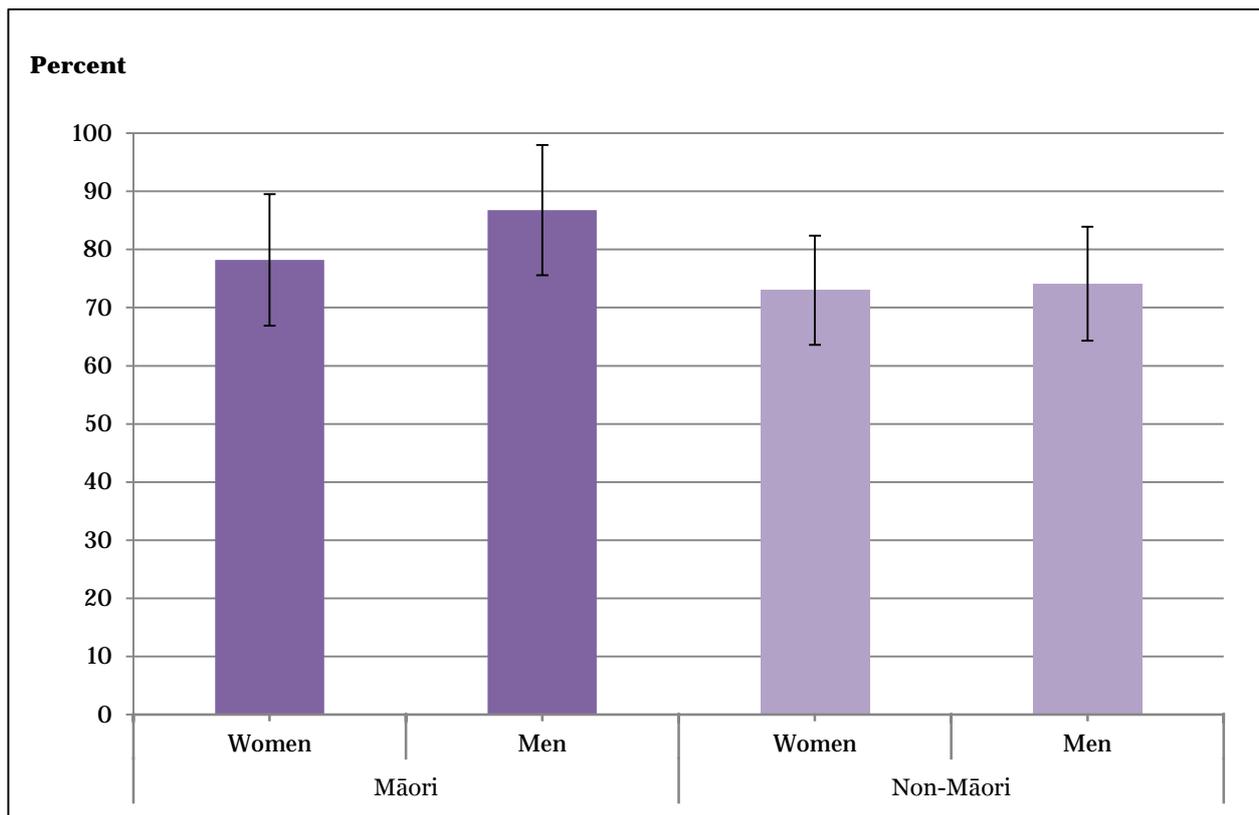
4.3.5 Men were more likely to receive daily household assistance than women

Informal carers were asked how often they had provided household assistance during the last three months, including help with shopping, transport, laundry, preparing meals, household chores, gardening and home maintenance.

Across all four groups, approximately three-quarters of carers provided at least some household assistance (Appendix Table 4.24). Sixty-six percent of carers of Māori men gave daily household assistance; this contrasted to 40 percent of carers of Māori women. Forty-three percent of carers of non-Māori men and only 20 percent of carers of non-Māori women gave daily household assistance. *Significantly more* informal carers of Māori gave daily household assistance than did carers of non-Māori and *significantly more* informal carers of men gave daily assistance than did informal carers of women, possibly because they were more likely to live in the same household.

Figure 4-6 shows the proportion of carers providing any household assistance, with Māori men the most likely to receive this support (Appendix Table 4.25).

Figure 4-6: Proportion of carers providing any household assistance, by LiLACS NZ participant ethnic group and sex

Source: LiLACS NZ

4.3.6 Māori men were more likely to receive assistance with food-related activities than non-Māori men

The LiLACS NZ study also asked informal carers about support with helping LiLACS NZ participants through a range of food-related activities. Māori men were *significantly more likely* than non-Māori men to receive help with food choices (63% vs. 42%), shopping (34% vs. 24%), food preparation (74% vs. 50%), preparing drinks and snacks (50% vs. 39%) and cooking and sharing of meals at least several times a week (76% vs. 50%) (Appendix Table 4.26).

4.3.7 Virtually all informal carers provided social and emotional support

The LiLACS NZ interview also asked about whether and how often other types of support were provided. The list included administrative/legal support, social and emotional support, cultural support, support for Māori cultural activities, spiritual support, family support, and transport (Figure 4-7, Appendix Table 4.27).

Figure 4-7: Other types of support given by informal carers, by ethnic group and sex of LiLACS NZ participant

Source: LiLACS NZ

The most common types of support were social and emotional, provided by virtually all carers (88%) and provided at least several times a week. Family support was also commonly provided (70%). Other forms of support provided by approximately half of the carers included transport to health services (54%) and administrative or legal support (49%).

There were some differences in other types of support across the LiLACS NZ participants. Support for Māori cultural activities was provided more often to Māori participants, not surprisingly. There was also a large difference in the provision of spiritual support, with Māori respondents being much more likely to receive support several times a week than were non-Māori respondents (44% vs. 28% of women, 39% vs. 19% of men).

4.4 The impact of caring on the caregiver

In order to investigate the impact of informal caring, informal carers were asked to rate their own general health. They were administered the COPE Index, a measure of carer support and carer stress, and the EQ-5D-3L, a health questionnaire indicating quality of life.

4.4.1 Caring impacted on informal carers' working lives

Sixty-two percent of informal carers had made phone calls or provided care in their work time, 18 percent had taken time in lieu, or worked flexitime in consultation with their supervisor or colleagues, and many had taken leave in order to care for the LiLACS NZ participant (15% annual leave, 14% leave without pay, 10% sick leave and 2% 'domestic' leave) (Appendix Table 4.28). When they had had to work, 40 percent had arranged with another family member to provide the care that they themselves normally provided and 9 percent had paid someone else to provide care which they would have preferred to provide themselves.
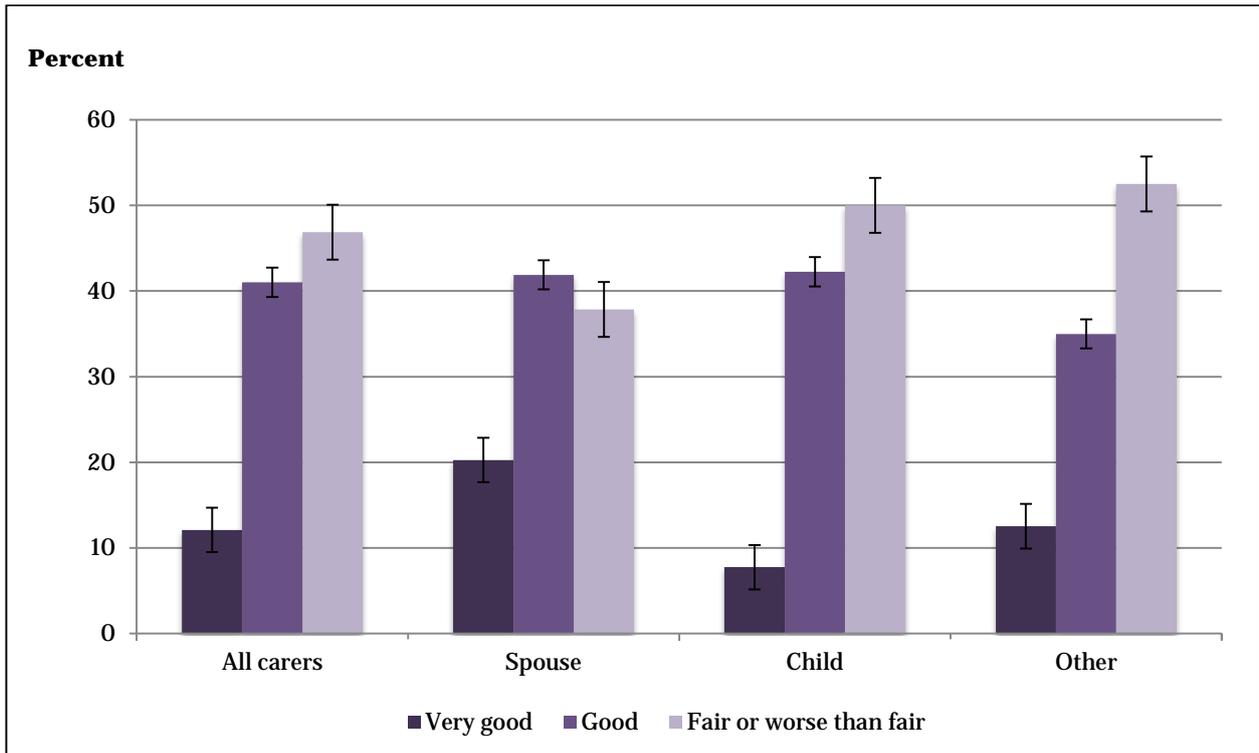
4.4.2 Spouse carers rated their health more positively

Informal carers were asked to rate their health in general as Very Good, Good, Fair, Poor or Very Poor. Twelve percent of respondents replied that their health was very good and 41 percent said that their health was good (Appendix Table 4.29).

'I am 87 years old and my wife is 84. We have been married for 62 years. We are good companions. My wife is a bit more active physically than I am but we do all things together and that is all very important.'

Figure 4-8 shows that spouse carers had better self-rated health than carers who were children or those who had other relationships with the LiLACS NZ participants, such as in-laws. This was perhaps surprising since the spouses tended to be in their 80s and the children in their 50s (Appendix Table 4.29). Of course, older people may rate their health in terms of expectations for their age, so comparisons across age groups are difficult.

Figure 4-8: General health rating of informal carers by relationship to LiLACS NZ participant
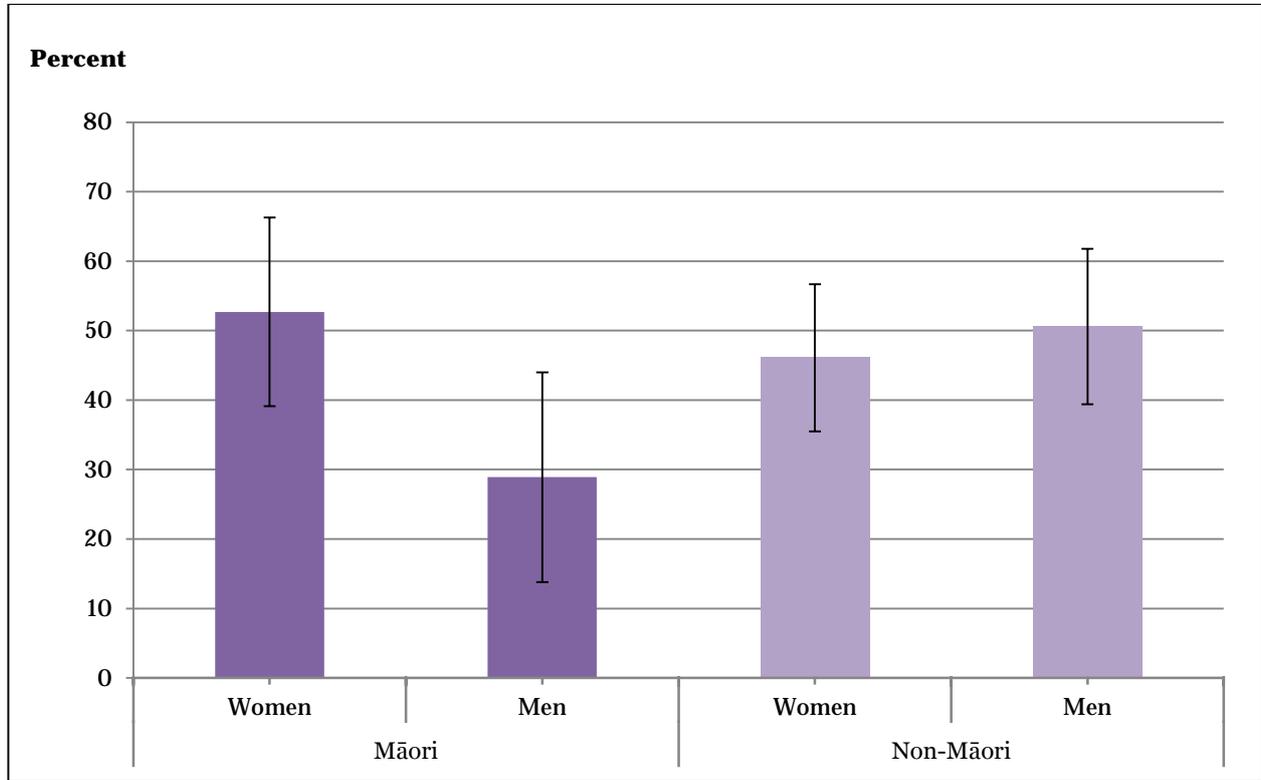
Source: LiLACS NZ

The self-rated health of formal carers was good; 56 percent of formal carers rated their health as very good (Appendix Table 4.30).

Overall, far more carers rated their health as fair, or worse than fair, than as very good, which is of concern.

There were *no significant differences* in the proportions of carers who said that they had very good health between those caring for Māori, non-Māori, men or women (Figure 4-9, Appendix Table 4.31).

Figure 4-9: Proportion of informal carers reporting 'Very Good' health by LiLACS NZ participant ethnic group and sex

Source: LiLACS NZ
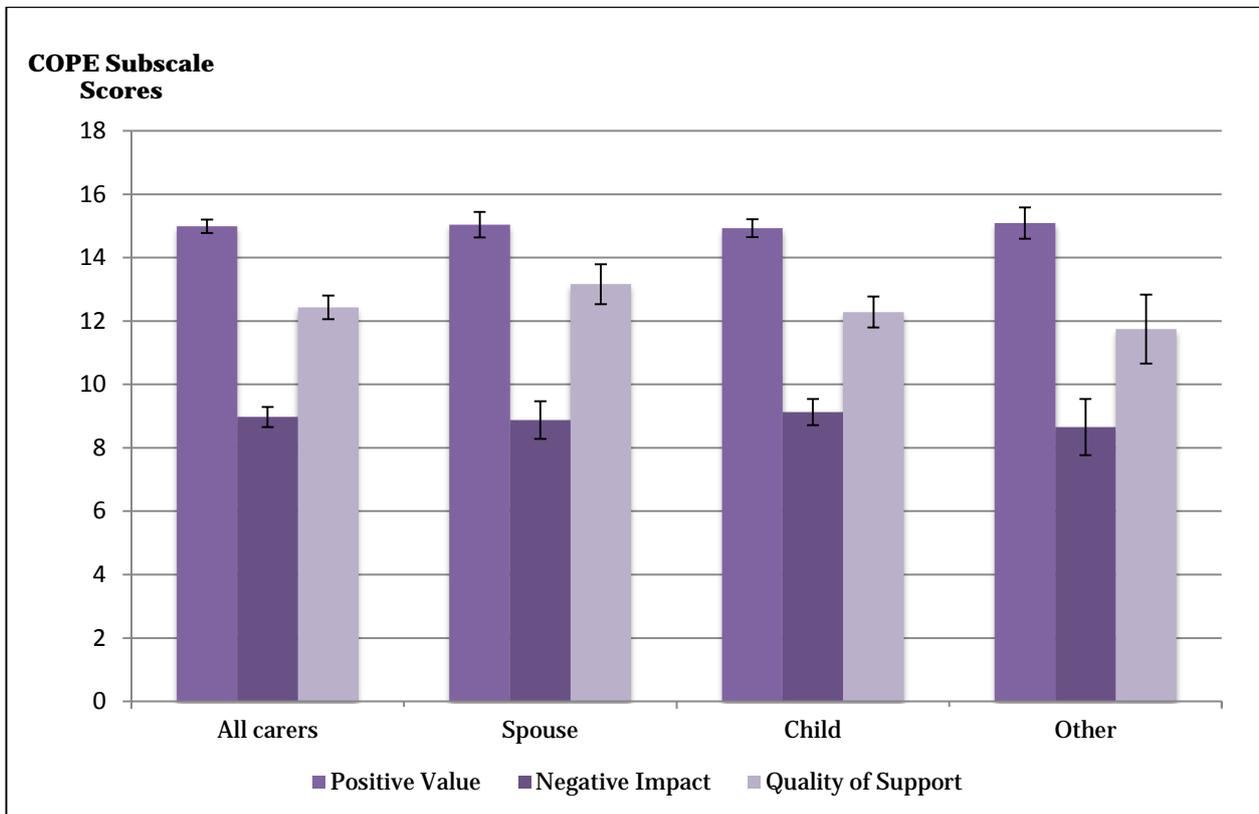
4.4.3 Positive and negative impacts of caring are not affected by carer relationship to LiLACS NZ participant

The COPE Index contains three subscales measuring the positive value of caregiving, the negative impact of caregiving, and the quality of support that carers received for caregiving.[71]

Informal carers scored an average of 15.0 out of 16.0 on the positive subscale, 9.0 out of 28.0 on the negative subscale, and 12.4 out of 16.0 for quality of support (Figure 4-10, Appendix Table 4.32). There were *no significant differences* on the COPE Index between carers with different relationships to LiLACS NZ participants. Compared to findings from a major study of carers from six European countries, carers in the Kaiāwhina study were as positive about caring and less negative.[71,72]

There were also *no significant differences* in carers' COPE scores between those caring for Māori, non-Māori, men or women (Tables 4.33, 4.36 and 4.37).

Figure 4-10: COPE subscale of informal carers by carer relationship to LiLACS NZ participants
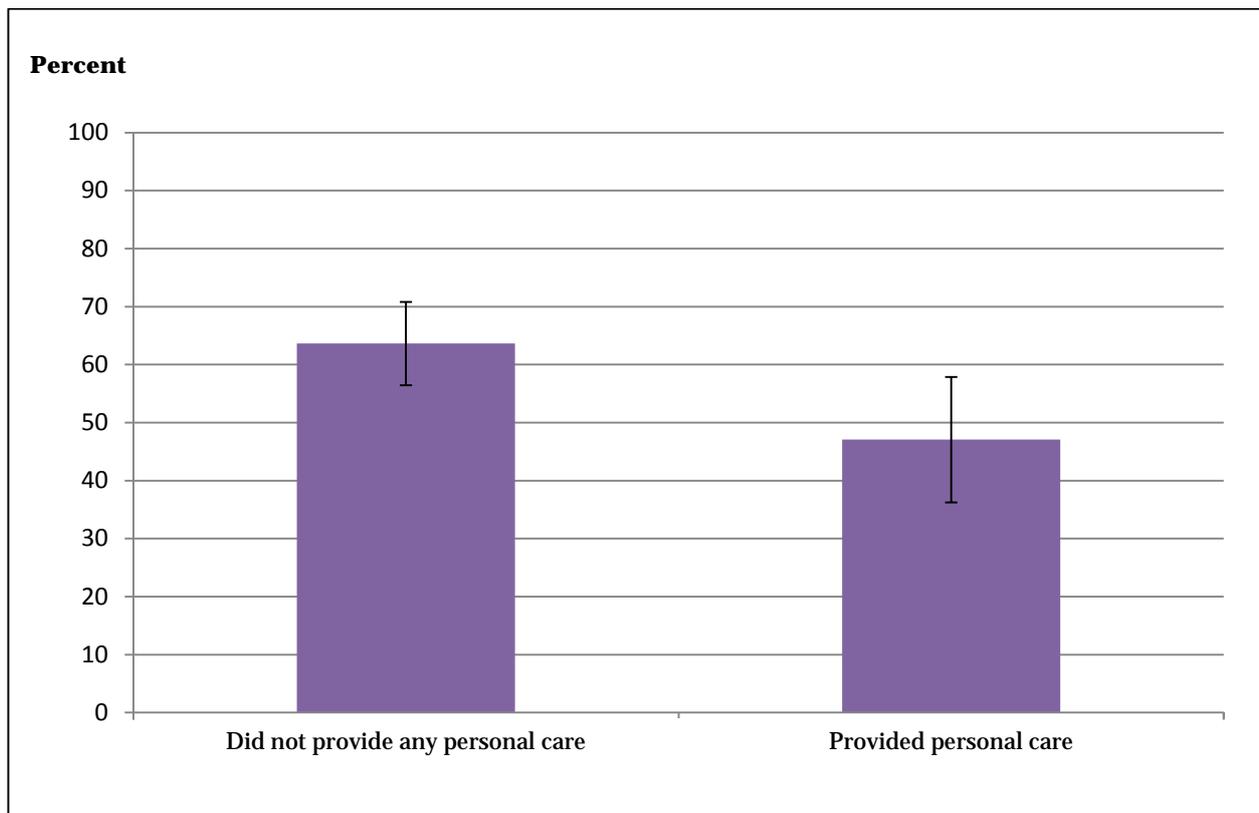
Source: LiLACS NZ

4.4.4 Providing personal care was associated with a less negative impact of care

Whether the type of support had an impact on a negative experience of caring was explored. High negative impact COPE scores were more common amongst those who did not give personal care (64% of people scored 8+ on the negative impact COPE dimension) than amongst those who did give personal care (47% of people scored 8+, Appendix Tables 4.34 and 4.35), adjusting for ethnic group and sex of the LiLACS NZ participant. In other words, carers who provided personal care were less likely to experience negative aspects of caring (Figure 4-11).

Figure 4-11: COPE Index lower than average negative impact score, by whether personal care was provided in the last three months

Source: LiLACS NZ
Note: Percentage of those with a lower than average negative impact subscale score (less than 8 on the COPE Index), that is, those having a better experience.
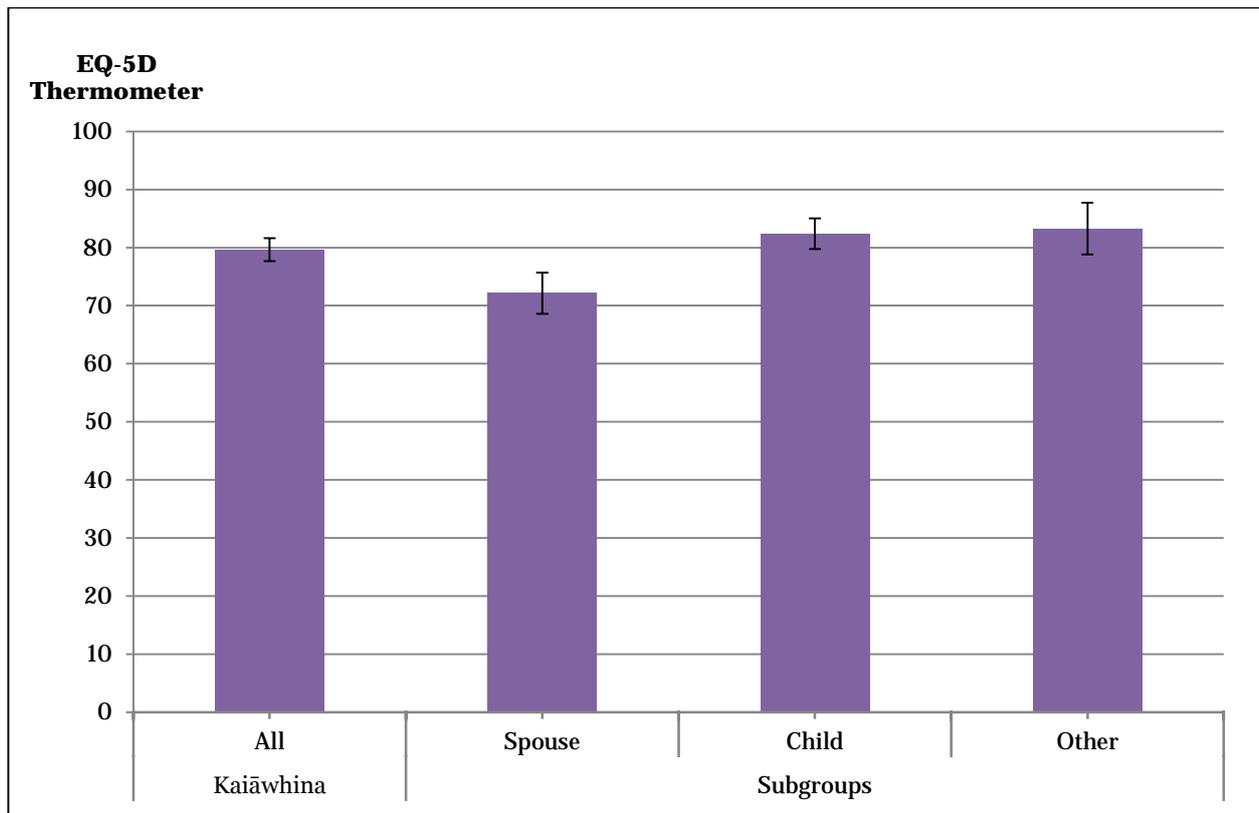
4.4.5 Carers for different groups of LiLACS NZ participants did not differ in assessment of the positive value of caring or in how they rated the quality of support given

There were no real differences found between those caring for Māori and non-Māori women and men, in terms of their scores on the COPE Index subscales of the positive value of caring or quality of support (Appendix Tables 4.36 and 4.37).

4.4.6 Spouse carers had lower quality of life and those caring for Māori women had higher quality of life

The EQ-5D-3L questionnaire asked about mobility, self-care, pain levels, anxiety and depression, and the ability to undertake usual activities. The final section of the EQ-5D-3L asked the carer to mark their overall quality of life on a thermometer between 0% and 100% with a higher rating (utility score) perceived as better quality of life and 100% as perfect. Figure 4-12 (Appendix Table 4.39) shows the mean EQ-5D-3L utility score of the informal carer and by their relationship to LiLACS NZ participants. Those who were spouses had a lower utility score.
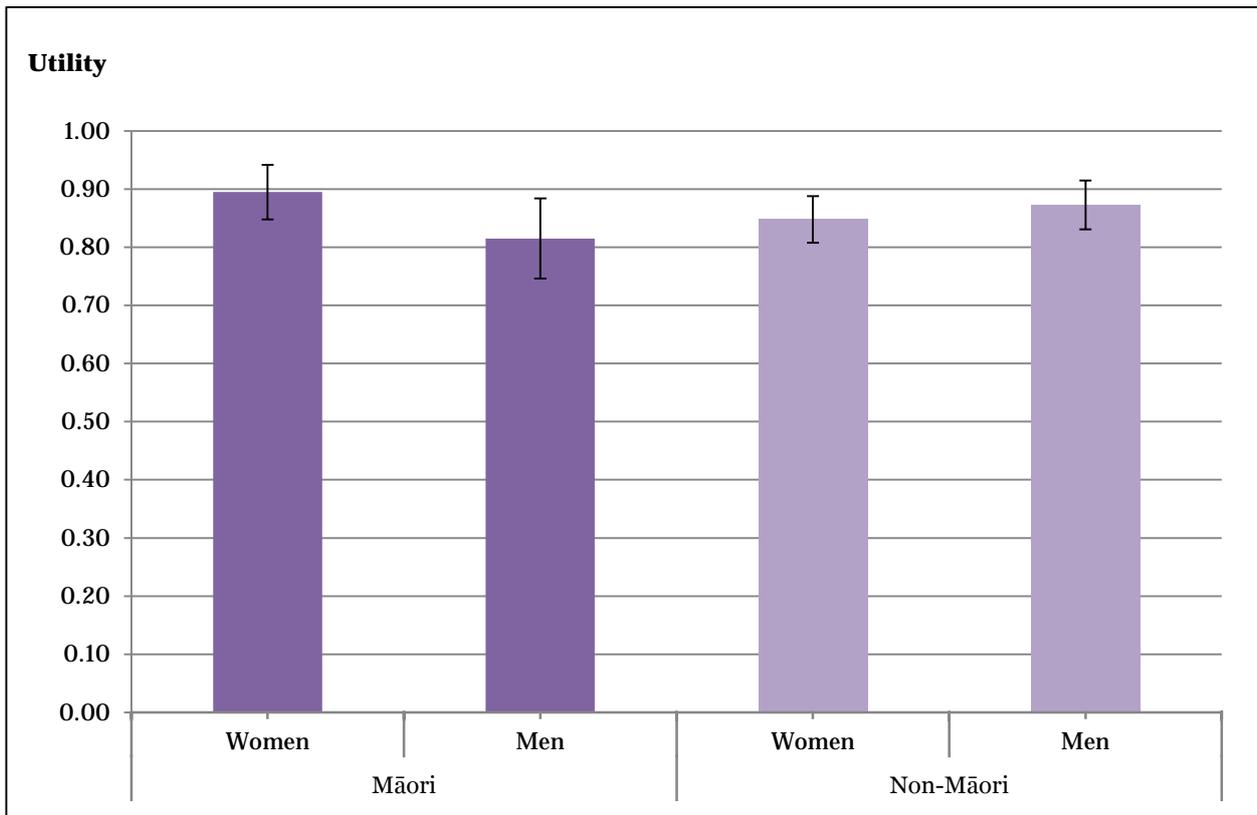
Figure 4-12: Mean EQ-5D-3L quality of life scores by carer type

Source: LiLACS NZ

Spouse carers, who were older than other groups, had lower quality of life using this measure. This is in contrast to the earlier finding on their self-rated health, a discrepancy that may arise from the more detailed questions in the EQ-5D-3L.

Figure 4-13 (Appendix Table 4.40) shows the overall quality of life ratings of carers by the ethnic group and sex of their LiLACS NZ participant. Those caring for Māori women had the highest quality of life and those caring for Māori men the lowest, which is consistent with the self-rated general health described earlier. These differences were not statistically significant.

Figure 4-13: EQ-5D-3L utility score for carers, by LiLACS NZ participant ethnic group and sex

Source: LiLACS NZ

4.5 The costs of informal caring

4.5.1 How are estimates formed?

The monetary cost of providing informal care relates directly to the amount of time that carers spend caring. The amount of time that carers spent caring for LiLACS NZ participants, in hours per week, was given earlier in this report. Several questions are important when calculating the cost of care, including: (i) Which wage rate should be placed on each hour that 'counts'? (ii) Which hours should 'count' when calculating costs?, and (iii) What should be done about the people who did not have a carer interviewed?

Many answers are possible for these types of questions and this report considers a range of options.

4.5.1.1 Which wage rate should be used?

Three different options can be considered here. The main wage rate is the median hourly earnings for community and personal service workers, which is $16.85 per hour. Overall, there are 189,000 people in New Zealand working at this type of job. It is the best match for caregiving. The 'median' figure means that half the people working at this type of job will earn more and half will earn less than this per hour.

The other options which could be considered are the minimum wage per hour ($14.75) or the median hourly earnings for all jobs as a whole, which is $22.83 per hour. The use of these figures then provide upper and lower bounds of the estimated costs. We outline the cost differences between these three types of estimates for LiLACS NZ carers below.

4.5.1.2 Which hours should 'count' when calculating costs?

There are two issues that need to be considered. Firstly, carers were asked about the number of hours that they spent caring for the LiLACS NZ participant in a typical week and could indicate 'up to 3 hours', '4-9 hours', and so on. The 'main time' estimate considers the average number of hours of care, so that 'up to 3 hours' is treated as 1.5 hours on average, 4-9 hours is treated as 6.5 hours on average and so on.

Other ways of dealing with this question (to see how much difference it makes) are to use either the lowest or the highest figures relevant. For example, for those who said that they spent more than 50 hours caring for the LiLACS NZ participant, analyses could treat this as 50 hours, considering a 'minimum time' estimate, or 60 or 80 hours respectively considering 'main time' or 'maximum time' estimates. While the LiLACS NZ participant may need a large amount of care, the carer is likely to do other things as well as caring within their time. Even if carers are responsible 24 hours a day, 7 days a week (168 hours), they do not provide care for all this time as they need to sleep, eat and do other things. These alternative measures also provide us with upper and lower bounds of the estimates.

The other issue is which types of carer should have their hours counted? This is a difficult subject and again there is no clear right or wrong answer. At one extreme, all hours would count, regardless of who provided the care. This might be considered a good answer if the question is from the perspective of how much it would cost to replace an informal carer with paid carers.
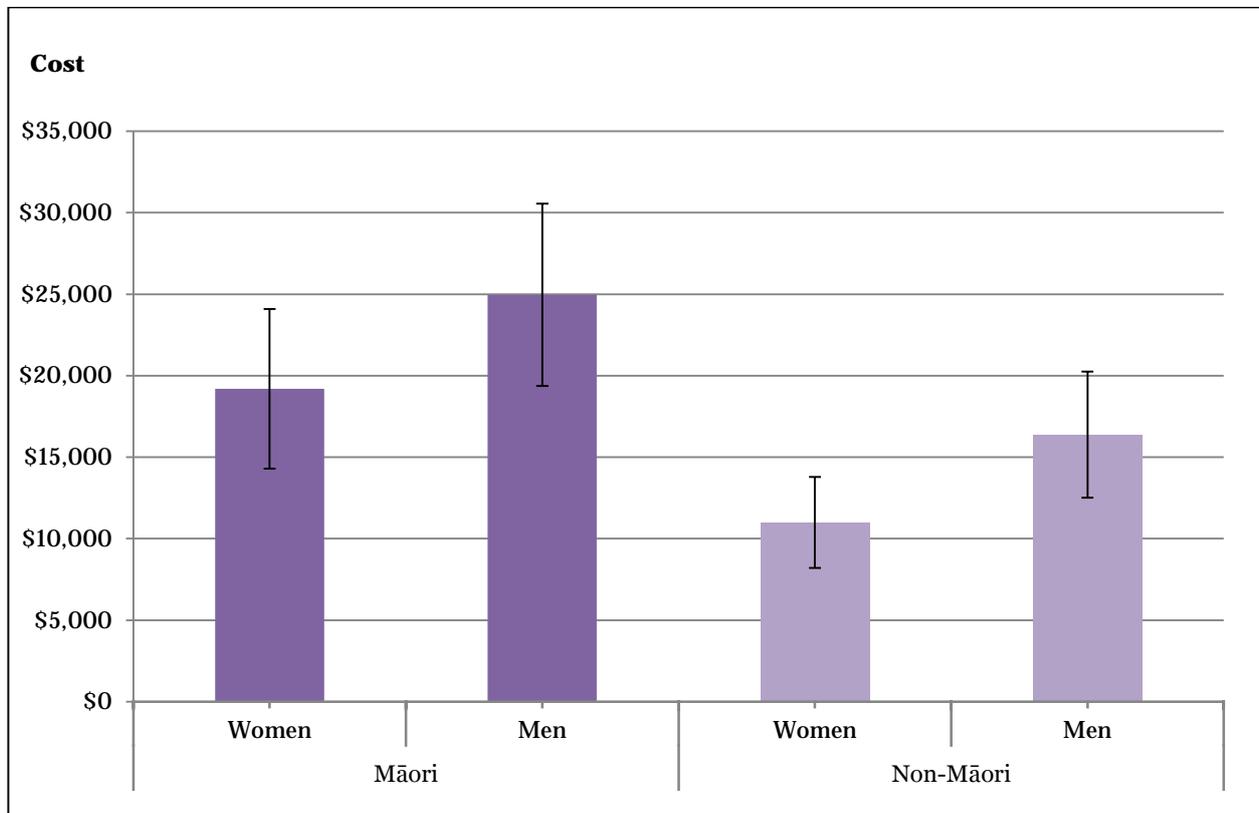
The other issue is which types of carer should have their hours counted? This is a difficult subject and again there is no clear right or wrong answer as it will depend on why the question is asked and whether caring activities are valued or seen as a burden. There are many ways of viewing this issue, and each answer depends in part on the motivation for the question. If we wished to honour the contribution of carers, an answer would need to provide a total number of hours spent caring by all carers. If the government instead wanted to know how much it would cost to replace an informal carer with paid carers, they might also want to know the average hours spent caring by all carers, so that they would know how much, on average, replacing each carer would cost. It is also possible to view informal caring as time spent caring instead of doing other things that might be captured in measures such as Gross Domestic Product. In this case, the answer would find out how much time people were unable to work or had to take time off work because of informal care. At this extreme, each hour is no longer treated as a contribution that is honoured but instead as a burden on the economy.

The decisions above make a big difference to the number of hours that would be considered, as 41 percent of carers were retired and only 47 percent of carers were currently working in a part-time or full-time job.

4.5.2 Average informal care costs were higher for Māori than for non-Māori

The Kaiāwhina questionnaire asks carers how much time they spend caring in a typical week. The carers choose from a set of categories and the middle point of these categories is used. For example, if a carer says that they spent between 10 and 39 hours caring, then the average of these numbers (24.5 hours) is used. For those who said that they spent over 50 hours a week caring, 60 hours is used instead. These figures are then multiplied by 52 weeks a year and by $16.85, which is the average wage of paid caregivers. This approach finds that the total cost of informal caregiving was around $10,000 a year higher for Māori men than for other groups, and around $8,000 a year lower for non-Māori women than for other groups, with both of these comparisons significant (Appendix Table 4.41). Overall, costs of care were *significantly higher* for men and for Māori participants (Figure 4-14).

Figure 4-14: Average yearly informal carer costs, by LiLACS NZ participant ethnic group and sex (N = 263)
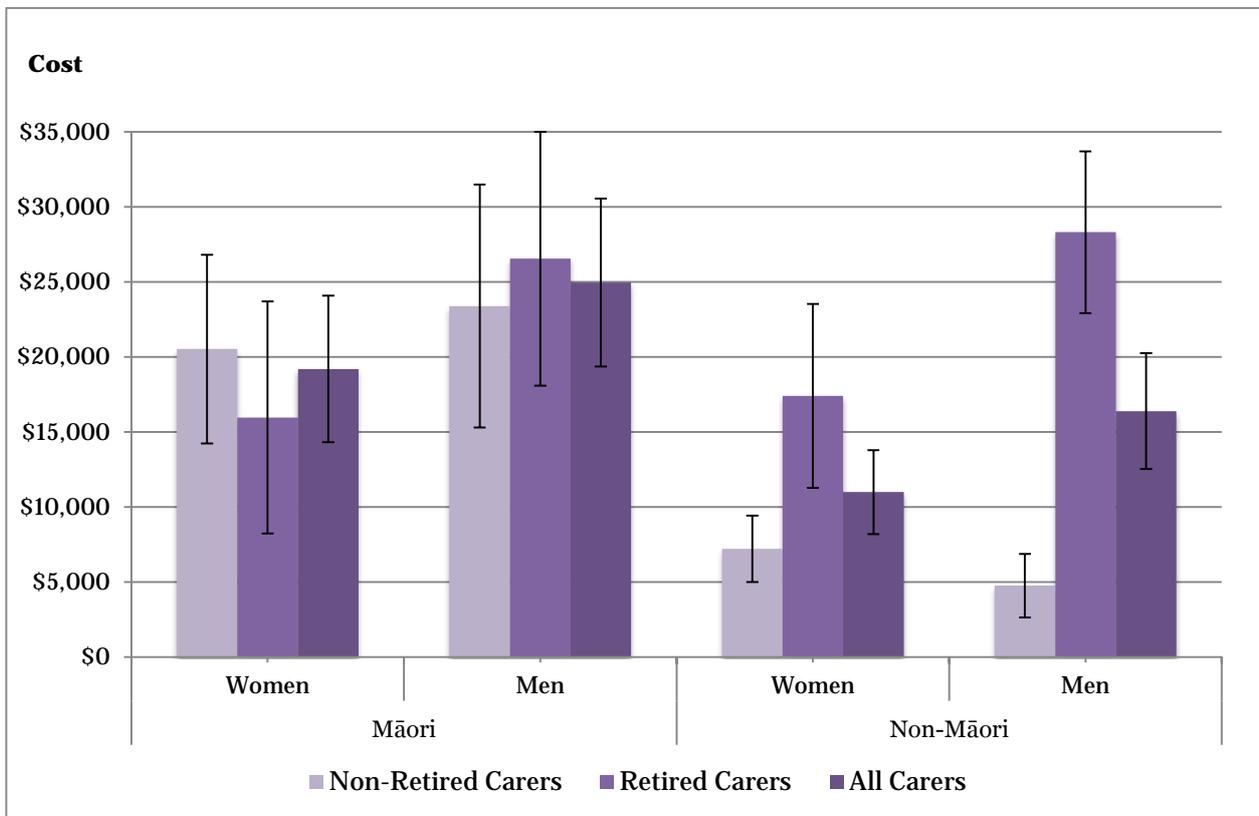
Source: LiLACS NZ
Note: Average yearly informal care costs are calculated as the estimated hours per informal carer multiplied by $16.85, divided by the total number of carers in this group.

Overall, the carers who were retired provided *significantly more* care compared to non-retired carers, at around $23,000 versus $12,000 a year. However, this was not the case across all LiLACS NZ participants, as for Māori participants these figures were around $21,500 for retired carers against $21,700 for non-retired carers. The overall figures are because of a large difference for the non-Māori participants, where retired carers provided around $23,000 in care and non-retired carers around $6,000 in care per year (Appendix Table 4.42).

In those economic analyses that do not consider the contributions of retired carers, the contribution of those 96 carers are not considered. If only the hours from the 154 non-retired carers are considered, the average cost per carer was similar for Māori women and men, but much lower for non-Māori women and men (Appendix Table 4.43), as those who remain provide less care.

For non-Māori women and men, informal care would cost around $11,000 and $16,400 a year, respectively, if we considered replacing the contributions from all types of carers but only around $7,200 and $4,800 a year if contributions from retired carers were removed (Figure 4-15).

Figure 4-15: Average yearly informal carer costs, by carer retirement status and LiLACS NZ participant ethnic group and sex (N = 261)
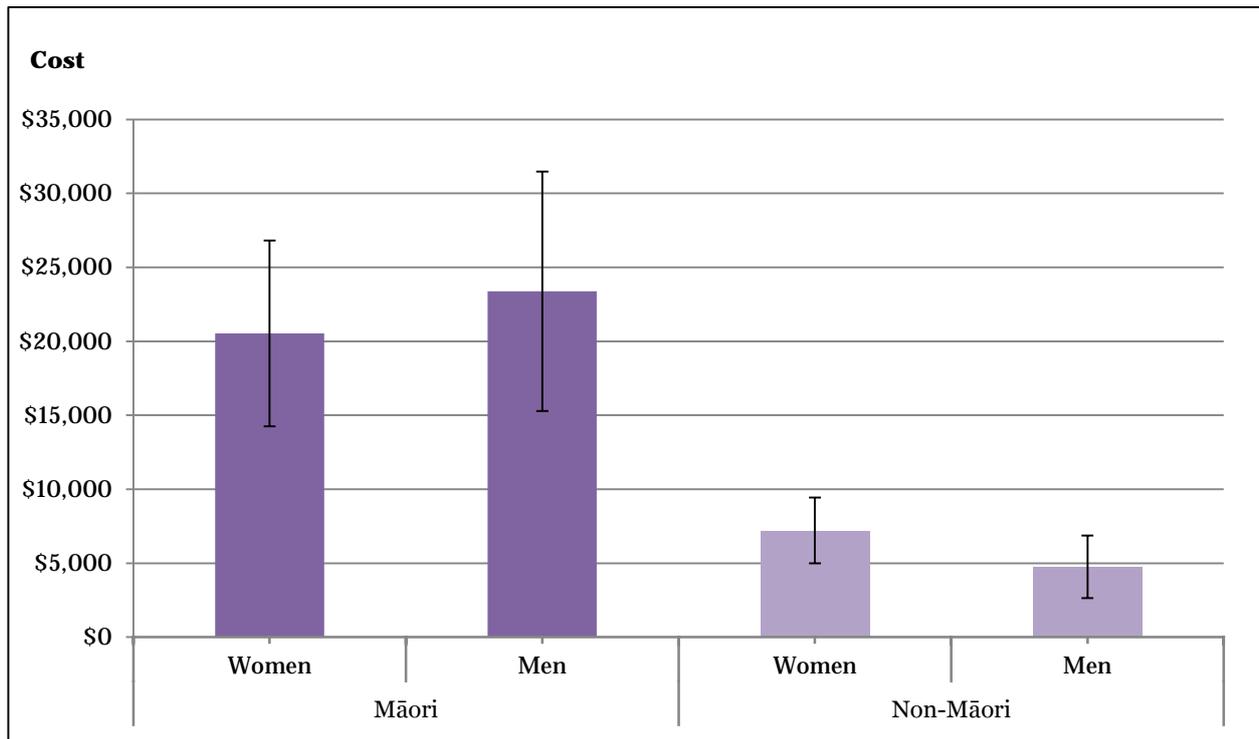
Source: LiLACS NZ
Note: Average yearly informal care costs are calculated as the estimated hours per informal carer multiplied by $16.85, divided by the total number of carers in this group.

There were also differences within the group of non-retired carers, with those who were employed providing less care on average (costed at around $9,000 compared to $23,000 a year for those who were not retired but not employed) than those who were retired (Appendix Table 4.44). Again, the same pattern was observed as before (Figure 4-16) with Māori non-retired carers providing more care than non-Māori but with no difference in the amount of care provided for male compared to female LiLACS NZ participants.

Figure 4-16: Average yearly costs for carers who were working, by LiLACS NZ participant ethnic group and sex (N = 123)

Source: LiLACS NZ

4.5.3 How carer earnings are calculated makes a big difference to cost estimates
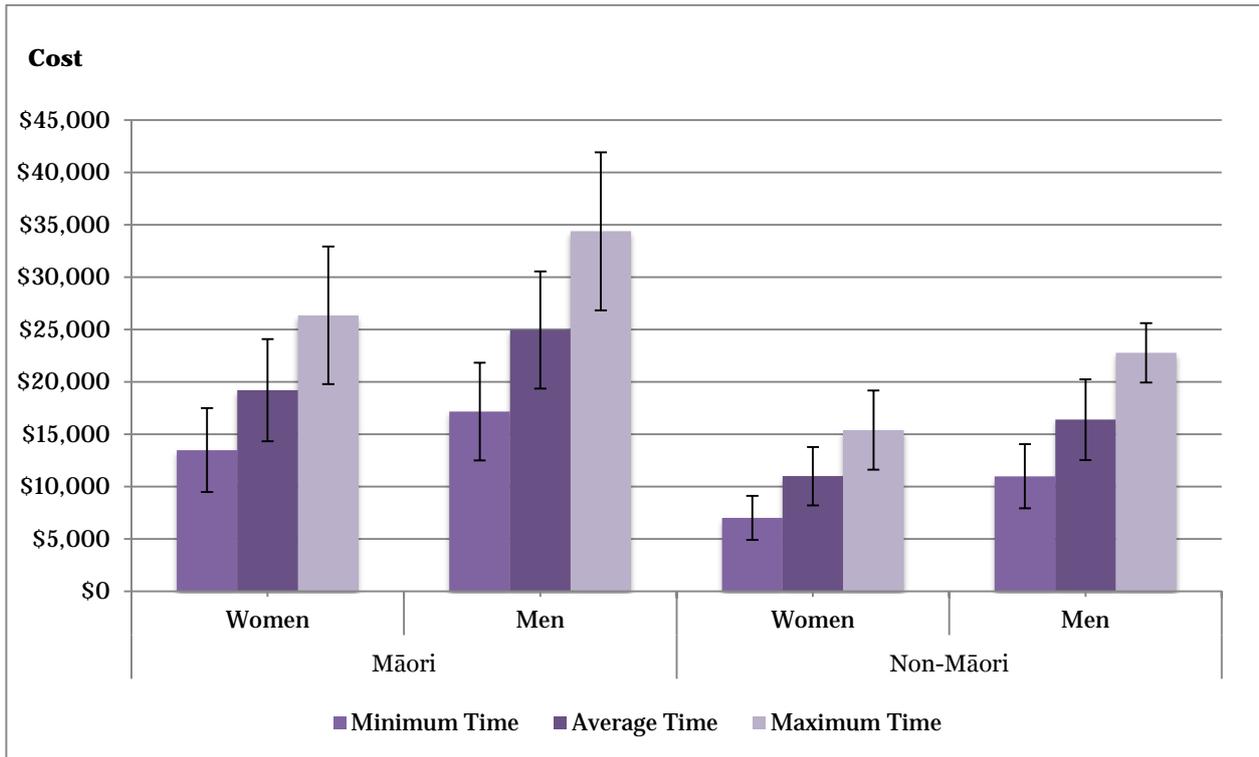
The calculations of all the cost figures above used the middle point of each time category and the estimated median caregiver earnings per hour. If the minimum and maximum times within each time response category had been used, the figures would be quite different (Appendix Table 4.45).

As can be seen in Figure 4-17, the yearly costs of care estimated with the minimum time are about 30 percent lower than the average estimate. The costs estimated with the maximum time are about 40 percent higher than the average estimate.

As the median hourly earnings for the whole population are about 35 percent higher than the median hourly earnings for caregivers, all of the figures provided would be about 35 percent higher if that method of calculation was used. In the same way, if a minimum wage had been used instead, all the figures would be about 12 percent lower.
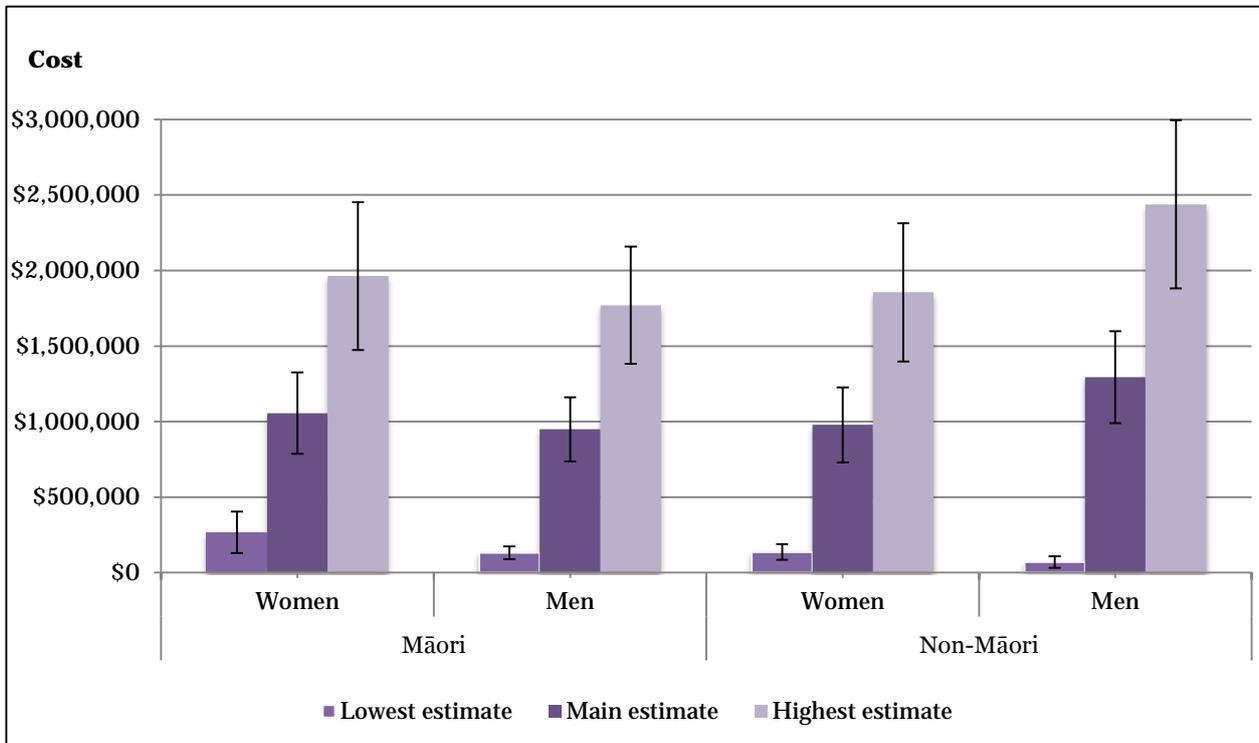
Figure 4-18 compares the main cost estimate with the two most extreme cases (Appendix Table 4.46). The main cost estimate uses the average time estimate, caregiver wage, and figures from all carers. The lowest cost estimate uses the minimum time estimates and minimum wage, and considers only working carers. The highest cost estimate uses the maximum time estimates, average wage, and considers all carers. Across all the carers in the study, the main estimate of total yearly costs is around $4.3 million. However, with different assumptions, this figure might be as low as $0.6 million or as high as $8.0 million. Across those whose data contributed to these figures, the averages range from $2,300 to $31,000 per person.

Figure 4-17: Average yearly costs for carers, by LiLACS NZ participant ethnic group and sex and time (N = 263)

Source: LiLACS NZ

Figure 4-18: Total yearly costs for carers within LiLACS NZ, by LiLACS NZ participant ethnic group and sex (N = 263)

Source: LiLACS NZ
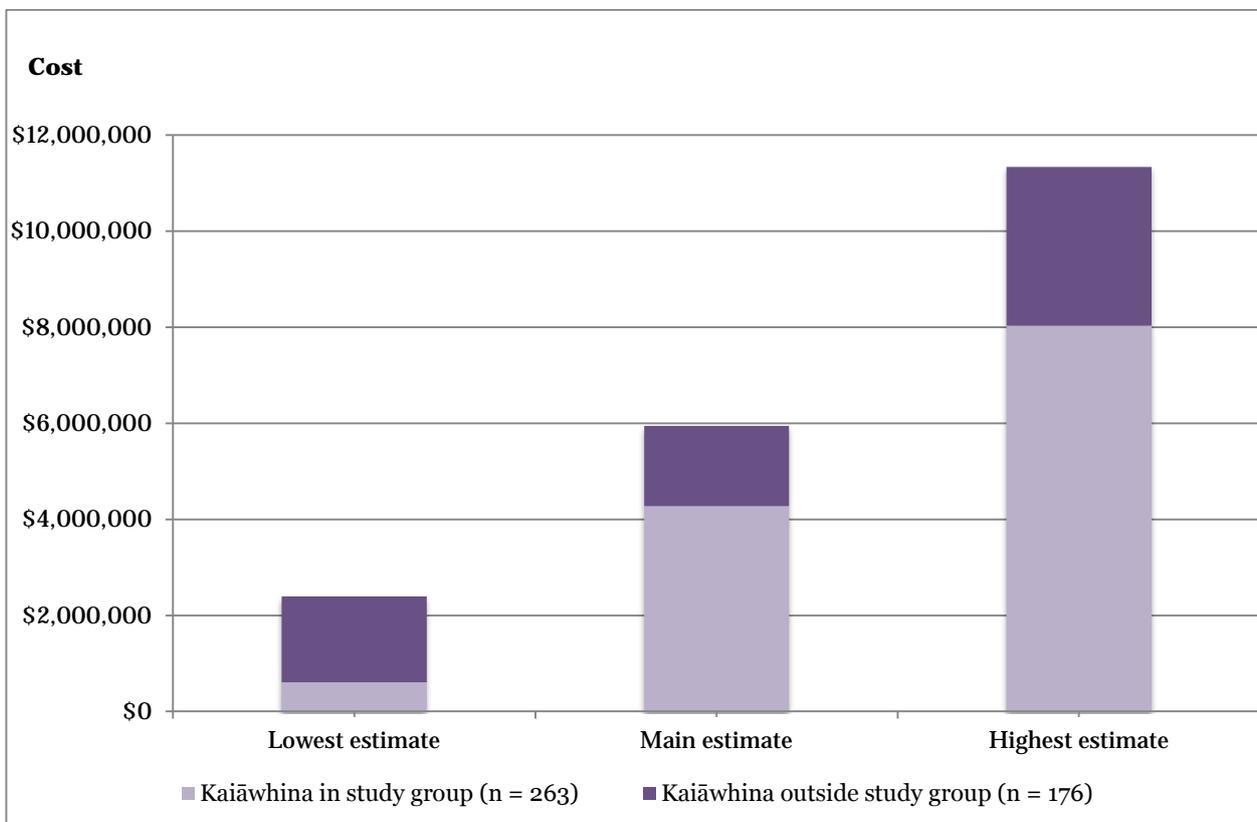
4.5.4 Most of the informal care costs for LiLACS NZ participants appear to fall within the Kaiāwhina study group

The estimates of total costs that appear above are based on the 261 participants whose carers were interviewed by LiLACS NZ in the Kaiāwhina study group. However, LiLACS NZ Wave 4 participants reported a total of 439 carers, meaning that the carers who were interviewed formed only 60 percent of the whole group. These other 176 LiLACS NZ participants did not have Kaiāwhina interviewed but may still have received informal care.

In order to consider the costs from the other 40 percent, potential values were identified for missing data. Costs were then estimated for the same three cases as in the previous section. The estimated cost of informal care for those outside the Kaiāwhina study group was around $1.7 million in the main cost estimate (Appendix Table 4.47). Including this amount means that we can estimate total costs across all of LiLACS NZ. An average yearly cost per LiLACS NZ participant (N = 439) of around $13,500 means a total carer cost of $5.9 million per year.

As shown in Figure 4-19, the cost using the highest estimate was around $3.3 million. Using the highest estimate would bring the total cost of informal care to around $11.3 million for the 439 LiLACS NZ participants, around $26,000 per participant. Also please note that 6 percent reported not needing a carer, so the additional amounts related to those who did not have a kaiāwhina may be overestimated.

Figure 4-19: Total estimated yearly informal care costs for LiLACS NZ participants whose Kaiāwhina participated and extrapolated to those Kaiāwhina who did not participate

Source: LiLACS NZ

It should also be noted that the distinction between formal and informal carers is blurred, with 56 percent of the formal carers also stating that they had done tasks that they were not paid for. These tasks varied from help with daily tasks like mowing lawns and shopping, to attending medical appointments with the participants and acting as an advocate with social support. Also, a carer's benefit is available to some informal carers, but in this study only 2 percent received such a benefit.

Key findings

- Informal (unpaid) carers were older than formal (paid) carers.
- Women predominated as carers, although a greater proportion of formal than informal carers were women.
- Most LiLACS NZ participants received informal care from carers of the same ethnic group, but 29 percent of LiLACS NZ Māori participants received informal care from non-Māori.
- Around half of informal carers were employed full or part time.
- Most informal carers lived close by the person they cared for, with nearly 40 percent living either in the same house or on the property.
- Over half the informal carers were sons, daughters, sons-in-law or daughters-in-law and around 30 percent were spouses.
- Informal carers started caring earlier for men than for women.
- Māori men received the most hours of care per week and non-Māori women the least.
- Spouse carers and carers for Māori men felt the most responsibility.
- Carers for non-Māori women were least likely to provide personal care.
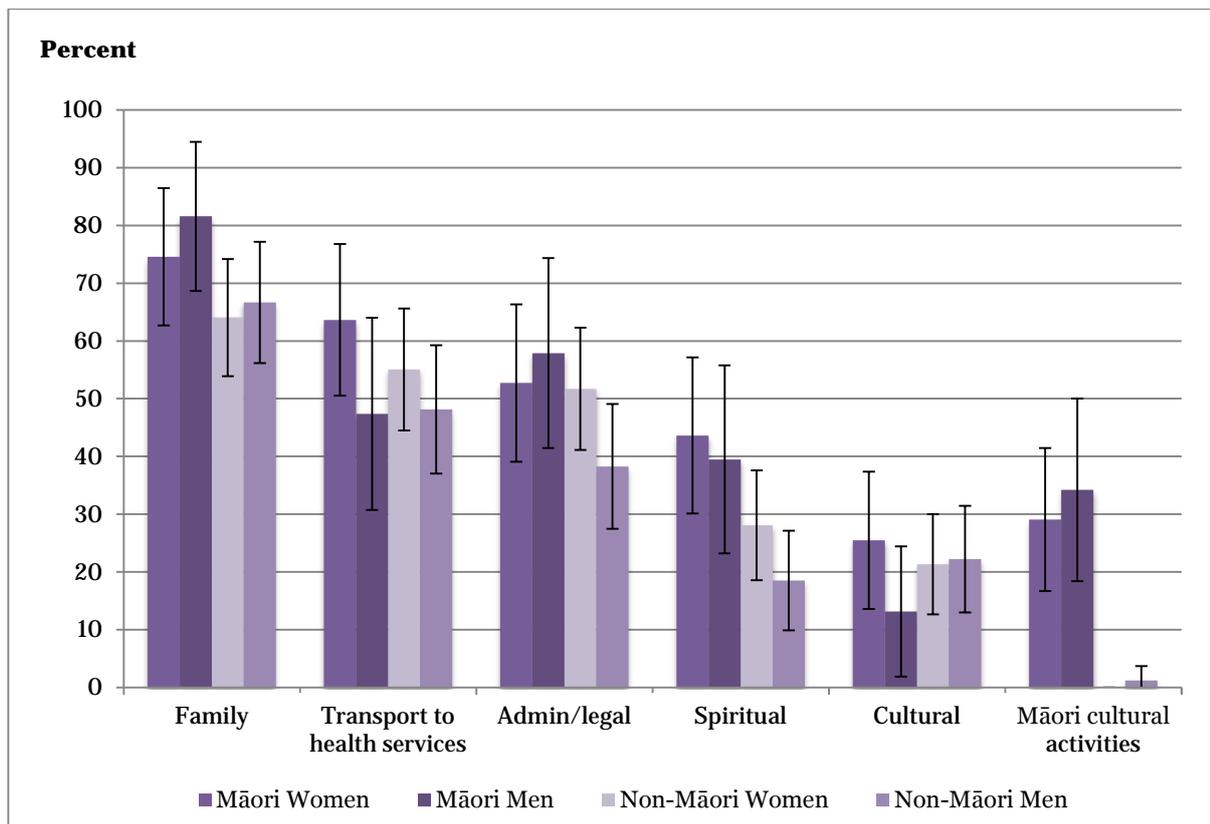- Māori men were more likely to receive daily household assistance than non-Māori women.
- Māori men were more likely to receive assistance with food-related activities than non-Māori men.
- Virtually all informal carers provided social and emotional support.
- Caring impacted on informal carers' working lives.
- Spouse carers rated their health more positively than did other informal carers despite their age.
- Carers of Māori men were least likely to say that they were in 'very good' health.
- Scores on the COPE Index (a measure of carer support and stress) were not affected by carer relationship to LiLACS NZ participant.
- Providing personal care was associated with a less negative impact of care for the carer.
- Carers for different groups of LiLACS NZ participants did not differ in their assessment of the positive value of caring or in how they rated the quality of support given.
- Spouse carers had a lower quality of life when assessed with the EQ-5D-3L (a quality of life measure) and those caring for Māori women had a higher quality of life.
- The mid-range economic value of the 263 carers in the Kaiāwhina study was estimated at $4.3 million annually.
- Average informal care costs were higher for Māori than non-Māori.
- How caregiver earnings are calculated makes a big difference to cost estimates.
- Providing personal care was associated with a less negative impact of care for the carer.

Section Five: Health, Health Service Use and Common Health Conditions in Advanced Age

5.1 Introduction

People aged 85+ in New Zealand have the highest rate of hospitalisation and preventable hospital admissions,[73,74] and receive more health and disability support per capita than any other age group.[10] Over the next two decades the proportion of the population aged 85+ will rise from 1 percent to 6 percent, the fastest growth of any age group. During any one year, one in ten of this group will die, one in five will be hospitalised for cardiovascular disease[75] and almost half will use residential care before their death.[10,76–79] LiLACS NZ data suggest that despite increasing frailty and co-morbidities, most of those in advanced age live independently in the community. Multi-morbidity is ubiquitous in advanced age, with 93 percent of LiLACS NZ participants having two or more health conditions diagnosed.

This section highlights the presence of several common chronic conditions in advanced age and examines the impact of these conditions on functional status, frailty, quality of life and health service use when depressive symptoms are also present. The level of disability experienced by people with chronic conditions is impacted by co-morbidities, particularly when physical and mental health conditions are co-morbid. The chronic conditions we examine are cardiovascular disease, chronic lung disease and diabetes mellitus. The prevalence and consequences of these conditions in advanced age and how psychological conditions, specifically depression, impact on outcomes are examined. Greater knowledge will assist clinicians and planners to understand health complexities and impacts amongst Māori and non-Māori people in advanced age and potentially alter treatment and management plans for both the chronic conditions examined as well as the mental health condition. Similarly, conditions in isolation may be managed differently than co-morbid conditions.

Appendix Table 5.1 shows the number of participants contributing data for each of a number of health and health service indicators.

> '**I think the highlights of this stage of life would be [that] I can still use my brain, I am still living in my own home, still able to drive, still doing my own housework… My mobility is not as good as it used to be but is not really a great problem as I am still working. Life is what you make it.**'

5.1.1 Depression

Depression is one of the most common mental health problems of people in advanced age,[80] and along with co-morbidities and frailty[81] is strongly related to functional status, quality of life and transitions in health status for older people. The combination of mental health problems with physical conditions increases the negative impact of the physical conditions and may also increase the severity of the mental health problem.

5.1.2 Cardiovascular disease

Cardiovascular disease (CVD) is frequent in advanced age. CVD is a phrase referring to several different conditions including cardiovascular disease (previous heart attack and/or current angina), congestive heart failure, cerebrovascular disease (stroke and ministroke), and/or peripheral vascular disease. New Zealand health statistics show that in a given year, CVD caused 89 percent of deaths among older (65+) non-Māori and 59 percent among older Māori.[74] New Zealand's rates of hospitalisation are high, with 8 to 10 percent of older Māori people being hospitalised for CVD in 2005-2007.

Co-morbidity with CVD is very common. One study found that around 15 percent of older people with heart failure had one or two co-occurring conditions, one-third had three or four, and *half* had five or more co-occurring conditions.[82] Thus the 'single disease' framework for primary care is challenged and it may be that, in primary care, considering combinations of disease is as important for the health practitioner as looking at any single disease.[83]

To identify those who had CVD, LiLACS NZ used information from the participants' self-report, the GP record review and diagnoses from the hospital.[32] In Wave 1 of LiLACS NZ we found that 66 percent of participants had hypertension, 22 percent prior myocardial infarction, 14 percent prior stroke and 15 percent heart failure. Overall, 67 percent of LiLACS NZ participants were found to have CVD.[32]

5.1.3 Chronic lung disease

Chronic obstructive lung disease is one of the most common of the major respiratory diseases and accounts for 95 percent of avoidable deaths from respiratory disease.[84] The 2006/2007 New Zealand Health Survey found that 6.6 percent of adults, or one in every 15 people over the age of 45 years, had this condition.[85] The actual prevalence may be higher as some people with chronic obstructive lung disease have not been diagnosed.

Smoking is the main cause of chronic obstructive lung disease. Māori and women have a higher prevalence of this disease. Hospital admission is common and New Zealand has the second highest rate of hospitalisations for this condition amongst OECD countries.[86] Amongst adults over 65 years of age, hospitalisation rates per 100,000 are 3,823 for Māori women, 802 for non-Māori women, 3,334 for Māori men and 1,010 for non-Māori men.[42]

In the LiLACS NZ study, participants and GPs were asked if the participant had chronic obstructive lung disease or emphysema or asthma. These diagnoses were combined to make up the category of chronic lung disease (CLD).

5.1.4 Diabetes mellitus

The incidence and prevalence of diabetes mellitus (DM) increases with age, with a prevalence of 13 percent for the New Zealand population aged 65 to 74 and 17 percent for those aged 75+.[87] DM is twice as prevalent amongst Māori compared to non-Māori and 1.4 times as prevalent amongst men compared to women. It is nearly twice as common in areas of the highest socioeconomic deprivation. DM complications include an increased risk of heart disease, renal disease and vision changes. For older people, management of DM may increase the number of medications needed and thus increase the chance of adverse drug reactions, increasing the risk of mortality. DM was diagnosed in LiLACS NZ if any of these sources reported DM: self-report, GP record review, diagnosis from the hospital records or if the blood test examining glucose and HbA1c indicated DM was present.

5.1.5 Health and health service use indicators

In this section of the report a number of health and health service use indicators have been analysed against depression alone and for depression in relation to CVD, CLD and DM.

The health indicators are: functional status (using the Nottingham Extended Activities of Daily Living Scale); frailty using the Fried phenotype[30] (which defines frailty as having three of five key deficits: slowness, weakness, weight loss, fatigue and low activity); and physical and mental health-related quality of life (HRQOL).

The health service use indicators are: GP visits (the percentage of participants making more than four visits to their GP per annum); hospital admission rates (per person per year); length of hospitalisation (nights in hospital per person per year); and costs of hospitalisation (given in 2015-16 NZ dollar equivalent). Hospital costs were calculated by multiplying the cost weights given by the Ministry of Health by a conversion factor 4751.58 to give 2015-16 dollar equivalent amounts.

Most of the analyses in this section use data from both the Māori and non-Māori cohorts instead of separating them, as was done in earlier sections of this report. Analysing the cohorts together gave greater statistical power and where differences between the ethnic groups are notable, separate results are presented.

Analyses are cross-sectional for each of the four waves of the study and include all those who participated in each wave. After the first wave, numbers in both LiLACS NZ cohorts declined, some having been lost through death and some through withdrawal (Figure 1-1, Section 1, gives full details of attrition).
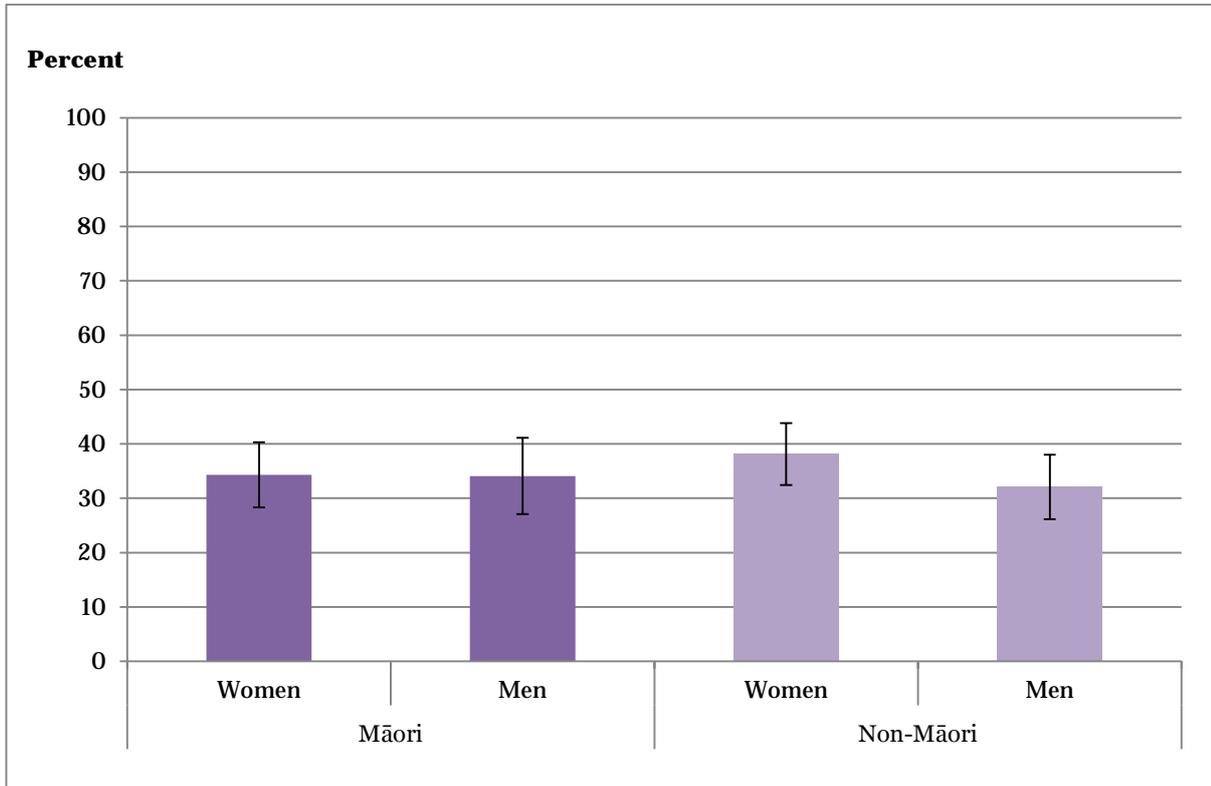
5.2 Depression

5.2.1 Depressive symptoms were present in 35 percent of LiLACS NZ participants at some time and those who were depressed often improved over time

LiLACS NZ participants were asked a standard questionnaire, the Geriatric Depression Scale (GDS),[29] in every wave of the study. The 15 questions give a score out of 15, a higher score indicating more depressive symptoms. For the purposes of this report, a score of 5 indicates a significant likelihood that the participant has depression[29] and is used as the cut-off point, thus 5 or more is referred to as 'depression', and 4 or less is considered 'no depression'.

In Wave 1, about one-third of Māori and non-Māori participants (34% in each cohort) scored 5 or more on the Geriatric Depression Scale (Figure 5-1, Appendix Table 5.2). Thirty-six percent of women and 33 percent of men showed depressive symptoms, a difference that was *not significant.* Depressive symptoms did not vary by socioeconomic deprivation.
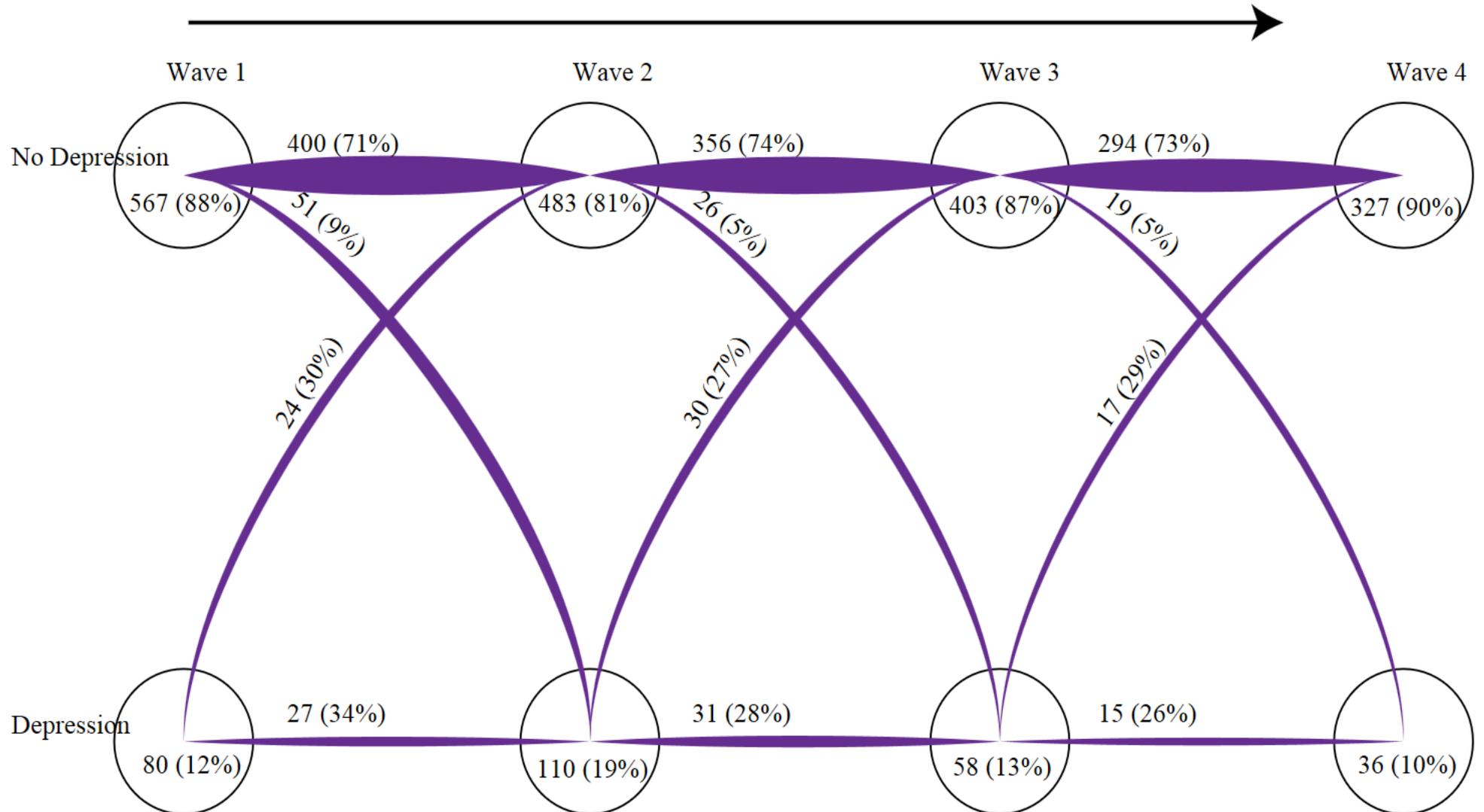
Figure 5-1: Prevalence of significant depressive symptoms in LiLACS NZ participants, Wave 1

Source: LiLACS NZ

Over time the proportion of participants without symptoms of depression stayed steady at 71 percent in Wave 1, 74 percent in Wave 2 and 73 percent in Wave 3, but there were changes for individuals, with up to 30 percent of those with depressive symptoms improving. However, more people developed depressive symptoms than improved. Figure 5-2 shows these transitions in depressive symptoms over time.

Figure 5-2: Transitions in depressive symptoms over time, Waves 1 to 4

	Wave 1	Wave 2	Wave 3	Wave 4
No Depression	567 (88%)	483 (81%)	403 (87%)	327 (90%)
	400 (71%)	356 (74%)	294 (73%)	
	51 (9%)	26 (5%)	19 (5%)	
	24 (30%)	30 (27%)	17 (29%)	
	27 (34%)	31 (28%)	15 (26%)	
Depression	80 (12%)	110 (19%)	58 (13%)	36 (10%)
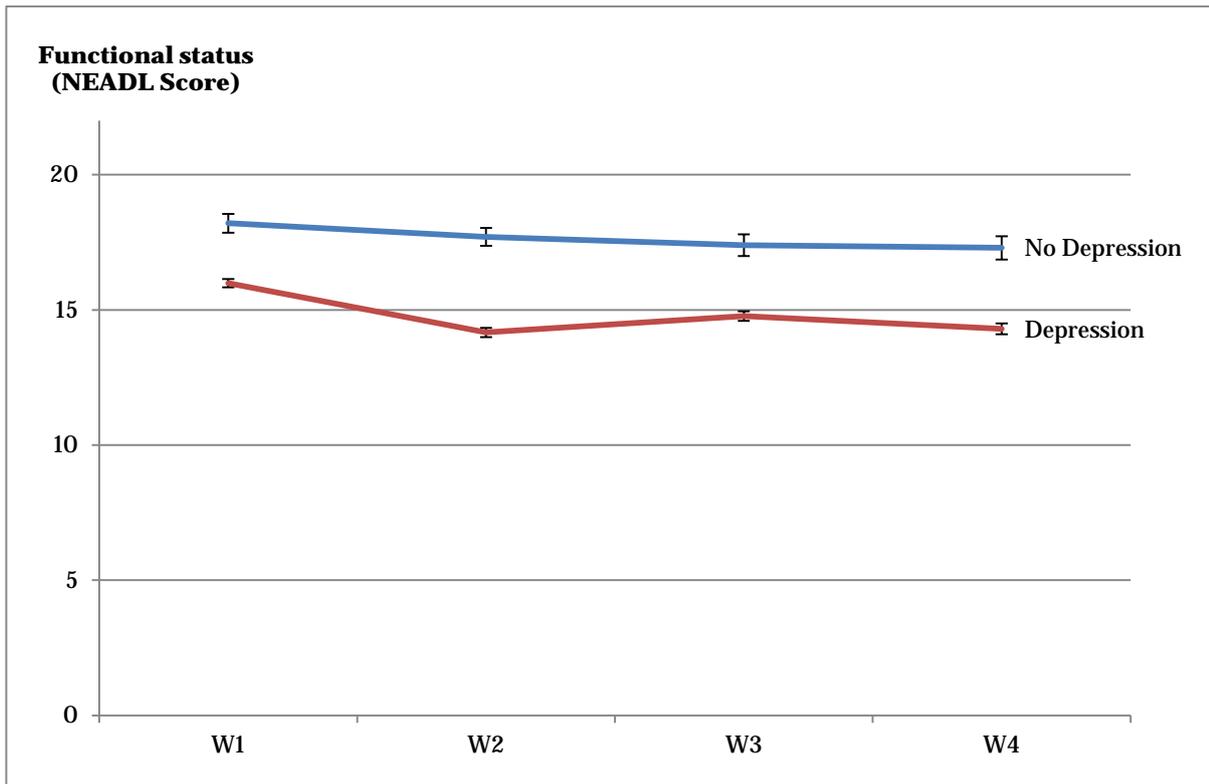
Source: LiLACS NZ. 'Depression' denotes a score of 5 or more on the Geriatric Depression Scale, associated with significant likelihood of depression. Numbers do not add to totals as some participants died or dropped out.

5.2.2 Depression was associated with lower functional status, higher frailty and poorer health-related quality of life

LiLACS NZ participants with depressive symptoms had *significantly lower* functional status, as measured by NEADL scores. This difference was maintained over Waves 1 to 4 of the study (Figure 5-3, Appendix Table 5.3) even though the specific individuals with depressive symptoms changed between waves.

Figure 5-3: Depression and functional status (mean NEADL scores), Waves 1 to 4
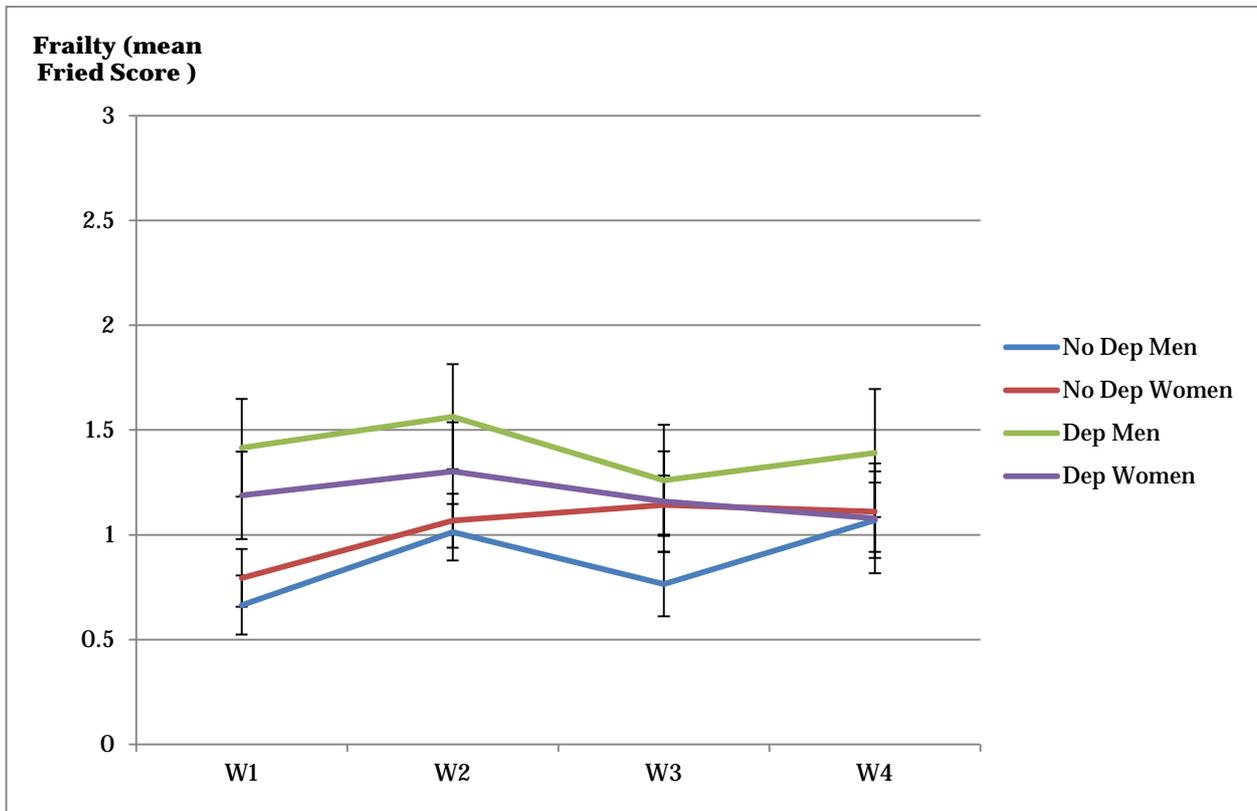
Source: LiLACS NZ
Note: NEADL – Nottingham Extended Activities of Daily Living Scale, higher score is better function

The relationship between depressive symptoms and functional status *did not significantly vary* by ethnic group, sex or socioeconomic deprivation, adjusting for age, ethnic group and sex (Appendix Table 5.3).

> **'Every year is its own age. There's good/bad just like everything else.'**

Depression was associated with frailty and this association was *significantly stronger* for men than for women, adjusting for age, ethnic group and wave of the study (Figure 5-4, Appendix Table 5.3). Whereas men normally had lower Fried scores than women, men with depression had higher Fried scores (greater frailty) than women with depression.

Figure 5-4: Depression and Fried frailty score by sex, Waves 1 to 4

Source: LiLACS NZ
Note: Dep - depression

There were *no significant differences* in the Fried scale scores between those with and without depression for Māori and non-Māori nor for those of different socioeconomic deprivation, adjusting for age and sex (Appendix Table 5.3).
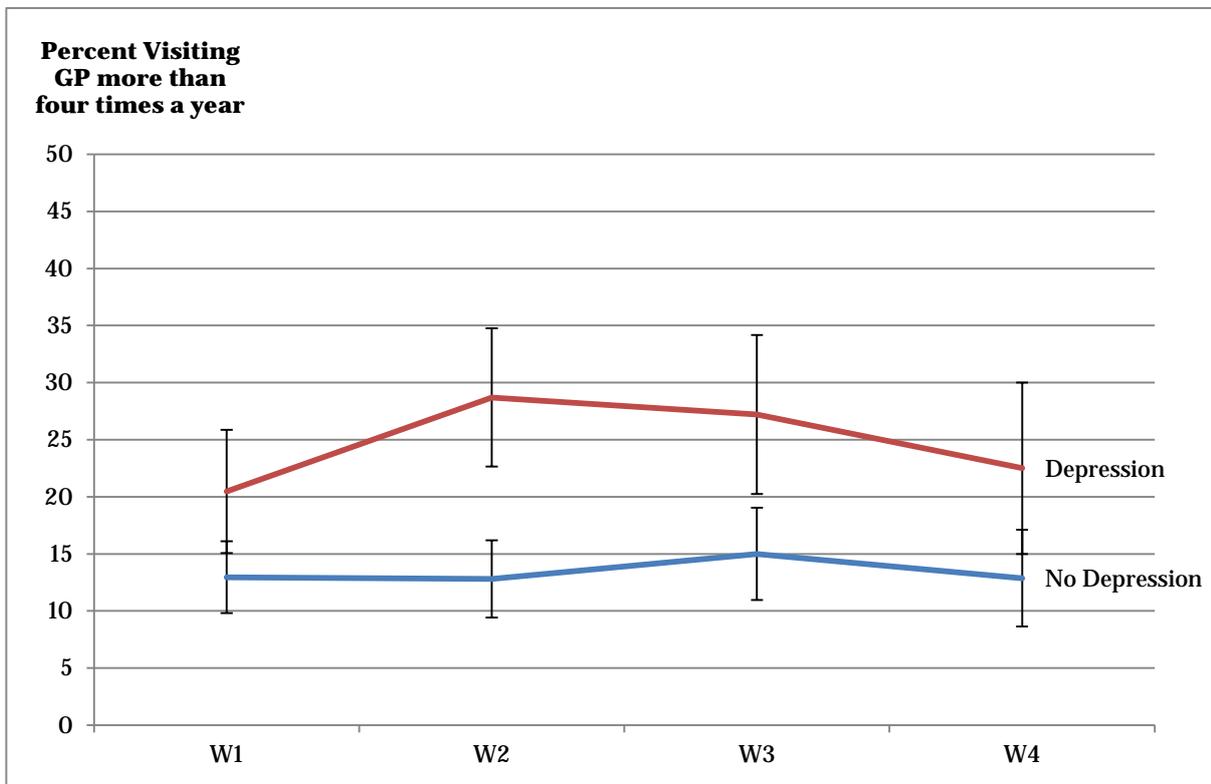
Quality of life, both physical and mental, was *significantly lower* for participants with depression than for those without. But there were *no significant differences* in the pattern of HRQOL scores by depression between Māori and non-Māori, women and men, nor by socioeconomic deprivation, adjusting for age (Appendix Table 5.3).

5.2.3. Depression was associated with higher health service use and cost

Participants with depression made *significantly more* GP visits than those without depression in each of the four waves of the study, adjusting for age, ethnic group, sex and wave of study (Figure 5-5, Appendix Table 5.3). This was most marked in Wave 2, where the percentage of participants with depressive symptoms who visited their GP more than four times a year was double that of those without depression.

This relationship between depression and GP visits *did not significantly vary* between Māori and non-Māori, women and men, nor by socioeconomic deprivation, adjusting for age, ethnic group, and sex.
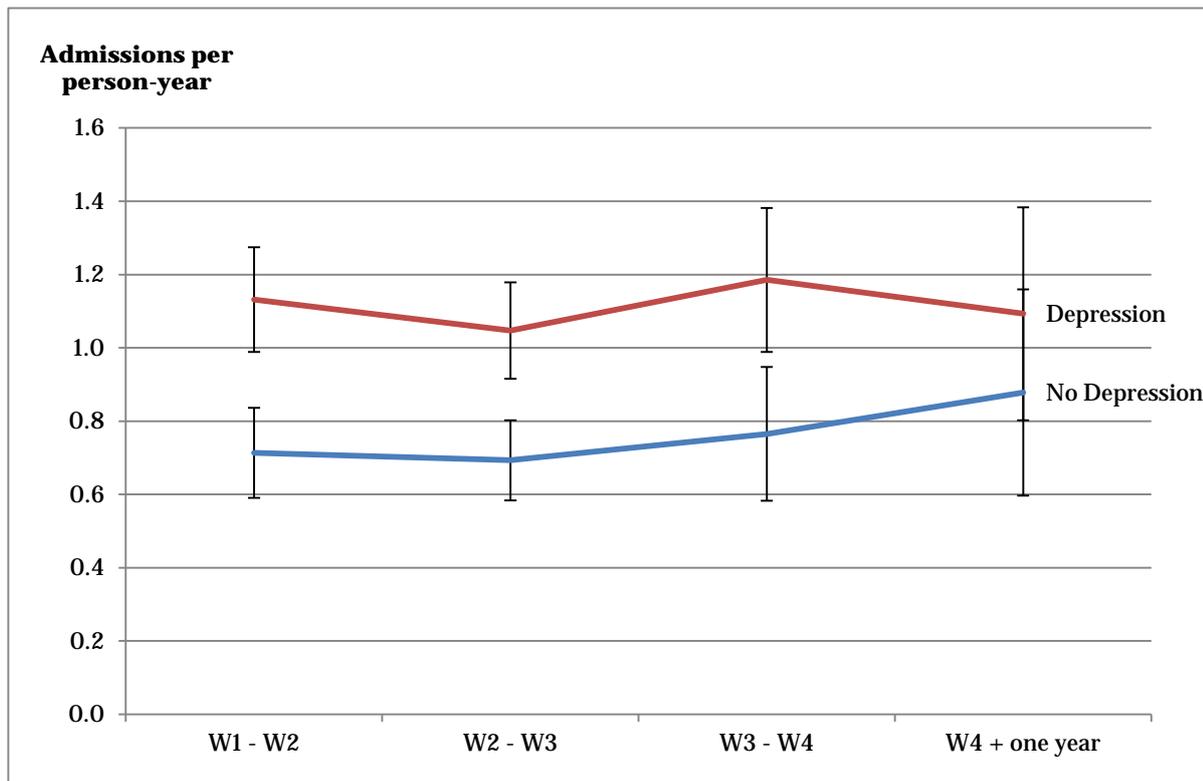
Figure 5-5: Depression and multiple GP visits, Waves 1 to 4

Source: LiLACS NZ

People with depressive symptoms had *significantly more* hospitalisations in each year of the study, adjusting for age, ethnic group, sex and wave of study. Figure 5-6 shows that people with depressive symptoms had, on average, more than one hospital admission each year (1.1), and those without depressive symptoms had less than one admission per year (0.7) (Appendix Table 5.4).

Figure 5-6: Depression and hospital admission rates, Waves 1 to 4

Source: LiLACS NZ

There was *no significant difference* in the pattern of hospitalisations by depressive symptoms between Māori and non-Māori, women and men, or by socioeconomic deprivation, adjusting for age, ethnic group, sex and wave of study.

Not only did participants with depressive symptoms have more hospital admissions, but participants with depressive symptoms stayed *significantly longer* (6.3 nights on average across the study compared to 4.0 nights) (Appendix Table 5.5).

More frequent and longer hospitalisations meant increased costs for participants with depressive symptoms (Appendix Table 5.6). Across the study, the hospitalisation costs per year were $6,396 for participants with depression and $4,429 for participants without depression.
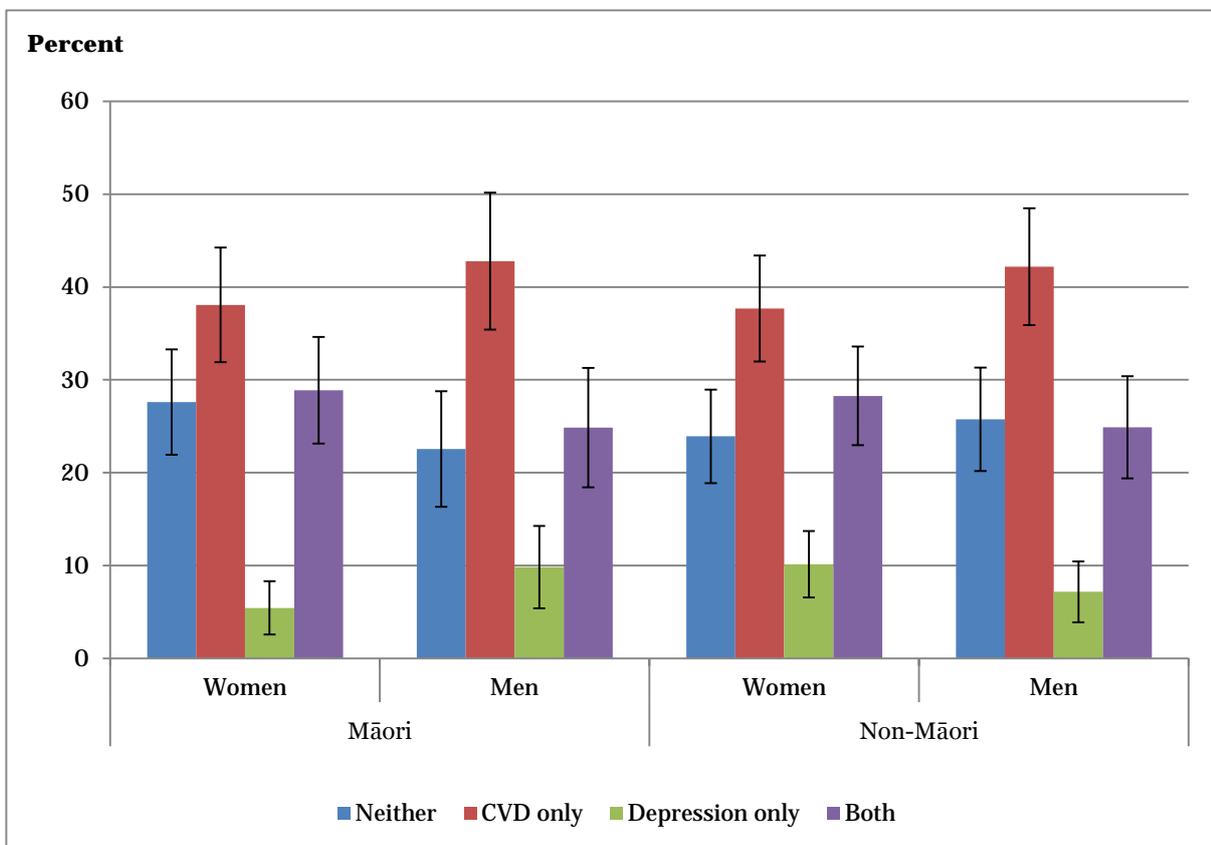
5.3 Cardiovascular disease and depression

5.3.1 Around four in ten participants had cardiovascular disease (CVD) without depression and around one-quarter had both depressive symptoms and CVD

At Wave 1, around one-quarter of participants had neither depressive symptoms nor CVD and around one-quarter had both depressive symptoms plus CVD (27%, for both Māori and non-Māori, Figure 5-7, Appendix Table 5.7). More women (29%) than men (25%) had both conditions but the difference was not significant.

Around four in ten had CVD alone with no depression (43% of Māori women, 38% of Māori men, 42% of non-Māori women and 38% of non-Māori men) and fewer than one in ten had depression alone (no CVD).

Figure 5-7: Cardiovascular disease and depression by ethnic group and sex, Wave 1
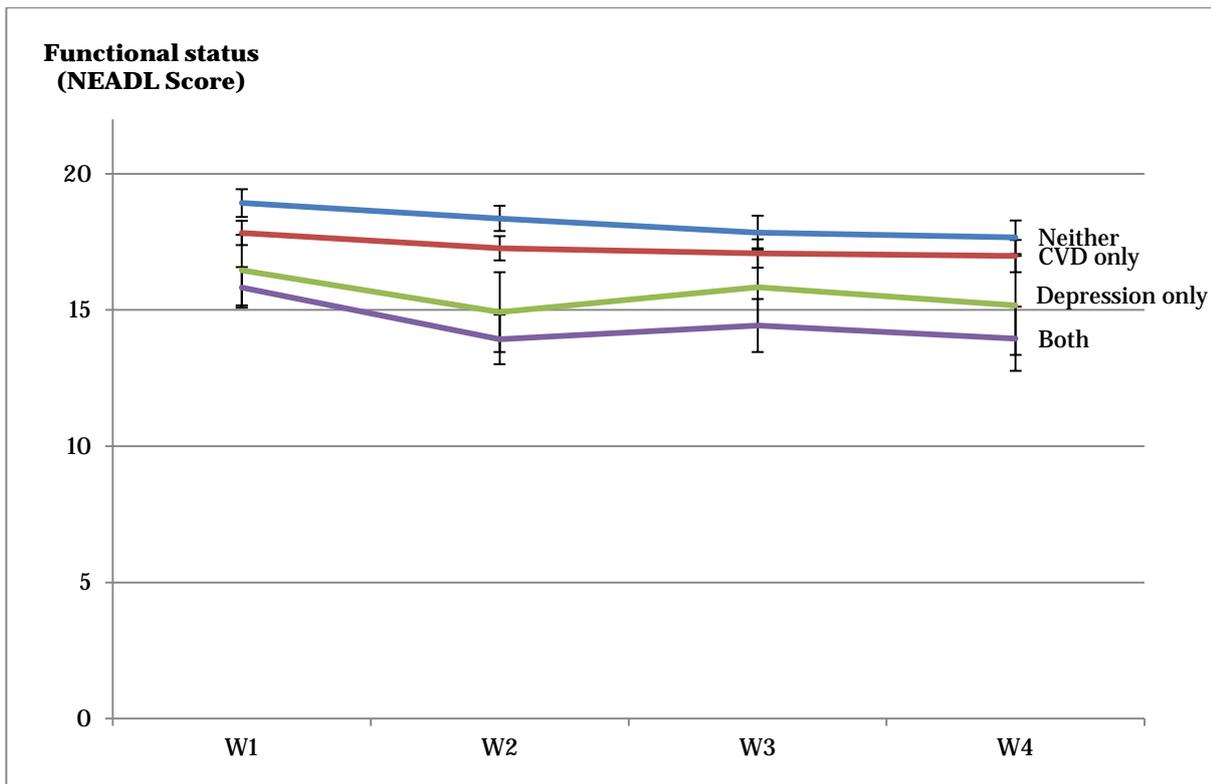
Source: LiLACS NZ
Note: CVD - clinically evident cardiovascular disease.

5.3.2 Depression increased the association of cardiovascular disease with lower functional status, frailty and lower quality of life

LiLACS NZ participants with neither depression nor CVD had *significantly higher* functional status compared to those with either depression or CVD. Those with both depression and CVD had *significantly lower* functional status than the other groups (Figure 5-8, Appendix Table 5.8). Depression was more strongly associated with functional status than was CVD, adjusted for sex, ethnicity, age, wave and SES.

Figure 5-8: Cardiovascular disease and depression by functional status (NEADL score), Waves 1 to 4

Source: LiLACS NZ
Note: NEADL Nottingham Extended Activities of Daily Living Scale, higher score is better function.

'I have given away all the duties I used to do and realise after having a heart attack that my life has changed dramatically.'
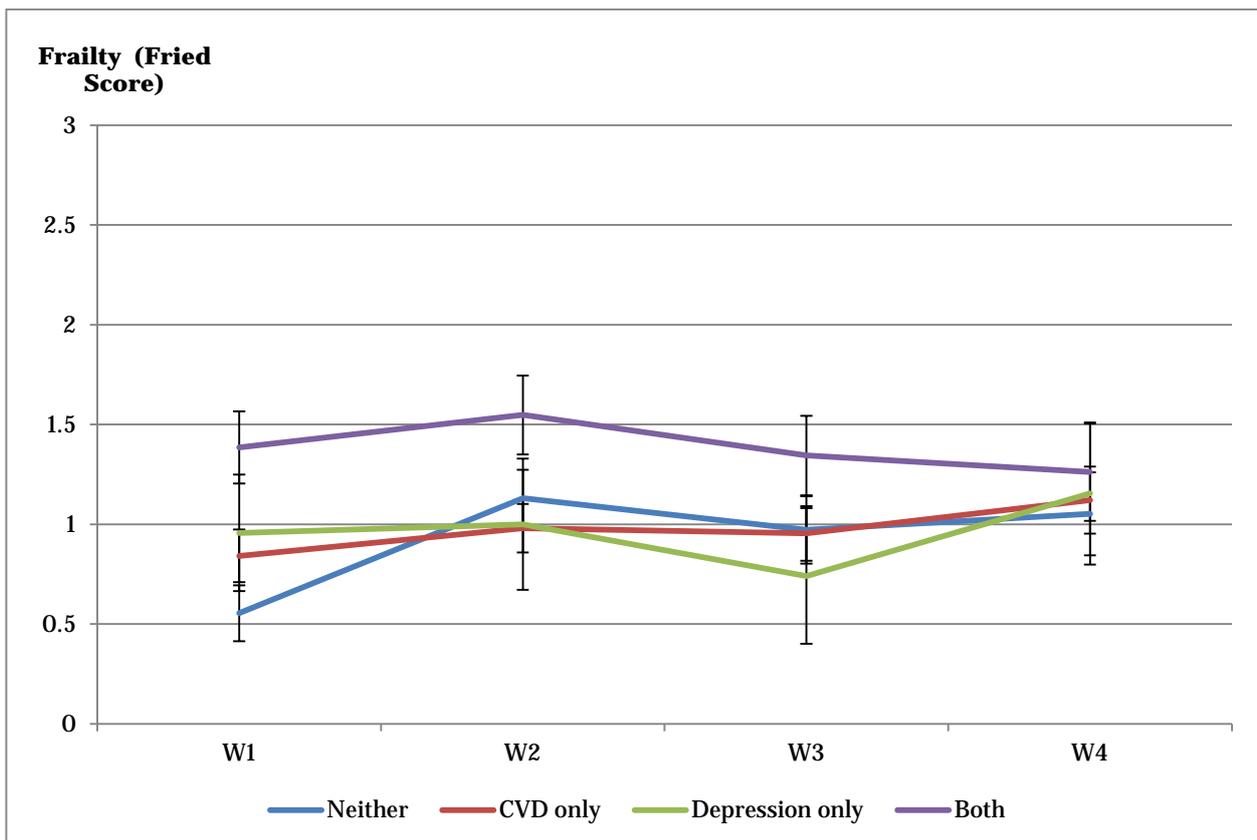
There was *no significant difference* in the depression/CVD-related differential in functional status between Māori and non-Māori, men and women nor by socioeconomic deprivation, adjusting for age, ethnic group, sex and wave of study (Appendix Table 5.8).

Frailty varied *significantly* with the presence or absence of depressive symptoms and CVD (Figure 5-9, Appendix Table 5.8). Those with both depressive symptoms and CVD were *significantly more likely* to be frail than those with neither, adjusting for age, ethnic group, sex and wave of the study. However, this difference attenuated over time and became less marked than was the case with functional status.

There was *no significant difference* in the depression/CVD-related differential for frailty scores between Māori and non-Māori, men and women, nor by socioeconomic deprivation, adjusting for age, ethnic group and sex (Appendix Table 5.8).

Those with depression or depression and CVD had *significantly lower* physical and mental HRQOL than did those with CVD only or with neither condition (Appendix Table 5.8) and this difference was not changed by ethnic group, sex or socioeconomic deprivation, adjusted for age and wave of study.

Figure 5-9: Cardiovascular disease and depression by frailty, Waves 1 to 4

Source: LiLACS NZ
Note: CVD - clinically evident cardiovascular disease.
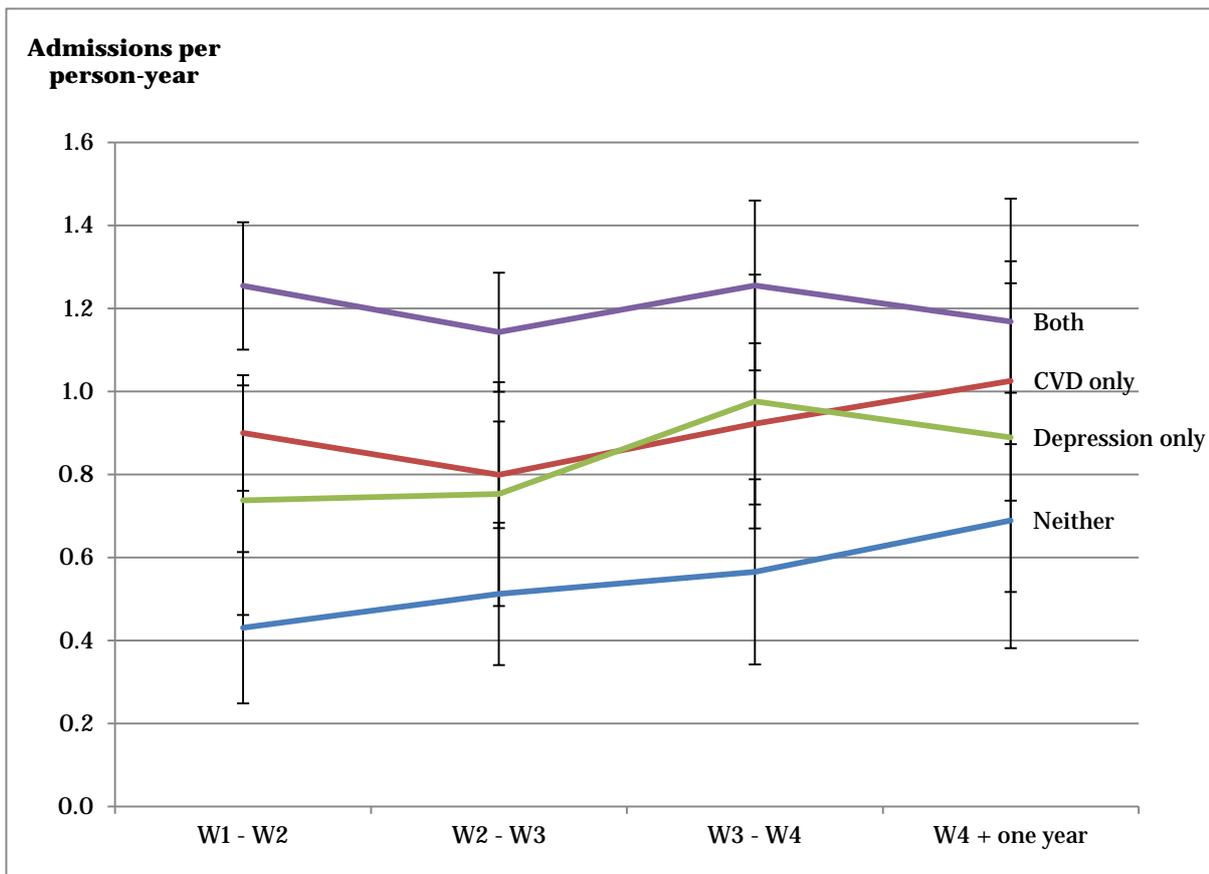
5.3.3 Depression associated with cardiovascular disease increased health service use and costs

Those with both depression and CVD had *significantly more* GP visits than those with either depression only or CVD only, adjusting for age, ethnic group, sex, and wave of the study (Appendix Table 5.8). Among the group with neither CVD nor depression, fewer than 10 percent paid more than four visits per year to their GP (7%), whereas around 27 percent of those with both conditions visited their GP more than four times a year.

There was *no difference* in the depression/CVD-related differential in GP visits between Māori and non-Māori, men and women or by socioeconomic deprivation, adjusting for age, ethnic group, sex and wave of study (Appendix Table 5.8).

In Wave 1, those with neither depressive symptoms nor CVD had approximately half the rate of hospital admissions of those with either condition; and those with both conditions had higher rates again (Figure 5-10, Appendix Table 5.9). Adjusting for age, sex, ethnic group and wave of the study, there were *significant differences* between the four groups. There was *no difference* in this pattern of depression/CVD-related hospital admissions between Māori and non-Māori, men and women, nor by socioeconomic deprivation, adjusting for age and wave (Appendix Table 5.9).

Figure 5-10: Cardiovascular disease and depression by hospital admissions, Waves 1 to 4

Source: LiLACS NZ
Note: CVD - clinically evident cardiovascular disease.

Not only did participants with depression and CVD have more hospital admissions, they also stayed *significantly longer* in hospital. On average they spent seven nights (6.9) per annum in hospital across all waves of the study compared to around three nights (2.7) for those with neither depression nor CVD (Appendix Table 5.10). Those who had depression only or CVD only had similar lengths of stay (4.4 and 4.8 days respectively).
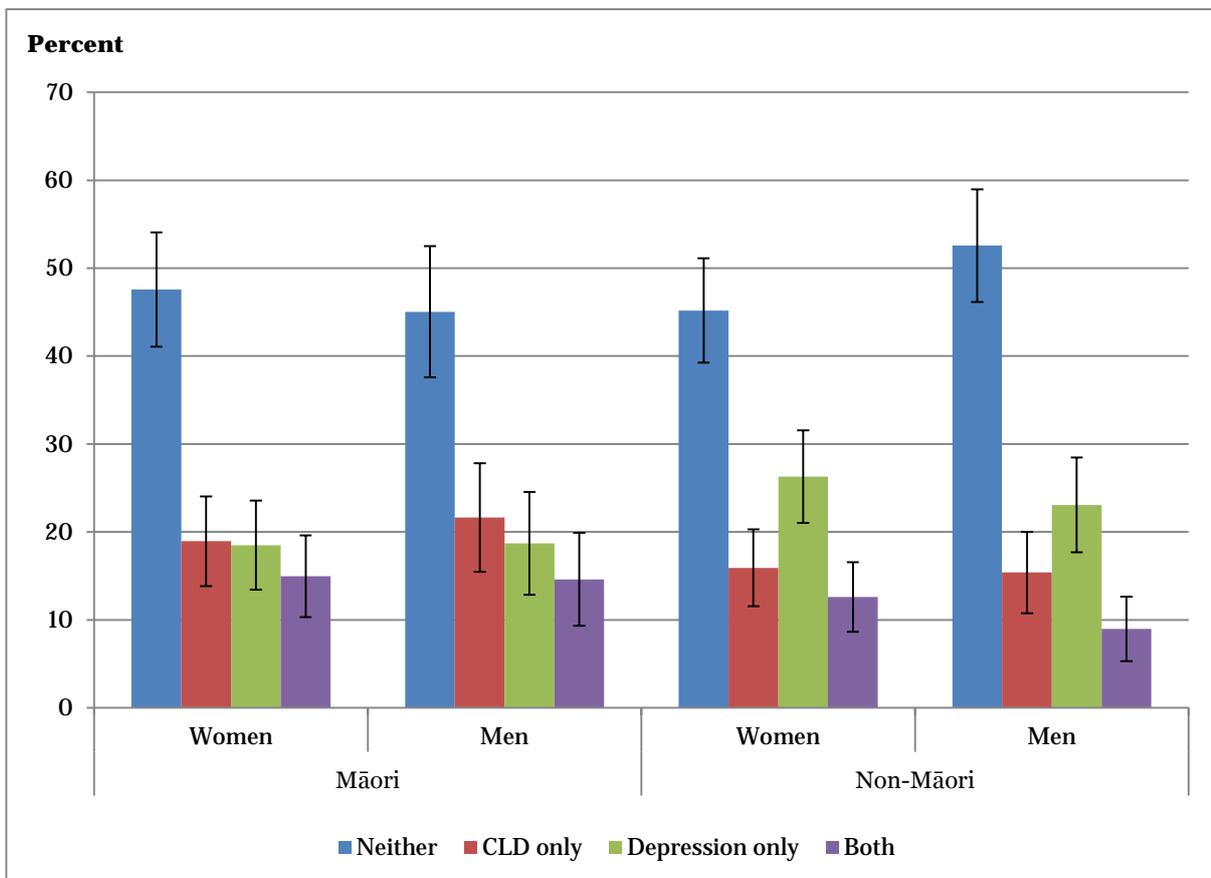
More frequent and longer hospitalisations meant costs were *significantly higher* for participants with depressive symptoms and CVD (an average of $6,947 over the study) compared to those with CVD alone ($5,090) or depression alone ($4,726) (Appendix Table 5.11).

5.4 Chronic lung disease and depression

5.4.1 Thirty percent of participants had chronic lung disease (CLD) and around ten percent had both depression and CLD

CLD was less common amongst LiLACS NZ participants than CVD; 30 percent of participants had CLD in Wave 1 of the study. *Significantly more* Māori (15%) had both depressive symptoms and CLD than did non-Māori (11%). Depression and CLD *did not differ significantly* between men and women, although fewer men (11%) than women (14%) had both conditions. Just under half of the participants had neither condition (Figure 5.11, Appendix Table 5.12).

Figure 5-11: Chronic lung disease and depression by ethnic group and sex, Wave 1
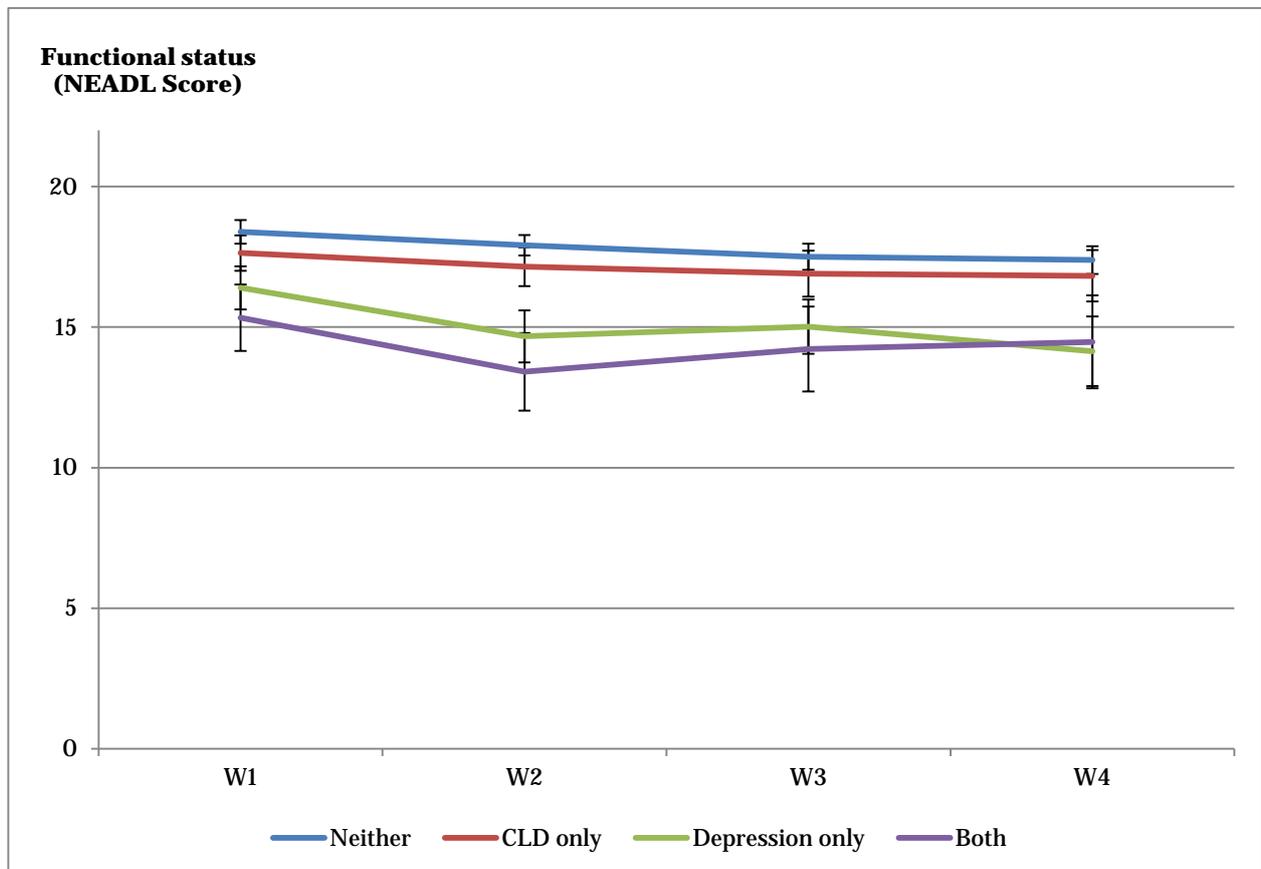
Source: LiLACS NZ
Note: CLD – chronic lung disease.

5.4.2 Depression increased the association of chronic lung disease with lower functional status, frailty and poorer quality of life

There was a *significant difference* in functional status between those with and those without CLD and depression, adjusting for age, ethnic group, sex and wave (Figure 5-12, Appendix Table 5.13). Those with neither CLD nor depression, as well as those with only CLD, had *significantly higher* functional status than those with both conditions or with depression only.

There was *no significant difference* in the depression/CLD-related differential in functional status between Māori and non-Māori, men and women, nor by socioeconomic deprivation, adjusting for age, ethnic group, sex and wave of study (Appendix Table 5.13).

Figure 5-12: Chronic lung disease and depression by functional status, Waves 1 to 4
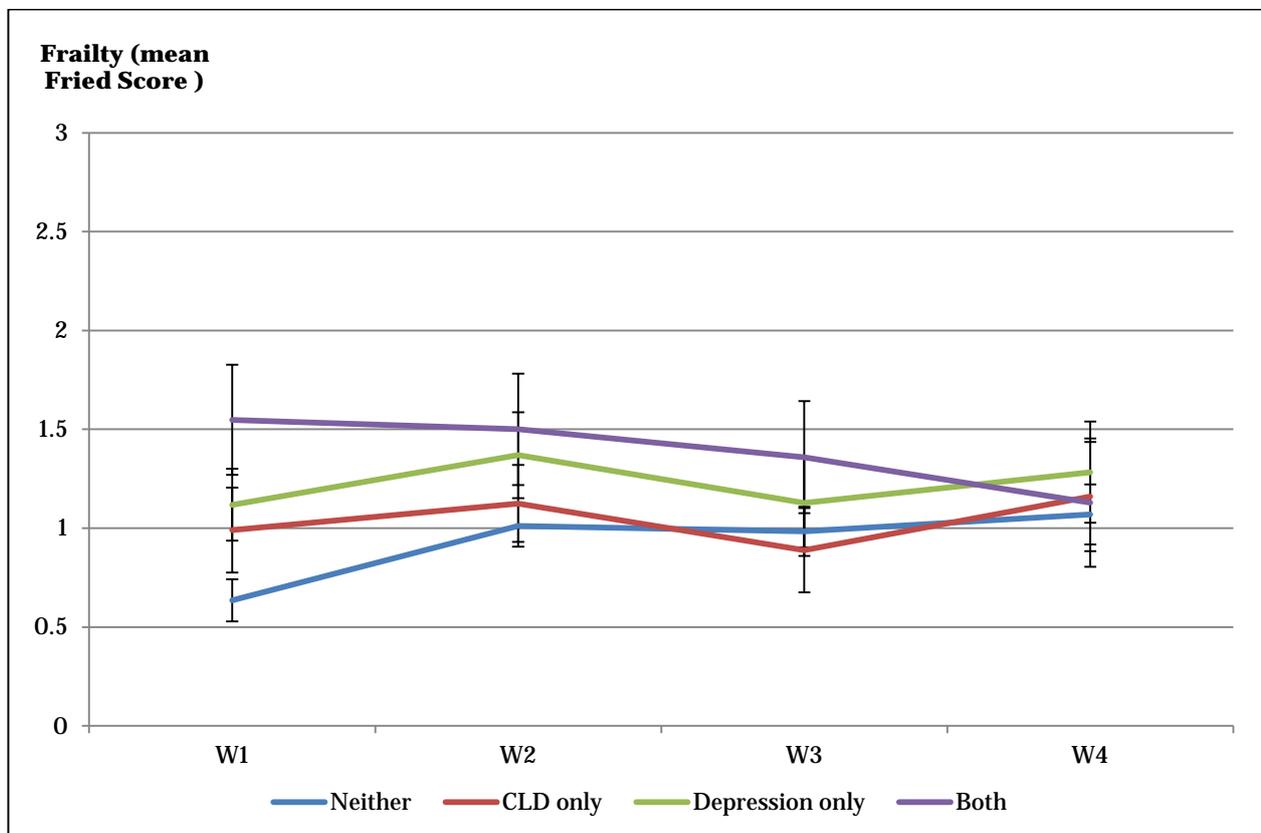
Source: LiLACS NZ
Note: CLD – chronic lung disease.

There was *a significant difference* in frailty between those with and those without CLD and depression, adjusting for age, ethnic group, sex and wave of study (Figure 5-13, Appendix Table 5.13). Those with neither CLD nor depression, as well as those with only CLD, were *significantly less frail* than those with both conditions or with depression only, although this relationship attenuated over time adjusting for age, ethnic group and sex. By Wave 4 there were fewer participants with both conditions. Those who dropped out of the study were more frail than those who continued, thus the apparent attenuation between those with both conditions and neither may have been due to the less well dropping out, rather than a true lessening in frailty level.

There were no differences in the depression/CLD-related differential in frailty between Māori and non-Māori, men and women, nor by socioeconomic deprivation, appropriately adjusting for age, ethnic group, sex and wave of study (Appendix Table 5.13).

Figure 5-13: Chronic lung disease and depression by Fried frailty score, Waves 1 to 4

 Source: LiLACS NZ
Note: CLD – chronic lung disease.

Those with depression or depression and CLD had *significantly lower* physical and mental HRQOL; those with CLD only or neither condition had *significantly higher* physical and mental HRQOL (Appendix Table 5.13).

There were no differences in the depression/CLD-related differential in HRQOL between Māori and non-Māori, men and women, nor by socioeconomic deprivation, appropriately adjusting for age, ethnic group and sex (Appendix Table 5.13).

5.4.3 Those with depression and CLD had increased health service use and costs
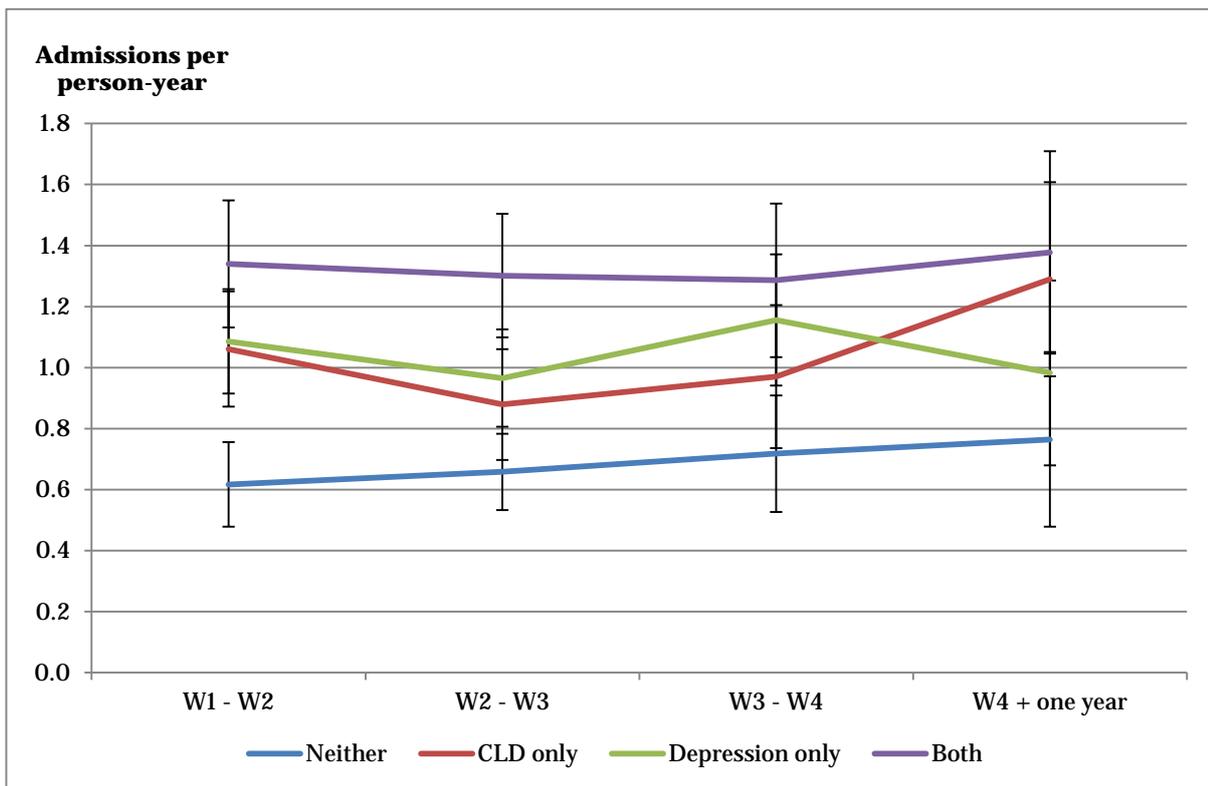
Participants with depression only were *significantly more likely* to visit GPs more than four times per annum than those with CLD only or those with neither condition (Appendix Table 5.13). Altogether, adjusting for age, ethnic group, sex and wave of the study, there was a *significant difference* between the four groups.

There was *no difference* in the depression/CLD-related differential on GP visits between Māori and non-Māori, men and women, nor by socioeconomic deprivation, adjusting for age, ethnic group and sex (Appendix Table 5.13).

Figure 5-14 shows annual hospital admissions for people with or without CLD and depressive symptoms (Appendix Table 5.14). Adjusting for age, ethnic group, sex, and wave of the study, there was *a significant difference* between the four groups. Those with neither condition had *significantly fewer* admissions per year than all other groups and those with both conditions had *significantly more* admissions.

There was *no difference* in the pattern of depression/CLD-related hospital admissions between Māori and non-Māori, men and women, nor by socioeconomic deprivation, adjusting for age, ethnic group, sex and wave of study (Appendix Table 5.14).

Figure 5-14: Chronic lung disease and depression by hospital admissions, Waves 1 to 4

Source: LiLACS NZ
Note: CLD – chronic lung disease.

Those with neither CLD nor depression had a *significantly shorter* length of stay in hospital than the other groups (Appendix Table 5.15).
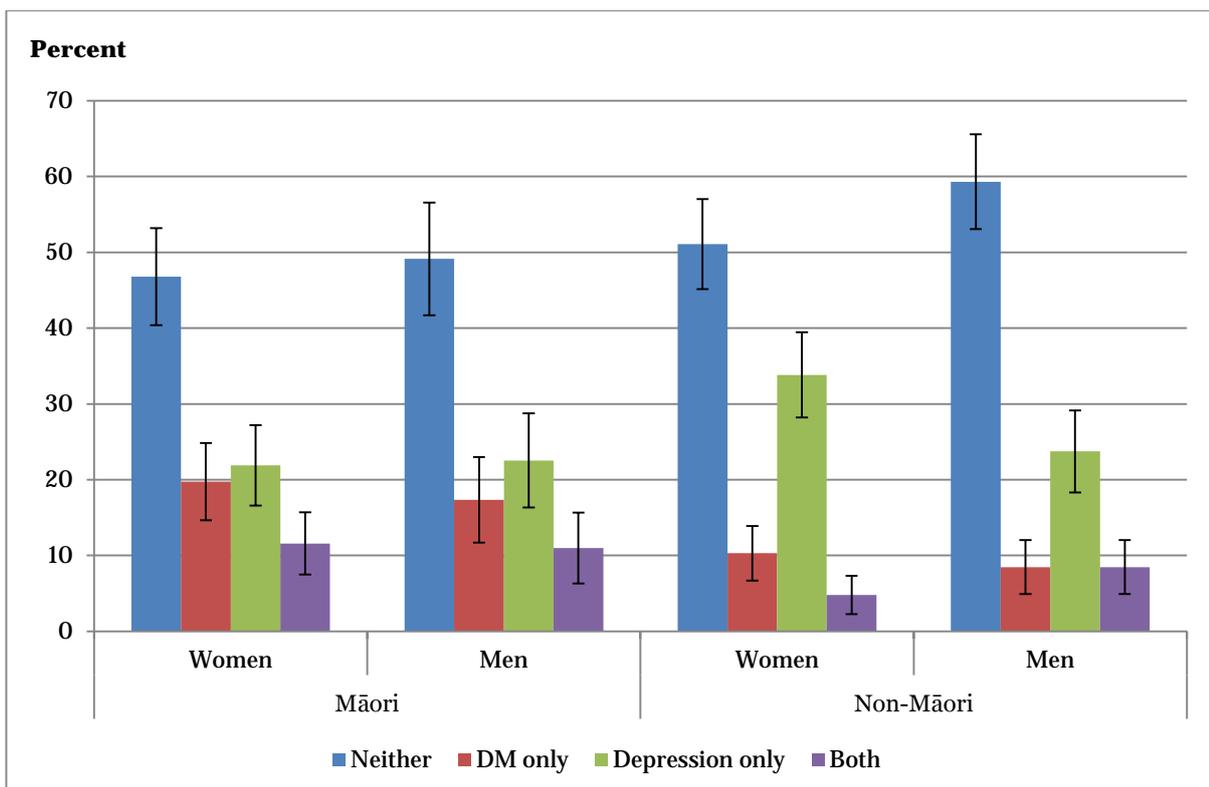
More frequent and longer hospitalisations meant increased costs for participants with both depressive symptoms and CLD (averaging $7,256 across the study) (Appendix Table 5.16). Costs of hospitalisation for those with depression only ($6,205) and CLD only ($5,370) were *significantly less* than costs for those with both conditions.

5.5 Diabetes mellitus and depression

5.5.1 Around 22 percent of participants had diabetes mellitus (DM) and 9 percent had both depression and DM

DM was also less common amongst LiLACS NZ participants than CVD; 22 percent of participants in Wave 1 of the study had DM, *significantly more* Māori (30%) than non-Māori (16%). There was no significant difference in the proportion of Māori who had both depressive symptoms and DM (11%) compared to non-Māori (7%). Ten percent of men and 8 percent of women had both depression and DM. Around half of the participants had neither condition (52%) (Figure 5-15, Appendix Table 5.17).

Figure 5-15: Diabetes mellitus and depression by ethnic group and sex, Wave 1

Source: LiLACS NZ
Note: DM – diabetes mellitus.

5.5.2 Depression increased the association of DM with lower functional status, frailty and poorer quality of life
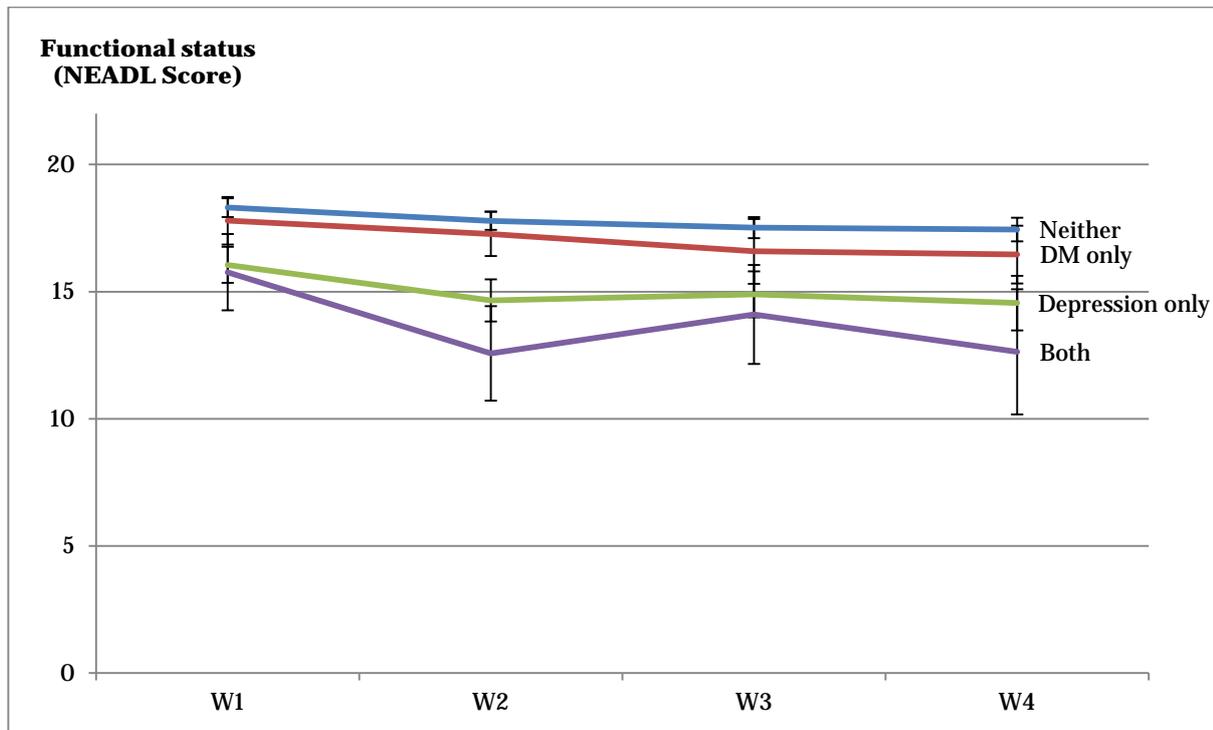
In relation to functional status, there was a significant difference between those with and those without DM and depression, adjusting for age, ethnic group, sex and wave (Figure 5-16, Appendix Table 5.18). Those with neither DM nor depression, as well as those with DM only, had *significantly higher* functional status than those with both conditions or with depression only.

There was *no difference* in the depression/ DM-related differential in functional status scores between Māori and non-Māori, men and women, nor by socioeconomic deprivation, adjusting for age, ethnic group, sex and wave of study (Appendix Table 5.18).

Those without DM or depression, as well as those with DM only, were *significantly less* frail than those with both conditions or with depression only, adjusting for age, ethnic group, sex and wave of study (Figure 5-17, Appendix Table 5.18).
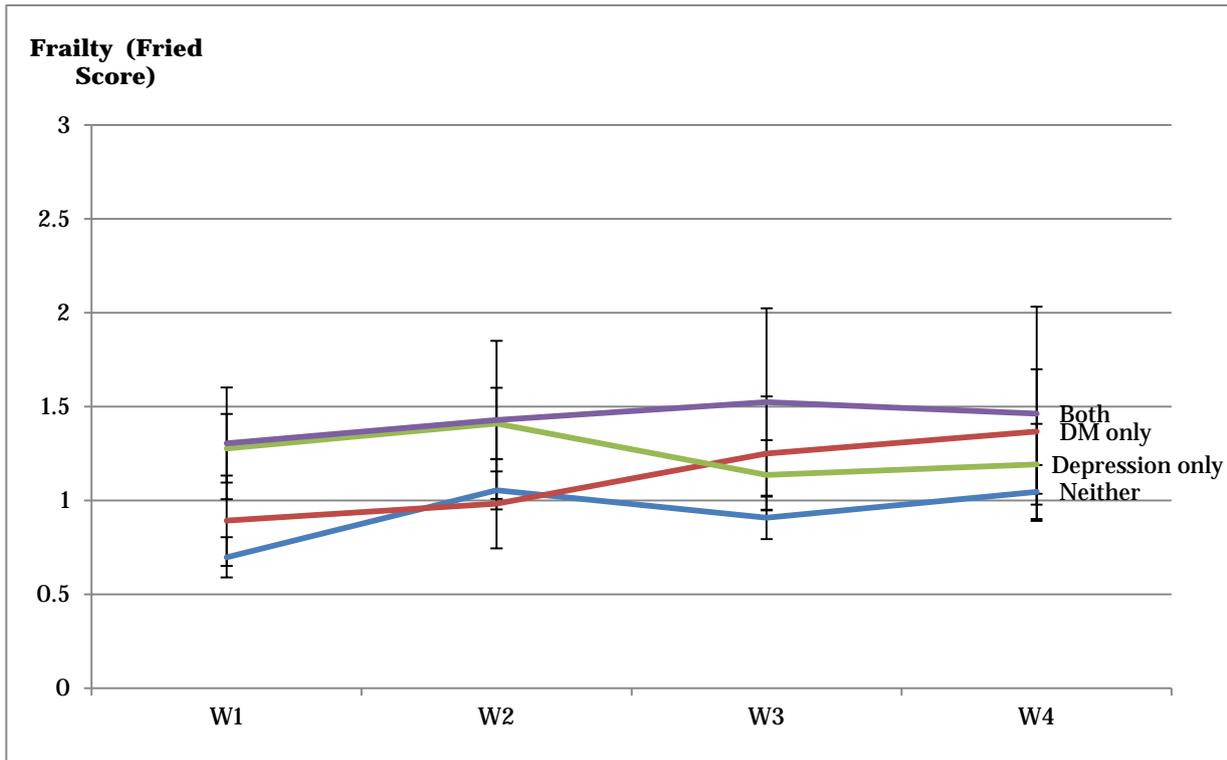
The frailty score for those with DM increased over time.

Figure 5-16: Diabetes mellitus and depression by functional status, Waves 1 to 4

Source: LiLACS NZ
Note: DM – diabetes mellitus.

Figure 5-17: Diabetes mellitus and depression by Fried frailty score, Waves 1 to 4

Source: LiLACS NZ
Note: DM – diabetes mellitus.

There were *no differences* in the pattern of the relationship between frailty and DM and depression between Māori and non-Māori, men and women, nor by socioeconomic deprivation, adjusting for age, ethnic group, sex and wave of study (Appendix Table 5.18).

Those with depression or depression and DM had *significantly lower* physical and mental HRQOL than those with DM only or neither condition (Appendix Table 5.18).

There were *no differences* in the pattern of the relationship between HRQOL scores and DM and depression, between Māori and non-Māori, men and women, nor by socioeconomic deprivation, adjusting for age, ethnic group, sex and wave of study (Appendix Table 5.18).
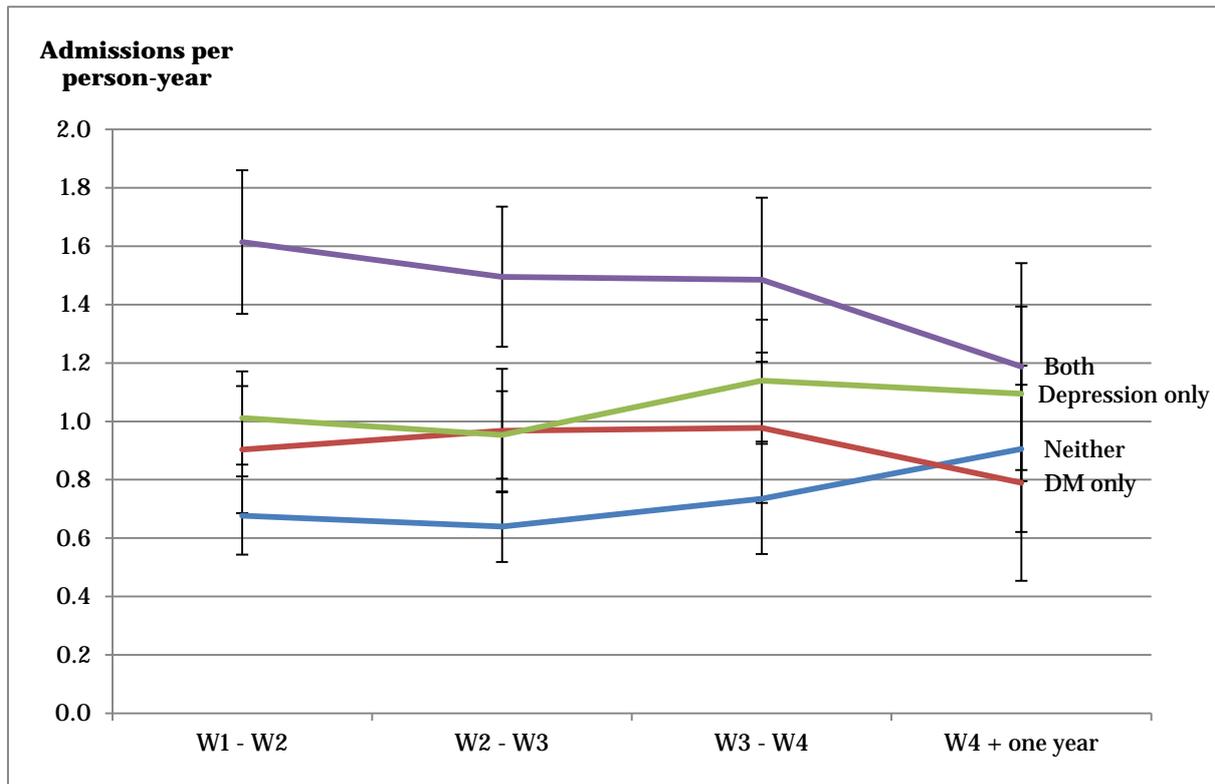
5.5.3 Those with depression and DM had increased health service use and costs

Participants with both depression and DM were *significantly more likely* to visit GPs more than four times per annum throughout the study than those with neither condition (Appendix Table 5.18), adjusting for age, ethnic group, sex and wave of the study.

There were *no differences* in the relationship between GP visits and DM and depression, between Māori and non-Māori, men and women, or by socioeconomic deprivation, adjusting for age, ethnic group and sex (Appendix Table 5.18).

Figure 5-18 shows annual hospital admissions for people with or without DM and depressive symptoms (Appendix Table 5.19). Adjusting for age, ethnic group, sex, and wave of the study, there was a significant difference between the four groups. Admissions per year were *significantly lower* for those with neither condition or with DM only, and those with depression only or both conditions had the most admissions. This difference attenuated over time adjusting for age, ethnic group and sex.

Figure 5-18: Diabetes mellitus and depression by hospital admissions, Waves 1 to 4

Source: LiLACS NZ
Note: DM – diabetes mellitus.

There was *no difference* between Māori and non-Māori, or between men and women in the ways depression and DM interacted in relation to hospital admissions. There was a *significant difference* by socioeconomic deprivation, adjusting for age, ethnic group and sex. Those with neither condition or with depression only had *significantly lower* rates of hospital admission if living in moderate socioeconomic deprivation compared with those living in high or low socioeconomic deprivation, a finding that is not easy to interpret.

Those with neither DM nor depression had *significantly shorter* lengths of stay in hospital than those with both conditions (Appendix Table 5.20).

More frequent and longer hospitalisations meant increased costs associated with participants with depressive symptoms and DM (Appendix Table 5.21). Those with both conditions had hospital costs across the study averaging $7,187 annually, compared to costs for those with DM alone ($5,590) and those with depression alone ($5,734).

5.6 Comparison of the relationships between depression, CVD, CLD and DM

CVD was the most prevalent condition amongst LiLACS NZ participants.

LiLACS NZ participants with depression alone had worse functional status and more frailty than those with CVD, CLD or DM alone. They had lower HRQOL than those without depression. Those with CVD alone had the lowest physical HRQOL, most frequent GP visits, most hospital admissions and highest hospital costs. Those with CLD alone had the longest stays in hospital.

Having depression was associated with more frequent hospitalisations compared to those without depression and the increased hospitalisations were similar in scale to hospitalisations for people who had CVD, CLD or DM (although this association changed over time).

'I have accomplished what I set out to do. I'm living a satisfactory life and I don't wish for anything more.'

The combination of depression and other common chronic conditions was associated with a greater functional and HRQOL burden than the chronic condition alone.

Those with a combination of depression and any of the common chronic conditions had greater hospital-related costs than those with any of the conditions alone.

Looking at the three conditions in combination with depression, CVD with depression was associated with the lowest mental HRQOL and CLD with depression was associated with the lowest physical HRQOL. DM with depression was associated with the poorest status on all other health indicators, but the combinations of depression with another condition in each instance gave similar results. The importance of depression as a driver of poorer health status and increased health service use is signified by the data in this section of the report and deserves further exploration with later waves of LiLACS NZ data.

While it is not possible to establish whether it is the depression that makes the impact of the chronic condition worse, or the chronic condition that makes the impact of the depression worse, it is clear that the combination leads to worse outcomes for older people. The prevalence of CVD is very high in this age group, and about one-third have depression. Chronic lung disease is less common but the health services use related to this condition is high.

Depression may also be related to incidents or ongoing psychological or health events and will be a topic of further work with the LiLACS NZ data sets.

From the analyses in this report, clinicians and planners may be prompted to think more systematically about the combination of chronic disease with depression. Finding the best strategy to reduce the impact of chronic disease and depression will require evaluation of trials to screen for and manage depression in the context of chronic disease management and also to focus on the management of chronic disease for people with depression.

5.7 Key findings

- Depressive symptoms were present in 35 percent of LiLACS NZ participants at any one time throughout the study; but there were many individuals who improved or worsened over time.

- Depression was associated with lower functional status, higher frailty and poorer health-related quality of life.

- Depression was associated with higher health service use and cost.

- Around four in ten participants had cardiovascular disease (CVD) and around one-quarter had both depressive symptoms and CVD.

- Depression increased the negative impact of CVD on functional status, frailty and quality of life.

- Depression associated with CVD increased health service use and costs.

- Thirty percent of participants had chronic lung disease (CLD) and around 13 percent had both CLD and depression.

- Depression increased the negative impact of CLD on functional status, frailty and quality of life.

- Depression associated with CLD increased health service use and costs.

- Around 22 percent of participants had diabetes mellitus (DM) and 9 percent had both depression and DM.

- Depression increased the negative impact of DM on functional status, frailty and quality of life.

- Depression associated with DM increased health service use and costs.

- Depression magnified the association, for each condition, with poorer health status and increased health service use and costs. Since CVD was the most prevalent condition, depression in relation to CVD contributed the most to negative outcomes for LiLACS NZ participants.

Glossary

advanced age	term used for our study population
adjusting	a statistical method for dealing with confounding variables, such as sex, ethnicity or socioeconomic deprivation
COPE index	a validated measure of carer support and carer stress
core questionnaire	the short three-page LiLACS NZ questionnaire
DHB	District Health Board
dyad	a LiLACS NZ participant matched with their carer
EQ-5D-3L	a health status questionnaire
Fried frailty assessment	an assessment of frailty, giving a score; frailty is defined as having three of five key deficits: slowness, weakness, weight loss, fatigue and low activity
full questionnaire	the full 72-page LiLACS NZ questionnaire
HRQOL	health-related quality of life, measured by the SF-12
kaiāwhina	carer
kaitiaki	guardians
kaumātua	Māori elders
kaupapa Māori process	a Māori methodology that enhances, protects and conserves te reo Māori me ngā tikanga Māori/Māori language and culture
koha	gift
LiLACS NZ	*Te Puāwaitanga O Ngā Tapuwae Kia Ora Tonu/* Life and Living in Advanced Age, a Cohort Study in New Zealand
NHI	National Health Index, a unique identifier assigned to everyone using New Zealand health or disability services
NZHIS	New Zealand Health Information Service
NEADL	Nottingham Extended Activities of Daily Living scale, which asks questions about everyday activities in order to assess dependence
NMDS	National Minimum Data Set, New Zealand's national hospital discharge data collection

NZDep	New Zealand Deprivation Index, a census-derived tool to estimate the relative socioeconomic deprivation of an area
QOL	quality of life
Rōpū Kaitiaki o ngā Tikanga Māori	LiLACS NZ guardianship group (referred to in the text as 'Rōpū Kaitiaki')
rūnunga	Māori tribal organisation
SF-12	a 12-item shorter version of the SF-36 questionnaire, widely used as a measure of quality of life; both versions can generate separate physical and mental composite scores
socioeconomic deprivation	as measured by NZDep, see above
te reo Māori	Māori language
whānau	extended family

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Appendix 1.1: Section 1 technical tables

Appendix Table 1.1: Retention and reasons for withdrawal from LiLACS NZ

	Total enrolled*	Wave 1 - Wave 2 n (%)						
		Death n (%)	Moved away n (%)	Refused contact n (%)	Other reason n (%)	Poor health n (%)	Preference n (%)	None stated n (%)
Māori	421	36 (9)	6 (1.4)	17 (4)	5 (1.2)	19 (4.5)	41 (9.7)	19 (4.5)
Women	244	20 (8)	3 (1.2)	13 (5.3)	3 (1.2)	11 (4.5)	24 (9.8)	10 (4.1)
Men	177	16 (9)	3 (1.7)	4 (2.3)	2 (1.1)	8 (4.5)	17 (9.6)	9 (5.1)
Non-Māori	516	37 (7)	4 (0.7)	6 (1.2)	2 (0.4)	23 (4.5)	29 (5.6)	11 (2.1)
Women	279	15 (5)	3 (1)	3 (1.1)	1 (0.3)	15 (5.4)	19 (6.8)	7 (2.5)
Men	237	22 (9)	1 (0.4)	3 (1.3)	1 (0.4)	8 (3.4)	10 (4.2)	4 (1.7)
TOTAL	937	73 (8)	10 (1.1)	23 (2.5)	7 (0.7)	42 (4.5)	70 (7.5)	30 (3.2)
n (% of retained previous year)		**Wave 2 - Wave 3** **n (%)**						
Māori	278 (66)	33 (12)	2 (0.7)	0	0	11 (4)	22 (7.9)	1 (0.4)
Women	160 (66)	11 (7)	2 (1.3)	0	0	9 (5.6)	10 (6.3)	0
Men	118 (67)	22 (19)	0	0	0	2 (1.7)	12 (10.2)	1 (0.8)
Non-Māori	403 (78)	29 (7)	1 (0.2)	1 (0.2)	0	9 (2.2)	13 (3.2)	0
Men	188 (79)	14 (7)	0	1 (0.5)	0	3 (1.6)	8 (4.3)	0
Women	215 (77)	15 (7)	1 (0.5)	0	0	6 (2.8)	5 (2.3)	0
TOTAL	681 (73)	62 (9)	3 (0.4)	1 (0.2)	0	20 (2.9)	35 (5.1)	1 (0.2)
n (% of retained previous year)		**Wave 3 - Wave 4** **n (%)**						
Māori	209 (75)	21 (10)	2 (1.0)	0	0	5 (2.4)	12 (5.7)	0
Women	128 (80)	12 (9)	0	0	0	5 (3.9)	6 (4.7)	0
Men	81 (69)	9 (11)	2 (2.5)	0	0	0	6 (7.4)	0
Non-Māori	350 (87)	32 (9)	1 (0.3)	0	0	12 (3.4)	14 (4.0)	0
Women	188 (87)	16 (9)	0	0	0	5 (2.7)	10 (5.3)	0
Men	162 (86)	16 (10)	1 (0.6)	0	0	7 (4.3)	4 (2.5)	0
TOTAL	559 (82)	53 (9)	3 (0.5)	0	0	17 (3.0)	26 (4.7)	0

*includes those not participating in current wave but enrolled in study.

Appendix 1.2: LiLACS NZ questions made use of in this report

Box 1 - Section 1

Code	Question	Options
AA2.	Sex	1 = Male 2 = Female
AA3.	Who do you live with most of the time?	1 = alone 2 = with spouse/partner only 3 = with spouse and child/other relative 4 = with spouse and non-relatives 5 = with child (not spouse) 6 = with other(s) not spouse or children
AB2.	Which ethnic group(s) do you belong to: Māori?	0 = No 1 = Yes
AF22.	What is your current marital status?	1 = I have never been married/partnered 2 = Married/ partnered 3 = Widow/Widower 4 = Separated 5 = Divorced
IA4.	I'd like to check how this accommodation is owned or rented. Do you…?	1 = Own it outright yourself or with spouse/partner 2 = Still pay a mortgage or loan yourself or with spouse/partner 3 = Rent (Private) 4 = Rent (Public) e.g. State or local council 5 = Pay part rent and part mortgage 6 = Live here rent free 7 = Other 8 = License to occupy
AA3.	Who do you live with most of the time?	1 = alone 2 = with spouse/partner only 3 = with spouse and child/other relative 4 = with spouse and non-relatives 5 = with child (not spouse) 6 = with other(s) not spouse or children
AA4.	What best describes your home?	1 = private dwelling, stand alone house 2 = private unit or apartment – independent 3 = unit or apartment on site with family dwelling 4 = retirement village – villa or own unit 5 = rest home 6 = private hospital (own or shared room) 7 = marae or iwi based housing 8 = other
A10.	Do you live in a rest home/private hospital?	0 = No 1 = Yes
AC1_m.	Could you have a conversation about a lot of everyday things...in Māori?	0 = No 1 = Yes
CC1.	Do you smoke or have you ever smoked cigarettes?	0 = never a smoker 1 = current 2 = past

Box 2 - Section 2

Code	Question	Options
AA2.	Sex	1 = Male 2 = Female
AB2.	Which ethnic group(s) do you belong to:	
	Māori	0 = No 1 = Yes
AF10.	Have you ever had children?	0 = No 1 = Yes
AF11.	How many sons currently living do you have?	
AF13.	How many daughters currently living do you have?	
AF16.	Do you have grandchildren?	0 = No 1 = Yes
AF16a.	How many?	
AF17.	Do you have great-grandchildren?	0 = No 1 = Yes
AF17a.	How many?	
AF18.	Do you have great-great-grandchildren?	0 = No 1 = Yes
AF18a.	How many?	
AF19.	How do you currently contribute to the development of your grandchildren or great-grandchildren?	
	Financial contributions	0 = No 1 = Yes
	Occasional support	0 = No 1 = Yes
	Shared parenting	0 = No 1 = Yes
	I am raising grandchildren as a parent	0 = No 1 = Yes
	Teach them my first language	0 = No 1 = Yes
	Emotional support/Love	0 = No 1 = Yes
	Other	0 = No 1 = Yes
AG7.	Are you in paid work now?	0 = No 1 = Yes
AG9.	Do you do any unpaid/voluntary work outside the household now?	0 = No 1 = Yes
AG9a.	What work do you do now?	
AG10.	During the past 7 days, did you work for pay or as a volunteer?	1 = No 2 = Yes, for pay 3 = Yes, as a volunteer 4 = Yes for pay and as a volunteer*
BC1a.	Do you walk around outside?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC1b.	Do you climb stairs?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC1c.	Do you get in and out of the car?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC1d.	Do you walk over uneven ground?	0 = No 1 = with help 2 = on my own; on my own with difficulty*

Code	Question	Options
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC1e.	Do you cross roads?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC1f.	Do you travel on public transport?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC2a.	Do you manage to feed yourself?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC2b.	Do you manage to make yourself a hot drink?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC2c.	Do you take hot drinks from one room to the other?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC2d.	Do you do the washing up?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC2e.	Do you make yourself a hot snack?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC3a.	Do you manage your own money when you are out?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC3b.	Do you wash small items of clothing?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC3c.	Do you do your own housework?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC3d.	Do you do your own shopping?	0 = No 1 = with help 2 = on my own; on my own with difficulty*

Code	Question	Options
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC3e.	Do you do a full clothes wash?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC4a.	Do you read newspapers or books?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC4b.	Do you use the telephone?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC4c.	Do you write letters?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC4d.	Do you go out socially?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC4e.	Do you manage your own garden?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC4f.	Do you drive a car?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC5a.	Do you manage your personal care for instance brushing your teeth and hair, washing your hands and face?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC5b.	Do you manage to go to the toilet?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC5c.	Do you get in/out of bed?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC5d.	Do you shower/bath yourself?	0 = No 1 = with help 2 = on my own; on my own with difficulty*

Code	Question	Options
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC5e.	Do you dress yourself?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
GC10.	Do you receive any regular support service	0 = No 1 = Yes
	Receive Any meal service	0 = No 1 = Yes
	Receive Home Help (cleaning)	0 = No 1 = Yes
	Receive Home Help (shopping)	0 = No 1 = Yes
	Receive Home Help (gardening)	0 = No 1 = Yes
	Receive Personal Care	0 = No 1 = Yes
	Receive Other	0 = No 1 = Yes*
GC12.	How often do you currently provide care or assistance for other people?	0 = Never 1 = Occasionally 2 = Once a week 3 = Two to five times weekly 4 = Daily*
GC13a.	Do you give care or assistance for…Financial help	0 = No 1 = Yes
	Who do you give help to? Someone in same household	0 = No 1 = Yes
	Who do you give help to? Family other household	0 = No 1 = Yes
	Who do you give help to? Other	0 = No 1 = Yes
GC13b.	Do you give care or assistance for…Transport	0 = No 1 = Yes
	Who do you give help to? Someone in same household	0 = No 1 = Yes
	Who do you give help to? Family other household	0 = No 1 = Yes
	Who do you give help to? Other	0 = No 1 = Yes
GC13c.	Do you give care or assistance for…Shopping	0 = No 1 = Yes
	Who do you give help to? Someone in same household	0 = No 1 = Yes
	Who do you give help to? Family other household	0 = No 1 = Yes
	Who do you give help to? Other	0 = No 1 = Yes
GC13d.	Do you give care or assistance for…Child care	0 = No 1 = Yes
	Who do you give help to? Someone in same household	0 = No 1 = Yes
	Who do you give help to? Family other household	0 = No 1 = Yes
	Who do you give help to? Other	0 = No 1 = Yes
GC13e.	Do you give care or assistance for…Personal care	0 = No 1 = Yes
	Who do you give help to? Someone in same household	0 = No 1 = Yes
	Who do you give help to? Family other household	0 = No 1 = Yes
	Who do you give help to? Other	0 = No 1 = Yes
GC13f.	Do you give care or assistance for…Other	0 = No 1 = Yes
	Who do you give help to? Someone in same household	0 = No 1 = Yes
	Who do you give help to? Family other household	0 = No 1 = Yes
	Who do you give help to? Other	0 = No 1 = Yes

Box 3 - Section 3

Code	Question	Options
AA2.	Sex	1 = Male 2 = Female
AB2.	Which ethnic group(s) do you belong to:	
	Māori	0 = No 1 = Yes
BC1a.	Do you walk around outside?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC1b.	Do you climb stairs?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC1c.	Do you get in and out of the car?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC1d.	Do you walk over uneven ground?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC1e.	Do you cross roads?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC1f.	Do you travel on public transport?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC2a.	Do you manage to feed yourself?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC2b.	Do you manage to make yourself a hot drink?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC2c.	Do you take hot drinks from one room to the other?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC2d.	Do you do the washing up?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes

Code	Question	Options
	Help received from family outside the household	0 = No 1 = Yes
BC2e.	Do you make yourself a hot snack?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC3a.	Do you manage your own money when you are out?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC3b.	Do you wash small items of clothing?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC3c.	Do you do your own housework?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC3d.	Do you do your own shopping?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC3e.	Do you do a full clothes wash?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC4a.	Do you read newspapers or books?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC4b.	Do you use the telephone?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC4c.	Do you write letters?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC4d.	Do you go out socially?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC4e.	Do you manage your own garden?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes

Code	Question	Options
	Help received from family outside the household	0 = No 1 = Yes
BC4f.	Do you drive a car?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC5a.	Do you manage your personal care for instance brushing your teeth and hair, washing your hands and face?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC5b.	Do you manage to go to the toilet?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC5c.	Do you get in/out of bed?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC5d.	Do you shower/bath yourself?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
BC5e.	Do you dress yourself?	0 = No 1 = with help 2 = on my own; on my own with difficulty*
	Help received from someone in the same household	0 = No 1 = Yes
	Help received from family outside the household	0 = No 1 = Yes
GC10.	Do you receive any regular support service	0 = No 1 = Yes*
	Receive Any meal service	0 = No 1 = Yes*
	Receive Home Help (cleaning)	0 = No 1 = Yes*
	Receive Home Help (shopping)	0 = No 1 = Yes*
	Receive Home Help (gardening)	0 = No 1 = Yes*
	Receive Personal Care	0 = No 1 = Yes*
	Receive Other	Specify …

Box 4 - Section 4

Code	Question	Options
LiLACS NZ Questionnaire		
AA2.	Sex	1 = Male 2 = Female
AB2.	Which ethnic group(s) do you belong to:	
	Māori	0 = No 1 = Yes
GC1.	When you need some extra help, can you count on anyone to help with daily tasks	
GC3.	Could you have used more help with daily tasks than you received	
GC15.	Regardless of how you answered the previous questions, who has provided you the most help, care and support in the last 3 months?	1 = Spouse 2 = Daughter 3 = Son 4 = Sibling 5 = Other relative 6 = Your neighbours 7 = Co-workers 8 = Church members 9 = Club members 10 = Professionals 11 = Any friend not included in these categories 12 = No-one
GC15a.	Are you comfortable for us to contact this person to speak to about the ways he/she has given you the help, care and support in the last 3 months?	0 = No 1 = Yes
GC15b.	Can I have his/her contact details to ask if he/she would be willing to take part in a study of their experience of providing this help, care and support to you?	0 = No 1 = Yes 2 = Don't know details
GC15c.	Is there anyone else you would like to name (particularly if the first named carer is a paid "formal care worker")?	0 = No 1 = Yes
GC15e.	Last year we contacted... Is this the same person?	0 = No 1 = Yes
Kaiāwhina Questionnaires: Formal and Informal Caregivers		
CR1.	Caregiver Status	1=Informal 2=Formal
CR2.	Sex	1 = Male 2 = Female
CR3a.	Age	
CR4_m.	Māori	0 = No 1 = Yes
CR5.	Would you say your health is:	1 = Very good 2 = Good 3 = Fair 4 = Poor 5 = Very Poor
Kaiāwhina Questionnaires: Informal Caregivers only		
CR6.	What is your relationship to the person you care for?	1 = Spouse / Partner 2 = Sibling 3 = Daughter / Son 4 = Daughter / Son -in-law 5 = Other family 6 = Friend / Neighbour 7 = Grandchild
CR7.	Your occupational status:	1 = Employed full-time 2 = Employed part-time 3 = Retired 4 = Not in paid employment 5 = Full-time student
CR7a.	Are you receiving?	0 = None 1 = Carer's benefit 2 = Other benefit 3 = Other support (specify)
CR8.	Where do you live in proximity to [name of the Participant]?	1 = In the same household as [name of the Participant] 2 = In different household but the same property as [name of the Participant] 3 = Within walking distance of [name of the Participant] 4 = Within 10 minutes' drive/bus journey 5 =Between 10 and 30 minutes' drive/bus journey 6 = Within 1 hour drive/bus, plane journey 7 = Over 1

Code	Question	Options
		hour drive/bus, plane journey. 8 = In South Island 9 = Overseas
CR9a.	How often have you done each of the following for [LiLACS NZ participant] in the past 3 months? Personal care	1 = Daily 2 = Several times a week 3 = Once a week 4 = Several times a month 5 = Once a month or less 6 = Never
CR9b.	Household assistance	1 = Daily 2 = Several times a week 3 = Once a week 4 = Several times a month 5 = Once a month or less 6 = Never
CR9b1_1.	How often are you involved in the following? Food choices	1 = Daily 2 = Several times a week 3 = Once a week 4 = Several times a month 5 = Once a month or less 6 = Never
CR9b1_2.	Food shopping	1 = Daily 2 = Several times a week 3 = Once a week 4 = Several times a month 5 = Once a month or less 6 = Never
CR9b1_3.	Food preparation	1 = Daily 2 = Several times a week 3 = Once a week 4 = Several times a month 5 = Once a month or less 6 = Never
CR9b1_4.	Cooking of meals	1 = Daily 2 = Several times a week 3 = Once a week 4 = Several times a month 5 = Once a month or less 6 = Never
CR9b1_5.	Preparing drinks and snacks	1 = Daily 2 = Several times a week 3 = Once a week 4 = Several times a month 5 = Once a month or less 6 = Never
CR9b1_6.	Sharing in the eating of meals	1 = Daily 2 = Several times a week 3 = Once a week 4 = Several times a month 5 = Once a month or less 6 = Never
CR9c.	Administrative/Legal Support	1 = Daily 2 = Several times a week 3 = Once a week 4 = Several times a month 5 = Once a month or less 6 = Never
CR9d.	Social and Emotional Support	1 = Daily 2 = Several times a week 3 = Once a week 4 = Several times a month 5 = Once a month or less 6 = Never
CR9e.	Cultural Support	1 = Daily 2 = Several times a week 3 = Once a week 4 = Several times a month 5 = Once a month or less 6 = Never
CR9f.	Spiritual Support	1 = Daily 2 = Several times a week 3 = Once a week 4 = Several times a month 5 = Once a month or less 6 = Never
CR9g.	Family Support	1 = Daily 2 = Several times a week 3 = Once a week 4 = Several times a month 5 = Once a month or less 6 = Never
CR9h.	Transport to health services	1 = Daily 2 = Several times a week 3 = Once a week 4 = Several times a month 5 = Once a month or less 6 = Never
CR9i.	Other	1 = Daily 2 = Several times a week 3 = Once a week 4 = Several times a month 5 = Once a month or less 6 = Never
CR9j.	Māori cultural activities	1 = Daily 2 = Several times a week 3 = Once a week 4 = Several times a month 5 = Once a month or less 6 = Never
CR10.	How long ago did you begin caring for [LiLACS NZ participant] in any of the ways you indicated in the last question?	1 = Within the past 12 months 2 = 1-2 years ago 3 = More than two years ago
CR10a.	If you began more than 2 years ago, when did you start?	Year

Code	Question	Options
CR11.	What is the total amount of time you spend giving such care in a typical week?	1 = 3 or less hours a week 2 = 4-9 hours a week 3 = 10-19 hours a week 4 = 20-49 hours a week 5 = 50+ hours a week
CR12.	How much responsibility do you feel you have in relation to [LiLACS NZ participant]'s care?	1 = All responsibility 2 = Most of the responsibility 3 = About half responsibility 4 = Less than half 5 = Hardly any responsibility
CR13.	Have there been occasions during the past 3 months when you provided help in a crisis?	0 = No 1 = Yes
CR13a.	If yes, about how many crises did you help out with within the past 3 months?	Number
CR16a.	In the last 3 months, please indicate if you used any of the following methods to provide help and support to [name of the Participant]. Taken leave without pay	1 = Never 2 = Once 3 = More than once
CR16b.	Taken annual leave	1 = Never 2 = Once 3 = More than once
CR16c.	Used your own sick leave	1 = Never 2 = Once 3 = More than once
CR16d.	Taken 'domestic' leave	1 = Never 2 = Once 3 = More than once
CR16e.	Taken time in lieu, or worked flexitime in consultation with supervisor/colleagues	1 = Never 2 = Once 3 = More than once
CR16f.	Paid someone else to provide care which you would have preferred to provide yourself	1 = Never 2 = Once 3 = More than once
CR16g.	Arranged with another family member to provide the care you normally provide	1 = Never 2 = Once 3 = More than once
CR16h.	Made phone calls or provided care yourself in work time	1 = Never 2 = Once 3 = More than once
Kaiāwhina Questionnaires: Formal Caregivers only		
CG1.	How long ago did you begin helping [name of the Participant]?	1 = Within the past 12 months 2 = 1-2 years ago 3 = More than two years ago
CG1a.	If you began more than 2 years ago, when did you start?	Year
CG2.	What is the total amount of time you spend helping [name of the Participant] in a typical week?	1 = 3 or less hours a week 2 = 4-9 hours a week 3 = 10-19 hours a week 4 = 20-49 hours a week 5 = 50+ hours a week
CG3.	Have there been occasions during the past 3 months when you provided help in a crisis to [name of the participant]?	0 = No 1 = Yes
CG3a.	If yes, about how many crises did you help out with within the past 3 months?	Number

Box 5 - Section 5

Code	Question	Options
LiLACS NZ Questionnaire		
AA2.	Sex	1 = Male 2 = Female
AB2.	Which ethnic group(s) do you belong to:	
	Māori	0 = No 1 = Yes
CB1_a.	Have you ever been told by a doctor that you have had a Heart attack/myocardial infarction	0 = No 1 = Yes 3= Don't Know
CB1_b.	Have you ever been told by a doctor that you have had Angina	0 = No 1 = Yes 3= Don't Know
CB1_c.	Have you ever been told by a doctor that you have had a Stroke	0 = No 1 = Yes 3= Don't Know
CB1_d.	Have you ever been told by a doctor that you have had a Transient Ischemic Attack / mini stroke	0 = No 1 = Yes 3= Don't Know
CB1_e.	Have you ever been told by a doctor that you have had High blood pressure	0 = No 1 = Yes 3= Don't Know
CB1_f.	Have you ever been told by a doctor that you have had Atrial fibrillation or irregular heartbeat	0 = No 1 = Yes 3= Don't Know
CB1_g.	Have you ever been told by a doctor that you have had Congestive heart failure	0 = No 1 = Yes 3= Don't Know
CB1_h.	Have you ever been told by a doctor that you have had Intermittent claudication	0 = No 1 = Yes 3= Don't Know
CB1_i.	Have you ever been told by a doctor that you have had Rheumatic fever	0 = No 1 = Yes 3= Don't Know
CB1_j.	Have you ever been told by a doctor that you have had Other heart or circulatory problem	0 = No 1 = Yes 3= Don't Know
EA1.	Are you basically satisfied with your life	0 = No 1 = Yes
EA2.	Have you dropped many of your activities and interests	0 = No 1 = Yes
EA3.	Do you feel that your life is empty	0 = No 1 = Yes
EA4.	Do you often get bored	0 = No 1 = Yes
EA5.	Are you in good spirits most of the time	0 = No 1 = Yes
EA6.	Are you afraid that something bad is going to happen to you	0 = No 1 = Yes
EA7.	Do you feel happy most of the time	0 = No 1 = Yes
EA8.	Do you often feel helpless	0 = No 1 = Yes
EA9.	Do you prefer to stay at home, rather than going out and doing new things	0 = No 1 = Yes
EA10.	Do you feel you have more problems with memory than most	0 = No 1 = Yes
EA11.	Do you think it is wonderful to be alive now	0 = No 1 = Yes
EA12.	Do you feel pretty worthless the way you are now	0 = No 1 = Yes
EA13.	Do you feel full of energy	0 = No 1 = Yes
EA14.	Do you feel that your situation is hopeless	0 = No 1 = Yes
EA15.	Do you think that most people are better off than you are	0 = No 1 = Yes

Code	Question	Options
EA16.	Have you ever been told by a doctor that you have had depression?	0 = No 1 = Yes
GA2a.	In the last year have you visited: a General practitioner	0 = Not at all 1 = About once a year 2 = About every 6 months 3 = About every 3 months 4 = About every month 5 = About every week 6 = Don't know
GB4_4.	Have you ever been told by a doctor or optician that you have had: Diabetic eye disease	0 = No 1 = Yes 2 = Don't know
GP Record review		
C_lung	Medical Record: Chronic lung disease	0 = No 1 = Yes 2 = Don't Know
Diabetes	Medical Record: Diabetes mellitus	0 = No 1 = Yes 2 = Don't Know
MI	Medical Record: Myocardial Infarction	0 = No 1 = Yes 2 = Don't Know
CHF	Medical Record: Congestive heart failure	0 = No 1 = Yes 2 = Don't Know
Carotid	Medical Record: Carotid endarterectomy	0 = No 1 = Yes 2 = Don't Know
C_bypass	Medical Record: Coronary bypass surgery	0 = No 1 = Yes 2 = Don't Know
A_bypass	Medical Record: Leg artery bypass surgery	0 = No 1 = Yes 2 = Don't Know
Repair	Medical Record: Repair of aortic aneurysm	0 = No 1 = Yes 2 = Don't Know
Pace	Medical Record: Pacemaker implant	0 = No 1 = Yes 2 = Don't Know
C_angio	Medical Record: Angioplasty of the coronary arteries	0 = No 1 = Yes 2 = Don't Know
A_angio	Medical Record: Angioplasty of the leg arteries	0 = No 1 = Yes 2 = Don't Know

Appendix 1.3: Statistical significance testing as used in this report

The following excerpt from 'Te Ohonga Ake 2: The Health Status of Māori Children and Young People in New Zealand' explains significance testing clearly.

Understanding Statistical Significance Testing

Inferential statistics are used when a researcher wishes to use a sample to draw conclusions about the population as a whole (e.g. weighing a class of 10 year old boys, in order to estimate the average weight of all 10 year old boys in New Zealand). Any measurements based on a sample however, even if drawn at random, will always differ from that of the population as a whole, simply because of chance. Similarly, when a researcher wishes to determine whether the risk of a particular condition (e.g. lung cancer) is truly different between two groups (smokers and non-smokers), they must also consider the possibility that the differences observed arose from chance variations in the populations sampled.

Over time, statisticians have developed a range of measures to quantify the uncertainty associated with random sampling error (e.g. to quantify the level of confidence we can have that the average weight of boys in our sample reflects the true weight of all 10 year old boys, or that the rates of lung cancer in smokers are really different to those in non-smokers). Of these measures, two of the most frequently used are:

P values: The p value from a statistical test tells us the probability that we would have seen a difference at least as large as the one observed, if there were no real differences between the groups studied (e.g. if statistical testing of the difference in lung cancer rates between smokers and non-smokers resulted in a p value of 0.01, this tells us that the probability of such a difference occurring if the two groups were identical is 0.01 or 1%.) Traditionally, results are considered to be statistically significant (i.e. unlikely to be due to chance) if the probability is <0.05 (i.e. less than 5%).

Confidence Intervals: A 95% Confidence Interval suggests that if you were to repeat the sampling process 100 times, 95 times out of 100 the confidence interval would include the true value. In general terms, if the 95% confidence intervals of two samples overlap, there is no significant difference between them (i.e. the p value would be $\geqslant 0.05$), whereas if they do not overlap, they can be assumed to be statistically different at the 95% confidence level (i.e. the p value would be <0.05).

Reference: Craig E, McDonald G, Adams J, Reddington A, Reddington A, Wicken A, Simpson J. 2012. Te Ohonga Ake 2: The health status of Māori children and young people in New Zealand. Dunedin. New Zealand Child and Youth Epidemiology Service.

The Signalling of Statistical Significance in this Report

In order to assist the reader to identify whether tests of statistical significance have been applied in a particular section, the significance of the associations presented has been signalled in the text with the words significant, or not significant in italics. Where the words significant or not significant do not appear in the text, then the associations described do not imply statistical significance or non-significance.

In addition, in this study, attrition in the later waves means that there are fewer in the later samples. Sample size is important in determining significance. Small samples need a much

larger percentage difference in order to be statistically significant. It is possible that there are real differences between some groups that do not show up as being statistically significant because there were not enough persons in the groups to reach the significant range in the p-value.

Appendix 1.4: Members, Te Rōpū Kaitiaki o Ngā Tikanga Māori

Name	Membership status	Duration
Mrs Leiana Reynolds	Current	Waves 1-5
Dr Waiora Port	Current	Waves 1-5
Mrs Betty McPherson	Current	Waves 1-5
Mr Hone Kameta	Current	Waves 1-5
Mrs Florence Kameta	Current	Waves 1-5
Dr Mere Kēpa	Current	Waves 5-6
Mrs Paea Smith	Past	Waves 1-5

Appendix 2.1: Section 2 technical tables

Descriptive statistics were used to present the count and percentage of the sample groups contributing to grandchildren, their contributions to grandchildren and the number of children and grandchildren.

Significance tests were performed by constructing multivariate generalised linear regression models, all models contained as covariates sex, ethnicity, age, wave of interview and socioeconomic status (NZDep) of the participant's meshblock of residence. 'Participation in voluntary activity or work' was the dependent variable and each group of interest was compared with the reference group adjusting for the other variables listed using logistic regression. The same approach was taken in the significance tables for number of children, contributions to grandchildren and giving care or assistance.

The difference in HRQOL between those volunteering or working and those not (Appendix Tables 2.4, 2.5), those contributing to grandchildren or not, giving care or assistance or not, and the type of assistance given was examined using linear regression adjusting for relevant variables as listed. Variables that *significantly* contribute to the regression models are indicated in the legend.

Appendix Table 2.1: Number of LiLACS NZ participants who answered the questions reported in Section 2.1

	Māori		Non-Māori	
	Men	**Women**	**Men**	**Women**
Wave 1 only				
Do you do any unpaid/voluntary work outside the household now?	104	154	187	213
Are you in paid work now?	104	154	188	212
Have you ever had children? How many sons currently living do you have? How many sons have died? How many daughters currently living do you have? How many daughters have died?	104	154	188	213
Do you have grandchildren? How many?	95	146	185	213
Do you have great-grandchildren? How many?	93	147	182	211
Do you have great-great-grandchildren? How many?	96	146	183	208
How do you currently contribute to the development of your grandchildren or great-grandchildren?	98	148	172	196
Waves 1–4: During the past 7 days did you work for pay or as a volunteer?				
Wave 1	64	80	103	91
Wave 2	92	130	174	193
Wave 3	58	98	149	155
Wave 4	42	75	117	129
Waves 1–4: How often do you currently provide care or assistance for other people?				
Wave 1	100	154	182	206
Wave 2	90	128	169	179
Wave 3	58	98	149	155
Wave 4	42	75	117	129

	Māori		Non-Māori	
	Men	**Women**	**Men**	**Women**
Do you give care or assistance for…(options a-f, full questionnaire)	100	155	183	206
Waves 1–4: NEADL (completed all 22 questions)				
Wave 1	102	154	188	212
Wave 2	92	132	175	195
Wave 3	58	97	149	156
Wave 4	42	75	117	129
Waves 1–4: SF-12 physical health related quality of life (completed all items)				
Wave 1	103	148	183	205
Wave 2	91	129	170	180
Wave 3	56	96	146	149
Wave 4	40	72	117	122
Waves 1–4: SF-12 mental health related quality of life (completed all items)				
Wave 1	103	148	183	205
Wave 2	91	129	170	180
Wave 3	56	96	146	149
Wave 4	40	72	117	122

Appendix Table 2.2: Volunteering and/or paid work outside the household for LiLACS NZ participants, Waves 1–4

	Women					
	Māori			Non-Māori		
	n	(%)	95% Confidence Interval	n	(%)	95% Confidence Interval
Wave 1						
Volunteering	21	14	(9 - 21)	43	20	(15 - 26)
Paid work	4	3	(1 - 7)	3	1	(0 - 4)
Either	24	16	(11 - 23)	44	21	(16 - 27)
Wave 2						
Volunteering	23	18	(12 - 25)	32	17	(12 - 23)
Paid work	2	2	(0 - 5)	3	2	(0 - 4)
Either	23	18	(12 - 25)	33	17	(12 - 23)
Wave 3						
Volunteering	23	23	(15 - 33)	24	15	(10 - 22)
Paid work	2	2	(0 - 7)	1	1	(0 - 4)
Either	24	24	(16 - 34)	25	16	(11 - 23)
Wave 4						
Volunteering	11	15	(8 - 25)	23	18	(12 - 26)
Paid work	2	3	(0 - 9)	1	1	(0 - 4)
Either	12	16	(9 - 26)	24	19	(12 - 26)

	Men					
	Māori			**Non-Māori**		
	n	(%)	95% Confidence Interval	n	(%)	95% Confidence Interval
Wave 1						
Volunteering	13	13	(7 - 21)	31	17	(12 - 23)
Paid work	6	6	(2 - 12)	4	2	(1 - 5)
Either	15	15	(9 - 24)	34	18	(13 - 25)
Wave 2						
Volunteering	14	15	(9 - 24)	22	13	(8 - 19)
Paid work	8	9	(4 - 16)	3	2	(0 - 5)
Either	20	22	(14 - 32)	25	14	(10 - 20)
Wave 3						
Volunteering	10	17	(9 - 29)	24	16	(11 - 23)
Paid work	2	3	(0 - 12)	7	5	(2 - 9)
Either	12	21	(11 - 33)	30	20	(14 - 27)
Wave 4						
Volunteering	7	17	(7 - 31)	13	11	(6 - 18)
Paid work	2	5	(1 - 16)	3	3	(1 - 7)
Either	9	21	(10 - 37)	16	14	(8 - 21)

Appendix Table 2.3: Participation in voluntary activity or work for LiLACS NZ participants, Waves 1–4: Significance table

Group of interest	Reference group	Adjusted Odds Ratio (95% CI)	Significant (*)	Adjustment variables
Any volunteering or work				
Men	Women	0.97 (0.69, 1.36)	ns	Age
Māori	Non-Māori	0.72 (0.45, 1.14)	ns	Age, sex
Māori men	Non-Māori men	0.73 (0.33, 1.62)	ns	Age
Māori women	Non-Māori women	0.70 (0.39, 1.25)	ns	Age
Most deprived areas	Least deprived areas	1.11 (0.69, 1.78)	ns	Age, ethnic group, sex
Most deprived areas - men	Least deprived areas - men	1.01 (0.48, 2.12)	ns	Age, ethnic group
Most deprived areas - women	Least deprived areas - women	1.19 (0.64, 2.20)	ns	Age, ethnic group

*Significant odds ratio for comparison of group of interest to the reference group. ns = no significant difference

Appendix Table 2.4: Physical HRQOL by engaging in any work for LiLACS NZ participants, Waves 1–4

	Adjusted Mean Score	Confidence Limits	Adjustment variables	p-value
No work	41.6	(40.9, 42.4)	Ethnic group, sex *, age, socioeconomic deprivation, function (11 item)**, time in study	0.004
Any work	43.3	(42.1, 44.4)		

*Sex and work interaction not significant
**Adjustment variable *significantly* contributed to model.

Appendix Table 2.5 Mental HRQOL by engaging in any work for LiLACS NZ participants

	Adjusted Mean Score	Confidence Limits	Adjustment variables	p-value
No work	54.3	(53.8, 54.9)	Age, ethnic group, sex*, socioeconomic deprivation, function (11 item)**, time in the study.	0.122
Any work	55.1	(54.2, 56.1)		

*Sex and work interaction not significant
**Adjustment variable *significantly* contributed to model.

Appendix Table 2.6: Numbers of children, grandchildren and great-grandchildren of LiLACS NZ participants, Wave 1. Number is presented unless percent specified.

	Women			
	Māori		Non-Māori	
	Mean	95% Confidence Interval	Mean	(95% CI)
Never had/raised children (%)	5	(2 - 10)	4	(2 - 8)
Number of children living	4.5	(4.0, 4.9)	3.1	(2.9, 3.3)
Have no grandchildren (%)	4	(2 - 9)	8	(5 - 12)
Number of grandchildren	15.9	(12.1, 19.8)	7.2	(6.5, 7.9)
Number of great-grandchildren	11.8	(9.1, 14.5)	4.1	(3.4, 4.9)
Number of great-great-grandchildren	0.48	(0.26, 0.70)	0.07	(0.01, 0.12)
	Men			
	Māori		Non-Māori	
	Mean	95% Confidence Interval	Mean	(95% CI)
Never had/raised children (%)	8	(3 - 15)	6	(3 - 10)
Number of children living	5.5	(4.2, 6.8)	3.2	(2.9, 3.5)
Have no grandchildren (%)	6	(2 - 13)	7	(4 - 12)
Number of grandchildren	16.0	(11.6, 20.5)	7.0	(6.1, 8.0)
Number of great-grandchildren	14.7	(0.0, 30.1)	2.9	(2.2, 3.5)
Number of great-great-grandchildren	2.67	(0.00, 6.80)	0.06	(0.00, 0.13)

Appendix Table 2.7: Children and grandchildren of LiLACS NZ participants Wave 1: Significance table

Group of interest	Reference group	Adjusted Mean Difference (95% CI)	Significant (*)	Adjustment variables
Number of children				
Men	Women	0.09 (0.01, 0.16)	*	Age
Māori	Non-Māori	0.39 (0.29, 0.48)	*	Age, sex
Māori men	Non-Māori men	0.47 (0.32, 0.62)	*	Age
Māori women	Non-Māori women	0.32 (0.19, 0.44)	*	Age
Most deprived areas	Least deprived areas	-0.14 (-0.24, -0.03)	*	Age, ethnic group, sex
Most deprived areas - men	Least deprived areas - men	-0.43 (-0.59, -0.28)	*	Age, ethnic group
Most deprived areas - women	Least deprived areas - women	0.1 (-0.04, 0.25)	ns	Age, ethnic group
Number of grandchildren				
Men	Women	-0.07 (-0.12, -0.02)	*	Age
Māori	Non-Māori	0.75 (0.69, 0.81)	*	Age, sex
Māori men	Non-Māori men	0.72 (0.63, 0.82)	*	Age
Māori women	Non-Māori women	0.76 (0.69, 0.83)	*	Age
Most deprived areas	Least deprived areas	0.18 (0.11, 0.25)	*	Age, ethnic group, sex
Most deprived areas - men	Least deprived areas - men	0 (-0.11, 0.11)	ns	Age, ethnic group
Most deprived areas - women	Least deprived areas - women	0.3 (0.21, 0.39)	*	Age, ethnic group

*Significant odds ratio for comparison of group of interest to the reference group. ns = no significant difference

Appendix Table 2.8: Contributions to grandchildren and great-grandchildren by LiLACS NZ participants, Wave 1

	Women					
	Māori			Non-Māori		
	n	(%)	95% Confidence Interval	n	(%)	95% Confidence Interval
Financial contributions	67	45	(37 - 54)	60	30	(24 - 37)
Occasional support	99	67	(59 - 74)	101	52	(44 - 59)
Shared parenting	54	36	(29 - 45)	12	6	(3 - 10)
I am raising grandchildren as a parent	18	12	(7 - 19)	1	1	(0 - 3)
I teach them my first language	46	31	(24 - 39)	38	19	(14 - 26)
Emotional support/Love	138	93	(88 - 97)	184	94	(90 - 97)
Other	6	7	(3 - 14)	13	8	(4 - 13)
Any	141	95	(90 - 98)	189	96	(93 - 99)

	Men					
	Māori			Non-Māori		
	n	(%)	95% Confidence Interval	n	(%)	95% Confidence Interval
Financial contributions	48	49	(39 - 59)	52	30	(23 - 37)
Occasional support	69	70	(60 - 79)	84	49	(41 - 57)
Shared parenting	45	46	(36 - 56)	13	8	(4 - 13)
I am raising grandchildren as a parent	16	16	(10 - 25)	1	1	(0 - 3)
I teach them my first language	43	44	(34 - 54)	24	14	(9 - 20)
Emotional support/Love	93	97	(91 - 99)	158	92	(87 - 95)
Other	4	8	(2 - 19)	8	5	(2 - 10)
Any	96	98	(93 - 100)	164	95	(91 - 98)

Appendix Table 2.9: Contributions to grandchildren and great-grandchildren by LiLACS NZ participants, Wave 1: Significance table

Group of interest	Reference group	Adjusted Mean Difference (95% CI)	Significant (*)	Adjustment variables
Financial contributions				
Men	Women	0.99 (0.71, 1.38)	ns	Age
Māori	Non-Māori	1.58 (1.05, 2.4)	*	Age, sex
Māori men	Non-Māori men	1.23 (0.59, 2.56)	ns	Age
Māori women	Non-Māori women	1.73 (1.03, 2.9)	*	Age
Most deprived areas	Least deprived areas	1.01 (0.64, 1.6)	ns	Age, ethnic group, sex
Most deprived areas - men	Least deprived areas - men	1.33 (0.63, 2.78)	ns	Age, ethnic group
Most deprived areas - women	Least deprived areas - women	0.83 (0.46, 1.5)	ns	Age, ethnic group
Most deprived areas - Māori	Least deprived areas - Māori	1.34 (0.63, 2.85)	ns	Age, sex
Most deprived areas - non-Māori	Least deprived areas - non-Māori	0.75 (0.41, 1.37)	ns	Age, sex
Occasional support				
Men	Women	0.93 (0.67, 1.29)	ns	Age
Māori	Non-Māori	1.73 (1.16, 2.6)	*	Age, sex
Māori men	Non-Māori men	2.26 (1.14, 4.49)	ns	Age
Māori women	Non-Māori women	1.5 (0.9, 2.49)	*	Age
Most deprived areas	Least deprived areas	0.78 (0.5, 1.22)	ns	Age, ethnic group, sex
Most deprived areas - men	Least deprived areas - men	0.72 (0.36, 1.45)	ns	Age, ethnic group
Most deprived areas - women	Least deprived areas - women	0.84 (0.47, 1.5)	ns	Age, ethnic group
Most deprived areas - Māori	Least deprived areas - Māori	1.47 (0.68, 3.14)	ns	Age, sex

Group of interest	Reference group	Adjusted Mean Difference (95% CI)	Significant (*)	Adjustment variables
Most deprived areas - non-Māori	Least deprived areas - non-Māori	0.6 (0.34, 1.04)	ns	Age, sex
Shared parenting				
Men	Women	1.13 (0.75, 1.71)	ns	Age
Māori	Non-Māori	9.07 (5.27, 15.6)	*	Age, sex
Māori men	Non-Māori men	11.3 (4.99, 25.61)	ns	Age
Māori women	Non-Māori women	7.82 (3.75, 16.32)	*	Age
Most deprived areas	Least deprived areas	1.32 (0.69, 2.5)	ns	Age, ethnic group, sex
Most deprived areas - men	Least deprived areas - men	1.62 (0.56, 4.69)	ns	Age, ethnic group
Most deprived areas - women	Least deprived areas - women	1.18 (0.53, 2.63)	ns	Age, ethnic group
Most deprived areas - Māori	Least deprived areas - Māori	1.56 (0.7, 3.44)	ns	Age, sex
Most deprived areas - non-Māori	Least deprived areas - non-Māori	0.9 (0.28, 2.9)	ns	Age, sex
Raising as parent				
Men	Women	1.08 (0.54, 2.18)	ns	Age
Māori	Non-Māori	25.1 (5.61, 112.55)	*	Age, sex
Māori men	Non-Māori men	17.2 (1.77, 166.79)	ns	Age
Māori women	Non-Māori women	27.8 (3.51, 220.18)	*	Age
Most deprived areas	Least deprived areas	1.11 (0.39, 3.17)	ns	Age, ethnic group, sex
Most deprived areas - men	Least deprived areas - men	1.07 (0.2, 5.8)	ns	Age, ethnic group
Most deprived areas - women	Least deprived areas - women	1.07 (0.27, 4.18)	ns	Age, ethnic group
Most deprived areas - Māori	Least deprived areas - Māori	0.95 (0.33, 2.76)	ns	Age, sex
Most deprived areas - non-Māori	Least deprived areas - non-Māori	Not observed in both	*	Age, sex
Teaching first language				
Men	Women	1 (0.68, 1.45)	ns	Age
Māori	Non-Māori	2.45 (1.55, 3.87)	*	Age, sex
Māori men	Non-Māori men	4.12 (1.97, 8.66)	ns	Age
Māori women	Non-Māori women	1.71 (0.96, 3.06)	*	Age
Most deprived areas	Least deprived areas	1.24 (0.74, 2.07)	ns	Age, ethnic group, sex
Most deprived areas - men	Least deprived areas - men	0.97 (0.43, 2.16)	ns	Age, ethnic group
Most deprived areas - women	Least deprived areas - women	1.44 (0.73, 2.86)	ns	Age, ethnic group
Most deprived areas - Māori	Least deprived areas - Māori	1.14 (0.53, 2.47)	ns	Age, sex

Group of interest	Reference group	Adjusted Mean Difference (95% CI)	Significant (*)	Adjustment variables
Most deprived areas - non-Māori	Least deprived areas - non-Māori			Age, sex
Emotional support and love				
Men	Women	0.95 (0.49, 1.85)	ns	Age
Māori	Non-Māori	1.25 (0.54, 2.9)	*	Age, sex
Māori men	Non-Māori men	4.9 (0.51, 47.42)	ns	Age
Māori women	Non-Māori women	0.75 (0.28, 2.02)	*	Age
Most deprived areas	Least deprived areas	1.09 (0.45, 2.63)	ns	Age, ethnic group, sex
Most deprived areas - men	Least deprived areas - men	1.56 (0.41, 5.96)	ns	Age, ethnic group
Most deprived areas - women	Least deprived areas - women	0.82 (0.24, 2.8)	ns	Age, ethnic group
Most deprived areas - Māori	Least deprived areas - Māori	3.89 (1.08, 13.92)	*	Age, sex
Most deprived areas - non-Māori	Least deprived areas non-Māori	0.48 (0.14, 1.64)	ns	Age, sex
Other				
Men	Women	0.81 (0.38, 1.71)	ns	Age
Māori	Non-Māori	0.83 (0.28, 2.53)	*	Age, sex
Most deprived areas	Least deprived areas	2.2 (0.45, 10.78)	ns	Age, ethnic group, sex
Most deprived areas - men	Least deprived areas - men	0.45 (0.09, 2.28)	*	Age, ethnic group
Most deprived areas - women	Least deprived areas - women	0.63 (0.25, 1.59)	ns	Age, ethnic group
Most deprived areas - Māori	Least deprived areas - Māori	0.6 (0.13, 2.67)	ns	Age, sex
Most deprived areas - non-Māori	Least deprived areas - non-Māori	0.68 (0.21, 2.25)	ns	Age, sex

*Significant odds ratio for comparison of group of interest to the reference group. ns = no significant difference

Appendix Table 2.10: Contributions to grandchildren and physical HRQOL by LiLACS NZ participants, Wave 1: Significance table

	Adjusted Mean Score	95% Confidence Interval	Adjustment variables	p-value***
No contributions	42.1	(37.3, 47.0)	Adjusted for ethnic group*, sex*, age, socioeconomic deprivation, function (11 item)**	0.923
Any contributions	42. 4	(41.4, 43.3)		
Combined analysis				
No financial contributions	41.4	(37.7, 45.2)	Ethnic group, sex*, age, socioeconomic deprivation, function (11item)**	0.663
Financial contributions	41.9	(38.2, 45.7)		
No occasional support	40.3	(36.4, 44.2)	Ethnic group, sex*, age, socioeconomic deprivation, function (11item)**	0.022
Occasional support	43.0	(39.4, 46.7)		
No shared parenting	41.9	(38.0, 45.7)	Ethnic group, sex*, age, socioeconomic deprivation, function (11item)**	0.833
Shared parenting	41.5	(37.4, 45.6)		

	Adjusted Mean Score	95% Confidence Interval	Adjustment variables	p-value***
I am not raising grandchildren as a parent	41.5	(38.4, 44.7)	Ethnic group, sex*, age, socioeconomic deprivation, function (11item)**	0.913
I am raising grandchildren as a parent	41.8	(36.3, 47.4)		
I do not teach them my first language	42.8	(39.2, 46.5)	Ethnic group, sex*, age, socioeconomic deprivation, function (11item)**	0.089
I teach them my first language	40.6	(36.6, 44.5)		
No emotional support/Love	41.3	(36.3, 46.3)	Ethnic group, sex*, age, socioeconomic deprivation, function (11item)**	0.733
Emotional support/Love	42.0	(39.0, 45.1)		
No Other	41.7	(38.5, 45.0)	Ethnic group, sex*, age, socioeconomic deprivation, function (11item)**	0.968
Other	41.6	(36.7, 46.6)		

*Sex interaction not significant
**Adjustment variable *significantly* contributed to model
***p-value for difference in adjusted mean score

Appendix Table 2.11: Contributions to grandchildren and mental HRQOL by LiLACS NZ participants, Wave 1: Significance table

	Adjusted Mean Score	95% Confidence Interval	Adjustment variables	p-value
No contributions	54.0	(50.3, 57.7)	Age, ethnic group, sex, socioeconomic deprivation, function (11 item)*	0.845
Any contributions	54.4	(53.7, 55.1)		
Combined analysis				
No financial contributions	56.3	(53.5, 59.1)	Age, ethnic group, sex, socioeconomic deprivation, function (11 item)*	0.032
Financial contributions	54.5	(51.7, 57.2)		
No occasional support	55.5	(52.6, 58.3)	Age, ethnic group, sex, socioeconomic deprivation, function (11 item)*	0.839
Occasional support	55.3	(52.6, 58.0)		
No shared parenting	54.9	(52.0, 57.8)	Age, ethnic group, sex, socioeconomic deprivation, function (11 item)*	0.451
Shared parenting	55.8	(52.8, 58.8)		
I am not raising grandchildren as a parent	55.1	(52.8, 57.4)	Age, ethnic group, sex, socioeconomic deprivation, function (11 item)*	0.771
I am raising grandchildren as a parent	55.7	(51.6, 59.8)		
I do not teach them my first language	55.1	(52.5, 57.8)	Age, ethnic group, sex, socioeconomic deprivation, function (11 item)*	0.652
I teach them my first language	55.6	(52.6, 58.5)		
No Emotional support/Love	55.4	(51.7, 59.1)	Age, ethnic group, sex, socioeconomic deprivation, function (11 item)*	0.962
Emotional support/Love	55.3	(53.1, 57.6)		
No Other	55.0	(52.6, 57.4)	Age, ethnic group, sex, socioeconomic deprivation, function (11 item)*	0.637
Other	55.7	(52.1, 59.4)		

*Significantly contributed to the model.

Appendix Table 2.12: Frequency of giving care or assistance by LiLACS NZ participants, Wave 1

| | Women | | | | | |
| | Māori | | | Non-Māori | | |
	n	(%)	95% Confidence Interval	n	(%)	95% Confidence Interval
Never	112	73	(65 - 80)	153	74	(68 - 80)
Occasionally	29	19	(13 - 26)	26	13	(8 - 18)
Once a week	4	3	(1 - 7)	7	3	(1 - 7)
Two to five times weekly	3	2	(0 - 6)	9	4	(2 - 8)
Daily	6	4	(1 - 8)	11	5	(3 - 9)
	Men					
Never	58	58	(48 - 68)	128	70	(63 - 77)
Occasionally	30	30	(21 - 40)	19	10	(6 - 16)
Once a week	3	3	(1 - 9)	7	4	(2 - 8)
Two to five times weekly	3	3	(1 - 9)	10	5	(3 - 10)
Daily	6	6	(2 - 13)	18	10	(6 - 15)

Appendix Table 2.13: Giving any care or assistance over time by LiLACS NZ participants, Waves 1–4

| | Women | | | | | |
| | Māori | | | Non-Māori | | |
	n	(%)	95% Confidence Interval	n	(%)	95% Confidence Interval
Wave 1	51	33	(26 - 41)	53	26	(20 - 32)
Wave 2	45	35	(27 - 44)	55	31	(24 - 38)
Wave 3	33	34	(24 - 44)	42	27	(20 - 35)
Wave 4	26	35	(24 - 47)	24	19	(12 - 26)
	Men					
Wave 1	45	45	(35 - 55)	55	30	(24 - 37)
Wave 2	31	34	(25 - 45)	55	33	(26 - 40)
Wave 3	21	36	(24 - 50)	52	35	(27 - 43)
Wave 4	16	38	(24 - 54)	43	37	(28 - 46)

Appendix Table 2.14: Giving any care or assistance by LiLACS NZ participants, Waves 1–4: Significance table

Group of interest	Reference group	Adjusted Odds Ratio (95% CI)	Significant (*)	Adjustment variables
Men	Women	1.39 (1.06, 1.82)	*	Age
Māori	Non-Māori	0.95 (0.67, 1.35)	ns	Age, sex
Māori men	Non-Māori men	1.2 (0.71, 2.03)	ns	Age
Māori women	Non-Māori women	0.8 (0.5, 1.3)	ns	Age

Group of interest	Reference group	Adjusted Odds Ratio (95% CI)	Significant (*)	Adjustment variables
Most deprived areas	Least deprived areas	0.91 (0.63, 1.31)	ns	Age, sex, ethnic group
Most deprived areas - men	Least deprived areas - men	0.89 (0.52, 1.53)	ns	Age, ethnic group
Most deprived areas - women	Least deprived areas - women	0.93 (0.57, 1.53)	ns	Age, ethnic group

*Significant odds ratio for comparison of group of interest to the reference group. ns = no significant difference

Appendix Table 2.15: Giving care or assistance by type (including those who stated they gave no assistance) for LiLACS NZ participants, Waves 1–4

	Women					
	Māori			Non-Māori		
	n	(%)	95% Confidence Interval	n	(%)	95% Confidence Interval
Wave 1						
Financial help	24	16	(10 - 22)	4	2	(0 - 4)
Transport	21	14	(9 - 19)	26	13	(8 - 18)
Shopping	16	10	(5 - 15)	17	8	(4 - 12)
Child care	17	11	(6 - 16)	5	2	(0 - 4)
Personal care	11	7	(3 - 11)	11	5	(2 - 8)
Other	8	5	(2 - 8)	18	9	(5 - 13)
Any	51	33	(26 - 41)	53	26	(20 - 32)
Wave 2 Any	45	35	(27 - 44)	55	31	(24 - 38)
Wave 3 Any	33	34	(24 - 44)	42	27	(20 - 35)
Wave 4 Any	26	35	(24 - 47)	24	19	(12 - 26)
	Men					
	Māori			Non-Māori		
	n	(%)	95% Confidence Interval	n	(%)	95% Confidence Interval
Wave 1						
Financial help	28	28	(19 - 37)	9	5	(2 - 8)
Transport	25	25	(17 - 33)	28	15	(9 - 21)
Shopping	16	16	(9 - 23)	21	12	(7 - 17)
Child care	15	15	(8 - 22)	3	2	(0 - 4)
Personal care	11	11	(5 - 17)	15	8	(4 - 12)
Other	8	8	(3 - 13)	24	13	(8 - 18)
Any	45	45	(35 - 55)	55	30	(24 - 37)
Wave 2 Any	31	34	(25 - 45)	55	33	(26 - 40)
Wave 3 Any	21	36	(24 - 50)	52	35	(27 - 43)
Wave 4 Any	16	38	(24 - 54)	43	37	(28 – 46)

*% is percent of all participants in that group

Appendix Table 2.16: Care or assistance given by LiLACS NZ participant divided by recipient, Wave 1

	Women					
	Māori			Non-Māori		
	n	(%)	95% Confidence Interval	n	(%)	95% Confidence Interval
Financial help						
Someone in same household	10	42	(22 - 63)	4	100	(40 - 100)
Family other household	15	63	(41 - 81)	4	100	(40 - 100)
Other	5	21	(7 - 42)	4	100	(40 - 100)
Transport						
Someone in same household	7	33	(15 - 57)	3	12	(2 - 30)
Family other household	9	43	(22 - 66)	2	8	(1 - 25)
Other	10	48	(26 - 70)	23	88	(70 - 98)
Shopping						
Someone in same household	9	53	(28 - 77)	5	29	(10 - 56)
Family other household	6	35	(14 - 62)	17	100	(80 - 100)
Other	4	24	(7 - 50)	12	71	(44 - 90)
Child care						
Someone in same household	6	33	(13 - 59)	6	100	(54 - 100)
Family other household	12	67	(41 - 87)	5	83	(36 - 100)
Other	18	100	(81 - 100)	6	100	(54 - 100)
Personal care						
Someone in same household	8	62	(32 - 86)	5	45	(17 - 77)
Family other household	3	23	(5 - 54)	11	100	(72 - 100)
Other	4	31	(9 - 61)	6	55	(23 - 83)
Other						
Someone in same household	1	11	(0 - 48)	2	11	(1 - 35)
Family other household	2	22	(3 - 60)	2	11	(1 - 35)
Other	6	67	(30 - 93)	15	83	(59 - 96)
	Men					
	Māori			Non-Māori		
	n	(%)	95% Confidence Interval	n	(%)	95% Confidence Interval
Financial help						
Someone in same household	12	44	(25 - 65)	4	44	(14 - 79)
Family other household	14	52	(32 - 71)	4	44	(14 - 79)
Other	7	26	(11 - 46)	1	11	(0 - 48)
Transport						
Someone in same household	11	48	(27 - 69)	12	44	(25 - 65)
Family other household	10	43	(23 - 66)	2	7	(1 - 24)
Other	5	22	(7 - 44)	14	52	(32 - 71)
Shopping						
Someone in same household	11	69	(41 - 89)	12	57	(34 - 78)
Family other household	3	19	(4 - 46)	2	10	(1 - 30)
Other	1	6	(0 - 30)	6	29	(11 - 52)

Child care						
Someone in same household	7	47	(21 - 73)	5	100	(48 - 100)
Family other household	7	47	(21 - 73)	3	60	(15 - 95)
Other	1	7	(0 - 32)	5	100	(48 - 100)
Personal care						
Someone in same household	5	42	(15 - 72)	12	71	(44 - 90)
Family other household	5	42	(15 - 72)	2	12	(1 - 36)
Other	1	8	(0 - 38)	1	6	(0 - 29)
Other						
Someone in same household	3	30	(7 - 65)	5	19	(7 - 39)
Family other household	3	30	(7 - 65)	4	15	(4 - 35)
Other	5	50	(19 - 81)	16	62	(41 - 80)

Note: Multiple answers were allowed so categories add up to over 100%.

Appendix Table 2.17: Giving any care or assistance by type of recipient, Wave 1: Significance table

Group of interest	Reference group	Adjusted Odds Ratio (95% CI)	Significant (*)	Adjustment variables
Same household				
Men	Women	2.04 (1.1, 3.79)	*	Age
Māori	Non-Māori	1.14 (0.47, 2.75)	ns	Age, sex
Māori men	Non-Māori men	0.41 (0.09, 1.92)	ns	Age
Māori women	Non-Māori women	2.29 (0.72, 7.33)	ns	Age
Most deprived areas	Least deprived areas	2.11 (0.85, 5.25)	ns	Age, ethnic group, sex
Most deprived areas - men	Least deprived areas - men	1.66 (0.47, 5.85)	ns	Age, ethnic group
Most deprived areas - women	Least deprived areas - women	2.73 (0.66, 11.26)	ns	Age, ethnic group
Most deprived areas - Māori	Least deprived areas - Māori	1.49 (0.39, 5.62)	ns	Age, sex
Most deprived areas - non-Māori	Least deprived areas - non-Māori	2.83 (0.76, 10.59)	ns	Age, sex
Family in Other household				
Men	Women	0.89 (0.5, 1.61)	ns	Age
Māori	Non-Māori	4.14 (1.84, 9.34)	*	Age, sex
Māori men	Non-Māori men	4.01 (1.13, 14.22)	*	Age
Māori women	Non-Māori women	4.55 (1.52, 13.63)	*	Age
Most deprived areas	Least deprived areas	0.94 (0.41, 2.15)	ns	Age, ethnic group, sex
Most deprived areas - men	Least deprived areas - men	0.87 (0.25, 3.02)	ns	Age, ethnic group
Most deprived areas - women	Least deprived areas - women	1.07 (0.35, 3.26)	ns	Age, ethnic group
Most deprived areas - Māori	Least deprived areas - Māori	2.09 (0.56, 7.86)	ns	Age, sex
Most deprived areas - non-Māori	Least deprived areas - non-Māori	0.49 (0.14, 1.66)	ns	Age, sex
Others				
Men	Women	0.57 (0.32, 1.01)	ns	Age
Māori	Non-Māori	0.28 (0.12, 0.64)	*	Age, sex
Māori men	Non-Māori men	0.72 (0.22, 2.37)	ns	Age
Māori women	Non-Māori women	0.12 (0.03, 0.4)	*	Age

Group of interest	Reference group	Adjusted Odds Ratio (95% CI)	Significant (*)	Adjustment variables
Most deprived areas	Least deprived areas	0.72 (0.33, 1.59)	ns	Age, ethnic group, sex
Most deprived areas - men	Least deprived areas - men	1.18 (0.35, 3.92)	ns	Age, ethnic group
Most deprived areas - women	Least deprived areas - women	0.38 (0.12, 1.24)	ns	Age, ethnic group
Most deprived areas - Māori	Least deprived areas - Māori	0.76 (0.21, 2.68)	ns	Age, sex
Most deprived areas - non-Māori	Least deprived areas - non-Māori	0.55 (0.18, 1.74)	ns	Age, sex

*Significant odds ratio for comparison of group of interest to the reference group. ns = no significant difference

Appendix Table 2.18: Physical HRQOL by giving care or assistance in LiLACS NZ participants

	Adjusted Mean Score	Confidence Limits	Adjustment variables	p-value
Waves 1–4				
No care/assistance	41.5	(40.8, 42.3)	Ethnic group, sex**, age, socioeconomic deprivation, function (11 item)**, time in study	<0.001
Giving any care/assistance	43.5	(42.5, 44.4)		
Wave 1				
No financial help	44.1	(41.4, 46.7)		0.552
Financial help	45.1	(41.7, 48.4)		
No transport	44.2	(41.2, 47.3)		0.664
Transport	44.9	(42.1, 47.7)		
No shopping	44.9	(41.9, 48.0)		0.707
Shopping	44.2	(41.1, 47.4)	Ethnic group, sex**,age, socioeconomic deprivation, function (11 item)**	
No Child care	43.8	(41.5, 46.1)		0.434
Child care	45.3	(41.6, 49.1)		
No personal care	44.4	(41.8, 47.1)		0.893
Personal Care	44.7	(41.1, 48.3)		
No Other	43.5	(41.3, 45.7)		0.172
Other	45.7	(42.2, 49.2)		

*Sex interaction not significant and did not contribute to the model
**Adjustment variable *significantly* contributed to model.

Appendix Table 2.19: Mental HRQOL by giving any care or assistance in LiLACS NZ participants

	Adjusted Mean Score	Confidence Limits	Adjustment variables	p-value
Waves 1–4				
No care/assistance	54.6	(54.0, 55.1)	Age, ethnic group, sex*, socioeconomic deprivation, function (11 item)**, time in study	0.397
Giving any care/assistance	54.3	(53.5, 55.0)		
Wave 1 only				
No financial help	55.1	(53.2, 57.1)		0.135
Financial help	53.2	(50.7, 55.7)		
No transport	54.4	(52.1, 56.7)	Age, ethnic group, sex*, socioeconomic deprivation, function (11 item)**	0.680
Transport	53.9	(51.8, 56.0)		
No shopping	54.5	(52.2, 56.8)		0.634
Shopping	53.8	(51.5, 56.2)		
No Child care	54.0	(52.2, 55.7)		0.805

	Adjusted Mean Score	Confidence Limits	Adjustment variables	p-value
Child care	54.3	(51.5, 57.2)		
No personal care	53.8	(51.9, 55.8)		0.645
Personal Care	54.5	(51.8, 57.2)		
No Other	53.6	(51.9, 55.3)		0.345
Other	54.7	(52.1, 57.4)		

*Sex interaction not significant and did not contribute to the model
**Adjustment variable *significantly* contributed to model.

Appendix 3.1: Section 3 technical tables

Technical explanation of analyses

Significance tests were performed by constructing multivariate generalised linear regression models, all models contained as covariates sex, ethnicity, age, wave of interview and socioeconomic status (NZDep) of the participant's meshblock of residence. In relation to sex, receipt of care, support service and informal care: where analyses were found to be significant, separate results are presented for subgroups.

The overall difference in HRQOL between those receiving and not receiving *either* support services or informal care, and then those receiving *both* support services and informal care was examined using linear regression. Tables present the adjusted mean difference between the two groups, averaging the difference over time.

Significance in adjustment variables is indicated with an asterisk in notes beneath the tables.

Appendix Table 3.1: Number of LiLACS NZ participants who answered questions or completed measures used for Section 3, Waves 1–4

	Māori		Non-Māori	
	Men	**Women**	**Men**	**Women**
Wave 1				
Age	173	237	236	276
Decile	176	244	237	279
Regular Support Service(s)	99	155	186	209
11-item functional scale	173	238	235	277
SF-12® physical HRQOL	103	148	183	205
SF-12® mental HRQOL	103	148	183	205
NEADL	102	154	188	212
Wave 2				
Regular Support Service(s)	92	132	169	193
11-item functional scale	112	152	183	209
SF-12® physical HRQOL	91	129	170	180
SF-12® mental HRQOL	91	129	170	180
NEADL	92	132	175	195
Wave 3				
Regular Support Service(s)	57	93	140	146
11-item functional scale	76	118	157	178
SF-12® physical HRQOL	56	96	146	149
SF-12® mental HRQOL	56	96	146	149
NEADL	58	97	149	156
Wave 4				
Regular Support Service(s)	41	72	115	117
11-item functional scale	60	100	128	148

	Māori		Non-Māori	
	Men	**Women**	**Men**	**Women**
SF-12® physical HRQOL*	40	72	117	122
SF-12® mental HRQOL	40	72	117	122
NEADL	42	75	117	129
Combined Waves 1–4 (scores in both Waves 1 and 4)				
Change in function	117	152	186	214
Change in SF-12® physical health	31	57	109	115
Change in SF-12® mental health	31	57	109	115

* Nine of these had not answered W1 SF-12®

Appendix Table 3.2: Functional change for LiLACS NZ participants, by ethnic group and sex, Waves 1–4

	Women					
	Māori			Non-Māori		
	n	(%)	95% Confidence Interval	n	(%)	95% Confidence Interval
Wave 1						
Score of 11 high function	114	48	(41, 54)	93	34	(28, 39)
9 or 10 moderate function	75	32	(26, 38)	128	46	(40, 52)
≤8 low function	49	21	(16, 26)	56	20	(16, 25)
Wave 2						
Score of 11 high function	55	36	(29, 44)	56	27	(21, 33)
9 or 10 moderate function	63	41	(34, 50)	99	47	(40, 54)
≤8 low function	34	22	(16, 30)	54	26	(20, 32)
Wave 3						
Score of 11 high function	40	34	(25, 43)	44	25	(19, 32)
9 or 10 moderate function	52	44	(35, 54)	85	48	(40, 55)
≤8 low function	26	22	(15, 31)	49	28	(21, 35)
Wave 4						
Score of 11 high function	34	34	(25, 44)	38	26	(19, 33)
9 or 10 moderate function	34	34	(25, 44)	66	45	(36, 53)
≤8 low function	32	32	(23, 42)	44	30	(23, 38)
	Men					
	Māori			Non-Māori		
	n	(%)	95% Confidence Interval	n	(%)	95% Confidence Interval
Wave 1						
Score of 11 high function	48	28	(21, 35)	71	30	(24, 37)
9 or 10 moderate function	65	38	(30, 45)	104	44	(38, 51)
≤8 low function	60	35	(28, 42)	60	26	(20, 32)

Wave 2						
Score of 11 high function	21	19	(12, 27)	37	20	(15, 27)
9 or 10 moderate function	43	38	(29, 48)	71	39	(32, 46)
≤8 low function	48	43	(34, 53)	75	41	(34, 48)
Wave 3						
Score of 11 high function	13	17	(9, 27)	28	18	(12, 25)
9 or 10 moderate function	19	25	(16, 36)	55	35	(28, 43)
≤8 low function	44	58	(46, 69)	74	47	(39, 55)
Wave 4						
Score of 11 high function	13	22	(12, 34)	15	12	(7, 19)
9 or 10 moderate function	18	30	(19, 43)	47	37	(28, 46)
≤8 low function	29	48	(35, 62)	66	52	(43, 60)

Note: Score based on 11 activities of daily living items asked in the core questionnaire

Appendix Table 3.3: Withdrawal, mortality and skipping waves by functional status, for LiLACS NZ participants, Waves 1–4

	Wave 1 N (% total)	Wave 1-2 N (% of current)	Wave 2 N (% total)	Wave 2-3 N (% of current)	Wave 3 N (% total)	Wave 3-4 N (% of current)	Wave 4 N (% total)
High function	326 (35)	-	169 (26)	-	125 (24)	-	100 (23)
No data for current Wave		9 (3)		3 (2)		2 (1)	
Dropped out	-	66 (20)	-	21 (12)	-	8 (6)	-
Died		10 (3)		7 (4)		5 (4)	
Medium function	372 (40)	-	276 (42)	-	211 (40)	-	165 (38)
No data for current Wave		5 (2)		5 (2)		6 (3)	
Dropped out	-	67 (18)	-	27 (10)	-	20 (9)	-
Died		20 (5)		15 (5)		14 (7)	
Low function	225 (24)	-	211 (32)		193 (36)	-	171 (39)
No data for current Wave		2 (1)		3 (1)		2 (1)	
Dropped out	-	46 (20)	-	21 (10)	-	11 (6)	-
Died		42 (19)		39 (18)		35 (18)	

Note: Cox proportional hazards model shows a hazard ratio for those with low function of 3.5 for mortality compared with those with high function.

Appendix Table 3.4: Maintaining or improving function over time, LiLACS NZ participants: Significance table

Group of interest	Reference group	Adjusted Odds Ratio (95% CI)	Significance (*)	Adjustment variables
Men	Women	0.68 (0.5, 0.92)	*	Age
Māori	Non-Māori	1.17 (0.8, 1.71)	ns	Age, sex
Māori women	Non-Māori women	0.81 (0.49, 1.35)	ns	Age
Māori men	Non-Māori men	1.83 (1.04, 3.23)	*	Age
Most deprived areas	Least deprived areas	1.38 (0.91, 2.08)	ns	Age, sex, ethnic group

Group of interest	Reference group	Adjusted Odds Ratio (95% CI)	Significance (*)	Adjustment variables
Most deprived areas – men	Least deprived areas – men	1.17 (0.63, 2.18)	ns	Age, ethnic group
Most deprived areas – women	Least deprived areas – women	1.53 (0.87, 2.68)	ns	Age, ethnic group
Most deprived areas – Māori	Least deprived areas – Māori	0.93 (0.46, 1.87)	ns	Age, sex
Most deprived areas – non-Māori	Least deprived areas - non-Māori	1.62 (0.95, 2.76)	ns	Age, sex

*Significant odds ratio for comparison of group of interest to the reference group; ns = no significant difference
Note: Each row is a separate model

Appendix Table 3.5: Maintaining or improving function over time, LiLACS NZ participants, fully adjusted model: Significance table

	% maintained or improved	95% Confidence Interval	p-value
Māori	75	(70, 80)	0.0142
Non-Māori	66	(61, 70)	
Female	74	(69, 77)	0.0654
Male	68	(63, 72)	
Age			0.0949
Socioeconomic deprivation			0.041
Ethnic group: Sex interaction*			
Māori: Female	74	(68, 80)	
Māori: Male	76	(69, 82)	
Non-Māori: Female	73	(67, 78)	
Non-Māori: Male	58	(52, 65)	0.0137

* The interaction term is significant, therefore we report each group separately
Note: All variables adjusted for in one model

Appendix Table 3.6: Maintaining or improving function over time, LiLACS NZ participants, by ethnic group and sex

	% that did stay same or improve	95% Confidence Interval	Adjustment variables	p-value
Māori				
Female	60%	(52, 67)	Age, socioeconomic deprivation	0.6593
Male	62%	(53, 71)		
Non-Māori				
Female	66%	(59, 72)	Age, socioeconomic deprivation	0.0006
Male	48%	(41, 55)		
Women				
Māori	59%	(50, 68)	Age, socioeconomic deprivation	0.2533
Non-Māori	66%	(59, 73)		
Men				
Māori	62%	(51, 72)	Age, socioeconomic deprivation	0.0722
Non-Māori	49%	(41, 57)		

Note: Each row is a separate analysis

Appendix Table 3.7: Change in physical health-related quality of life, LiLACS NZ participants, by functional change, Waves 1–4

	Adjusted Mean change in Score	95% Confidence Interval	W1 Score W4 Score	95% Confidence Interval	p-value
Decreased function	-0.9	(-3.0, 1.2)	42.1 41.6	(40.2, 44.0) (40.0, 43.3)	0.3049
Maintained or improved function	-2.3	(-4.7, -0.01)	46.0 43.0	(44.3, 47.8) (41.4, 44.7)	

Adjustment variables: age, ethnic group*, sex, socioeconomic deprivation, function (11 item)

Appendix Table 3.8: Change in mental health-related quality of life, LiLACS NZ participants, by functional change, Waves 1–4

	Adjusted Mean change in Score	95% Confidence Interval	W1 Score W4 Score	95% Confidence Interval	p-value
Decreased function	0.03	(-1.7, 1.7)	55.3 55.6	(54.2, 56.5) (54.4, 56.8)	0.5073
Maintained or improved function	0.80	(-1.1, 2.7)	55.0 55.8	(53.8, 56.2) (54.7, 56.9)	-

Adjustment variables: age, ethnic group, sex, socioeconomic deprivation, function (NEADL score)

Appendix Table 3.9: Receiving any support service by function, LiLACS NZ participants, Waves 1–4

	Women					
	Māori			Non-Māori		
	n	(%)	95% Confidence Interval	n	(%)	95% Confidence Interval
Do you receive any regular support service?						
Wave 1	99	44	(36 - 52)	118	56	(49 - 63)
Wave 2	77	45	(36 - 54)	109	56	(49 - 64)
Wave 3	34	41	(31 - 52)	94	64	(56 - 72)
Wave 4	25	53	(41 - 65)	76	65	(56 - 74)
Function (NEADL mean score) those not receiving support services						
Wave 1	18.8		(18, 19.6)	18.0		(16.9, 19.1)
Wave 2	17.9		(16.9, 19)	16.5		(15.2, 17.9)
Wave 3	18.6		(17.6, 19.5)	18.4		(17.4, 19.4)
Wave 4	18.3		(17.1, 19.5)	17.9		(16.4, 19.3)
Function (NEADL mean score) those receiving support services						
Wave 1	15.7		(14.3, 17)	17.6		(17, 18.1)
Wave 2	15.7		(14.5, 16.9)	16.6		(15.9, 17.4)
Wave 3	16.3		(14.8, 17.8)	16.2		(15.3, 17)
Wave 4	14.8		(12.8, 16.7)	16.7		(15.9, 17.5)

	Men					
	Māori			Non-Māori		
	n	(%)	95% Confidence Interval	n	(%)	95% Confidence Interval
Do you receive any regular support service?						
Wave 1	42	42	(33 - 53)	91	49	(42 - 56)
Wave 2	41	45	(34 - 55)	79	47	(39 - 55)
Wave 3	20	35	(23 - 49)	60	43	(35 - 51)
Wave 4	16	39	(24 - 55)	55	48	(38 - 57)
Function (NEADL mean score) those not receiving support services						
Wave 1	17.4		(16.3, 18.6)	18.4		(17.7, 19.2)
Wave 2	16.6		(15.4, 17.8)	16.8		(16.1, 17.6)
Wave 3	15.8		(14.7, 16.9)	16.8		(16.1, 17.4)
Wave 4	14.5		(13, 16)	16.3		(15.3, 17.3)
Function (NEADL mean score) those receiving support services						
Wave 1	16.7		(15.6, 17.8)	17.1		(16.4, 17.8)
Wave 2	13.5		(11.8, 15.1)	16.3		(15.4, 17.2)
Wave 3	14.9		(12.3, 17.5)	16.8		(15.9, 17.6)
Wave 4	16.5		(14.9, 18.1)	16.8		(16, 17.7)

Appendix Table 3.10: Receiving support services for LiLACS NZ participants, Waves 1–4, adjusted for age, ethnic group and sex: Significance table

Group of interest	Reference group	Adjusted Odds Ratio (95% CI)	Significance (*)	Adjustment variables
Men	Women	0.67 (0.49, 0.93)	*	Age
Māori	Non-Māori	0.78 (0.53, 1.16)	ns	Age, sex
Māori men	Non-Māori men	1.11 (0.61, 2.01)	ns	Age
Māori women	Non-Māori women	0.61 (0.36, 1.03)	ns	Age
Most deprived areas	Least deprived areas	0.88 (0.57, 1.36)	ns	Age, sex, ethnic group
Most deprived areas - men	Least deprived areas – men	1.06 (0.56, 1.99)	ns	Age, ethnic group
Most deprived areas – women	Least deprived areas – women	0.75 (0.41, 1.38)	ns	Age, ethnic group
Most deprived areas - Māori	Least deprived areas – Māori	0.78 (0.39, 1.58)	ns	Age, sex
Most deprived areas – non-Māori	Least deprived areas non-Māori	0.92 (0.52, 1.62)	ns	Age, sex

*Significant odds ratio for comparison of group of interest to the reference group. ns = no significant difference
Note: Each row is a separate model

Appendix Table 3.11: Receiving support services for LiLACS NZ participants, Waves 1–4, fully adjusted model: Significance table

	Receiving any support service (%)	95% Confidence Interval	p-value
Māori	47	(39, 54)	0.239
Non-Māori	53	(47, 58)	
Female	55	(50, 61)	0.007
Male	44	(38, 50)	
Age	change per extra year in age	-	0.007
NZ Dep	change per lower decile	-	0.409
Functional status (11 item)	change per extra point	-	0.017
Wave	change per extra year in study	-	0.3318

Note: Interaction term not significant (not shown)

Appendix Table 3.12: Overall difference in physical HRQOL by receipt of services, LiLACS NZ participants, Waves 1–4: Significance table

	Adjusted Mean Score	95% Confidence Interval	Adjustment variables	p-value
No support services	44.0	(43.2, 44.8)	Age, ethnic group, sex*, socioeconomic deprivation, function (11 item)*, time in study	<.0001
Support services	40.2	(39.4, 41.0)		

*significant contribution to model
Note: Ethnic group sex interaction not significant

Appendix Table 3.13: Change in physical HRQOL by receipt of services, LiLACS NZ participants: Significance table

	Adjusted Mean change in Score	95% Confidence Interval	Score at W1 Score at W4	95% Confidence Interval	p-value
No support services	-2.7	(-4.8, -0.6)	48.0 44.7	(46.4, 49.5) (43.1, 46.2)	0.0191
Any support services W1	0.5	(-1.8, 2.8)	39.5 39.8	(37.5, 41.4) (38.1, 41.5)	-

Adjustment variables: age*, ethnic group, sex, socioeconomic deprivations, function (NEADL score)
*significant contribution to model

Appendix Table 3.14: Change in mental HRQOL by receipt of services, adjusted for sex, age, functional status, socioeconomic deprivation: Significance table

	Adjusted Mean Score	95% Confidence Interval	Score at W1 Score at W4	95% Confidence Interval	p-value
No support services	0.04	(-1.7, 1.8)	55.3 55.6	(54.2, 56.3) (54.8, 56.7)	0.6422
Support services	0.6	(-1.3, 2.5)	55.1 55.6	(53.7, 56.4) (54.2, 56.9)	

Adjustment variables: age, ethnic group, sex, socioeconomic deprivations, function (NEADL score)

Appendix Table 3.15: Receiving informal care, LiLACS NZ participants, Waves 1–4

| | Women | | | | | |
| | Māori | | | Non-Māori | | |
	n	(%)	95% Confidence Interval	n	(%)	95% Confidence Interval
Wave 1	53	34	(27, 42)	61	29	(23, 35)
Wave 2	58	44	(35, 53)	78	40	(33, 47)
Wave 3	44	45	(35, 56)	65	42	(34, 50)
Wave 4	47	63	(51, 74)	64	50	(41, 59)
	Men					
Wave 1	38	37	(28, 47)	44	23	(18, 30)
Wave 2	48	52	(42, 63)	86	49	(42, 57)
Wave 3	39	67	(54, 79)	91	61	(53, 69)
Wave 4	31	74	(58, 86)	77	66	(56, 74)

Note: If the respondent indicated during the NEADL or ADL section of the interview that they received help from somebody in any of the 27 tasks listed, they were classed as receiving informal support.

Appendix Table 3.16: Receiving informal care, LiLACS NZ, Waves 1–4

Group of interest	Reference group	Adjusted Odds Ratio (95% CI)	Significant (*)	Adjustment variables
Receiving informal care				
Men	Women	1.39 (1.06, 1.82)	*	Age
Māori	Non-Māori	1.63 (1.17, 2.27)	*	Age, sex
Māori men	Non-Māori men	1.30 (0.79, 2.15)	ns	Age
Māori women	Non-Māori women	1.86 (1.18, 2.91)	*	Age
Most deprived areas	Least deprived areas	0.59 (0.41, 0.85)	*	Age, sex, ethnic group
Most deprived areas – men	Least deprived areas – men	0.59 (0.35, 0.99)	*	Age, ethnic group
Most deprived areas – women	Least deprived areas – women	0.59 (0.36, 0.98)	*	Age, ethnic group
Most deprived areas –Māori	Least deprived areas – Māori	0.64 (0.35, 1.18)	ns	Age, sex
Most deprived areas –non-Māori	Least deprived areas – non-Māori	0.6 (0.38, 0.96)	*	Age, sex

*Significant odds ratio for comparison of group of interest to the reference group. ns = no significant difference
Note: Each row is a separate model
Adjustment variables: age, ethnic group, sex, socioeconomic deprivations

Appendix Table 3.17: Receipt of informal care by functional status (11 item questionnaire), LiLACS NZ, Waves 1–4

	Women					
	Māori			Non-Māori		
	n	(%)	95% Confidence Interval	n	(%)	95% Confidence Interval
Wave 1						
High function	5	6	(2, 14)	2	3	(0, 9)
Moderate function	32	55	(42, 68)	39	37	(28, 47)
Low function	16	94	(71, 100)	20	71	(51, 87)
Wave 2						
High function	3	6	(1, 17)	5	9	(3, 20)
Moderate function	36	62	(48, 74)	42	44	(34, 54)
Low function	19	79	(58, 93)	31	70	(55, 83)
Wave 3						
High function	4	11	(3, 25)	6	14	(5, 28)
Moderate function	25	60	(43, 74)	30	39	(28, 51)
Low function	15	83	(59, 96)	29	81	(64, 92)
Wave 4						
High function	9	35	(17, 56)	3	9	(2, 23)
Moderate function	15	60	(39, 79)	30	49	(36, 62)
Low function	23	96	(79, 100)	31	94	(80, 99)
Men						
Wave 1						
High function	1	3	(0, 18)	3	5	(1, 15)
Moderate function	22	46	(31, 61)	23	25	(17, 35)
Low function	15	60	(39, 79)	18	45	(29, 62)
Wave 2						
High function	1	6	(0, 30)	1	3	(0, 14)
Moderate function	14	39	(23, 57)	25	36	(25, 49)
Low function	33	83	(67, 93)	60	87	(77, 94)
Wave 3						
High function	1	13	(0, 53)	2	7	(1, 24)
Moderate function	10	63	(35, 85)	23	44	(30, 59)
Low function	28	82	(65, 93)	66	94	(86, 98)
Wave 4						
High function	1	17	(0, 64)	0	0	(0, 23)
Moderate function	9	64	(35, 87)	20	44	(30, 60)
Low function	21	95	(77, 100)	57	98	(91, 100)

Note: High function = score of 11 on the core functional status items; moderate function = score of 9-10; low function = score ≤8

Appendix Table 3.18: Receipt of informal care by ethnic group, sex, functional status and socioeconomic deprivation: Significance table

	% receiving informal care adjusted	Confidence Limits	p-value
Non-Māori	35%	(30%, 40%)	0.0006
Māori	50%	(43%, 57%)	
Male	39%	(34%, 45%)	0.1055
Female	45%	(40%, 51%)	
Age	change per extra year in age		0.8909
NZ Dep: Deciles 1-4	48%	(40%, 56%)	0.0792
Deciles 5-7	42%	(35%, 48%)	
Deciles 8-10	37%	(32%, 43%)	
High baseline function	7%	(5%, 10%)	<.0001
Medium	47%	(43%, 52%)	
Low	85%	(81%, 88%)	
Wave	change per extra year in study		<.0001

Note: Excluding 'other' help. There was no deprivation function interaction.

Adjustment variables: age, sex, ethnic group*, socioeconomic deprivation, function*, time in study*. *significant contribution to model

Appendix Table 3.19: Difference in physical HRQOL by receipt of informal care; all groups: Significance table

	Adjusted Mean Score	95% Confidence Interval	Beta	Standard Error	95% Confidence Interval	p-value
No informal care	42.1	(41.2, 42.9)	1.4	0.6	(0.8, 2.6)	0.8854
Any informal care	42.1	(41.3, 43.0)	0	-	-	

Note: Excluding 'other' help.
Adjustment variables: age, sex, ethnic group*, socioeconomic deprivation*, function*, time in study, care: sex interaction*.
Interaction term significant, separate sex models presented. *significant contribution to model

Appendix Table 3.20: Overall difference in physical HRQOL by receipt of informal care; women: Significance table

	Adjusted Mean Score	95% Confidence Interval	p-value
No informal care	42.5	(41.2, 43.7)	0.0003
Any informal care	40.0	(39.0, 41.0)	

Adjustment variables: age, ethnic group*, socioeconomic deprivation, function*, time in study.

Appendix Table 3.21: Overall difference in physical HRQOL by receipt of informal care; men: Significance table

	Adjusted Mean Score	95% Confidence Interval	p-value
No informal care	41.9	(40.5, 43.3)	0.0375
Any informal care	43.3	(42.1, 44.5)	

Note: Adjustment variables: age, ethnic group, socioeconomic deprivation, function*, time in study. *significant contribution to model

Appendix Table 3.22: Overall difference in physical HRQOL by informal care, women only, adjusted for support services: Significance table

	Adjusted Mean Score	95% Confidence Interval	Beta	Standard Error	95% Confidence Interval	p-value
No informal care	42.1	(40.7, 43.4)	1.4	1.1	(-0.7, 3.5)	0.0571
Any informal care	40.6	(39.6, 41.7)	-	-	-	

Adjustment variables: age, ethnic group*, socioeconomic deprivation, function*, time in study, support services*. *significant contribution to model

Appendix Table 3.23: Overall difference in physical HRQOL by informal care, men only, adjusted for support services: Significance table

	Adjusted Mean Score	95% Confidence Interval	p-value
No informal care	41.6	(40.2, 42.9)	0.0065
Any informal care	43.5	(42.4, 44.7)	

Adjustment variables: age, ethnic group, socioeconomic deprivation, function*, time in study, support services*.
*significant contribution to model

Appendix Table 3.24: Change over time in physical HRQOL by informal care

	Adjusted Mean change in Score	95% Confidence Interval	Score at W1 Score at W4	95% Confidence Interval	p-value
No baseline informal care	-1.5	(-3.6, 0.5)	45.3 / 43.0	(44.0, 46.7) / (41.7, 44.4)	0.3606
Any baseline informal care	0.02	(-2.8, 2.8)	39.3 / 40.0	(35.9, 42.7) / (37.6, 42.4)	

Adjustment variables: age, ethnic group*, socioeconomic deprivation, function*, time in study, support services interaction *significant*. *significant contribution to model

Appendix Table 3.25: Change over time in physical HRQOL by informal care for those with formal support

	Change over 3 years	95% Confidence Interval	Score at W1 Score at W4	95% Confidence Interval	p-value
No informal care	-0.5	(-3.7, 2.6)	41 / 39.8	(38.8, 43.2) / (37.8, 41.8)	0.0391
Informal care	4.2	(-0.1, 8.5)	34.8 / 39.7	(30.8, 38.7) / (36.3, 43)	

Adjustment variables: age, sex, ethnic group, socioeconomic deprivation, age, ethnic group*, function, time in study. *significant contribution to model

Appendix Table 3.26: Change over time in physical HRQOL by informal care for those with no formal support

	Change over 3 years	95% Confidence Interval	Score at W1 Score at W4	95% Confidence Interval	p-value
No informal care	-3.1	(-6.2, -0.1)	48.9 / 45.7	(47.5, 50.4) / (44, 47.4)	0.7586
Informal care	-4	(-7.8, -0.1)	44.1 / 40.4	(38.8, 49.4) / (36.7, 44.1)	

Adjustment variables: age*, ethnic group, socioeconomic deprivation, function, time in study, *significant contribution to model

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Appendix Table 3.27: Overall difference in mental HRQOL by informal care: Significance table

	Adjusted Mean Score	95% Confidence Interval	p-value
No informal care	54.0	(53.2, 54.7)	0.0896
Any informal care	54.7	(54.1, 55.3)	

Note: Adjustment variables: age, sex, ethnic group, socioeconomic deprivation, function*, time in study. *significant contribution to model

Appendix Table 3.28: Overall difference in mental HRQOL by informal care, adjusted for support services: Significance table

	Adjusted Mean Score	95% Confidence Interval	p-value
No informal care	54.1	(53.5, 54.8)	0.0841
Informal care	54.9	(54.2, 55.5)	

Note: Excluding 'other' help. Adjustment variables: age, sex, ethnic group, socioeconomic deprivation, function*, time in study, support services. *significant contribution to model

Appendix Table 3.29: Change over time in mental HRQOL by informal care, adjusted for support services: Significance table

	Adjusted Mean change in Score	95% Confidence Interval	Score at W1 Score at W4	95% Confidence Interval	p-value
No Informal care	0.3	(-1.4, 2.1)	55.3 56.0	(54.5, 56.2) (55.1, 57.0)	0.9176
Any informal care	0.2	(-2.1, 2.6)	54.6 54.3	(52.4, 56.8) (52.5, 56.1)	

Note: Excluding 'other' help. Interaction terms not significant. Adjustment variables: age, sex, socioeconomic deprivation, function, time in study, support services. *significant contribution to model

Appendix 4.1: Section 4 technical tables

Descriptive statistics are used to describe the kaiāwhina sample. Differences between groups were tested using Fischer's exact test, t-tests of chi-square as indicated in the tables' notes. Where categorical questions were added to create a sum, the midpoint of the interval was generally taken.

Probit regression was used to examine the COPE scores as the dependent variable against sex, ethnic group and whether participant received personal care.

Appendix Table 4.1: Number of LiLACS NZ and Kaiāwhina study participants answering key Section 4 questions

	Māori		Non-Māori	
	Women	**Men**	**Women**	**Men**
Wave 4 LiLACS NZ questionnaire				
Regardless of how you answered the previous question, who has provided you the most help, care and support in the last 3 months? (You can identify up to two persons.)				
First person identified (including 'no one')	100	61	146	127
Second person identified (including 'no one')	39	22	36	19
Are you comfortable for us to contact this person to speak about the ways he/she has given you the help, care and support in the last 3 months?	70	50	102	85
Last year we contacted … Is this the same person?	76	51	100	61
Can I have his/her contact details …	72	53	103	87
SF-6D Quality of Life [calculated based on BA1-BA7]	74	41	123	117
Site – Home, Site – Residential Care, Site – Other [calculated based on site]	74	44	125	116
Age [calculated based on Wave 1 data]	100	61	148	128
Daily tasks: "no help", "desired more support with daily tasks" [calculated based on GC1, GC3]	74	41	121	110
Emotional support: "no support", "no help", "desired more emotional support" [calculated based on GC4, GC6]	75	42	122	108
Number of carers identified	100	61	146	127
Whether carers identified	100	61	146	127
Types of carers identified	100	61	146	127
Whether consent was provided to contact the nominated carer	98	60	131	112
Wave 4 Kaiāwhina questionnaire				
Caregiver Status	58	45	94	80
What is your relationship to the person you care for? (Informal only)	52	36	86	78
How long ago did you begin helping [name of the Participant]? (Formal only)	7	8	7	2
Types of carer relationships [calculated based on CR6, CG1]	62	46	96	82
Sex	61	46	96	82
Age	59	42	93	81
Ethnicity	62	43	94	81

Would you say your health is:	62	46	96	82
Your occupational status:	59	38	89	80
Where do you live in proximity to [name of the Participant]?	59	38	89	80
How often have you done each of the following for [LiLACS NZ participant] in the past 3 months? Personal care	55	38	88	80
Household assistance	55	38	89	80
How often are you involved in the following? Food choices	44	33	67	59
Food shopping	44	33	67	59
Food preparation	44	33	67	59
Cooking of meals	44	33	67	59
Preparing drinks and snacks	44	33	67	59
Sharing in the eating of meals	44	33	67	59
Administrative/Legal Support	55	38	89	80
Social and Emotional Support	55	38	89	80
Cultural Support	54	38	89	80
Spiritual Support	55	38	89	80
Family Support	55	38	89	80
Transport to health services	55	38	89	80
Maori cultural activities	52	38	89	79
How long ago did you begin caring for [LiLACS NZ participant] in any of the ways you indicated in the last question?	55	38	89	80
What is the total amount of time you spend giving such care in a typical week?	55	38	89	80
How much responsibility do you feel you have in relation to [LiLACS NZ participant]'s care?	55	38	89	80
Have there been occasions during the past 3 months when you provided help in a crisis	55	38	89	80
If yes, about how many crises did you help out with within the past 3 months?	23	20	34	24
In the last 3 months, please indicate if you used any of the following methods to provide help and support to [name of the Participant]. Taken leave without pay	23	13	48	37
Taken annual leave	23	13	48	37
Used your own sick leave	23	13	48	37
Taken "domestic" leave	23	13	48	37
Taken time in lieu, or worked flexitime in consultation with supervisor/colleagues	23	13	48	37
Paid someone else to provide care which you would have preferred to provide yourself	23	13	48	37
Arranged with another family member to provide the care you normally provide	23	13	48	37
Made phone calls or provided care yourself in work time	23	13	48	37
EQ5D	55	38	89	80
COPE	55	38	89	80

Appendix Table 4.2: LiLACS NZ participants giving consent for carer contact by ethnic group and sex

Consent granted	Māori		Non-Māori	
	Women	Men	Women	Men
No	30 (30%)	9 (15%)	42 (29%)	34 (27%)
Yes	70 (70%)	52 (85%)	104 (71%)	93 (73%)
Total	100	61	146	127

Note: Differences in patterns tested using Fisher Exact Test, p = 0.132

Appendix Table 4.3: LiLACS NZ participant nominations and their relationship to formal and informal carers by ethnic group and sex

CR6: What is your relationship to the …	LiLACS NZ Participant nominations, %		Carer sample interviewed, %		P-value
	Mean	95% Confidence Interval	Mean	95% Confidence Interval	
Spouse	24%	(20 – 27)	27%	(0.21 - 0.32)	0.366
Sibling	2%	(1 – 3)	2%	(0.00 - 0.04)	0.636
Child	47%	(43 – 52)	51%	(0.45 - 0.57)	0.324
Other family (including son-in-law, daughter-in-law)	8%	(6 – 10)	4%	(0.02 - 0.07)	0.052
Other non-professional	12%	(0.09 - 0.15)	6%	(0.04 - 0.09)	0.019
Other professional	8%	(0.06 - 0.10)	10%	(0.06 - 0.13)	0.408
Total N	479	-	279*	-	-

Note: Nominations refer to frequency in proportion to all nominations. T-test assumes independent samples with equal variance.
*There were some missing data for this question, with 279 recorded responses to this question out of 286 carer interviews.

Appendix Table 4.4 Carer characteristics by LiLACS NZ participants

Characteristics	Māori	Non-Māori	All
All carers n = 286 (100%)			
Age (SD)	60.4 (14.1)	65.8 (14.6)	63.4 (14.5)
Ethnic group			
Māori (%)	75 (71%)	4 (2%)	79 (28%)
Non-Māori (%)	30 (29%)	172 (98%)	202 (72%)
Sex			
Female (%)	81 (76%)	131 (74%)	212 (74%)
Male (%)	26 (24%)	47 (26%)	73 (26%)
Formal carers n = 25 (8.7%)			
Age (SD)	51.1 (12.1)	48.0 (15.7)	49.6 (13.6)
Ethnic group			
Māori (%)	11 (79%)	1 (10%)	12 (50%)
Non-Māori (%)	3 (21%)	9 (90%)	12 (50%)
Sex			
Female (%)	12 (80%)	10 (100%)	22 (88%)
Male (%)	3 (20%)	0 (0%)	3 (12%)

Characteristics	Māori	Non-Māori	All
Informal carers n = 261 (91%)			
Age (SD)	64.1 (13.4)	67.2 (13.0)	66.3 (13.1)
Ethnic group			
Māori (%)	64 (70%)	3 (2%)	67 (26%)
Non-Māori (%)	27 (30%)	163 (98%)	190 (74%)
Sex			
Female (%)	69 (75%)	121 (72%)	190 (73%)
Male (%)	23 (25%)	47 (28%)	70 (27%)
Employment status			
Full time (%)	26 (28%)	53 (32%)	79 (30%)
Part time (%)	12 (13%)	31 (18%)	43 (17%)
Not employed (includes retired, fulltime student) (%)	55 (59%)	84 (49%)	139 (53%)
Distance from participant			
Live in the same house/or house on same property (%)	58 (62%)	66 (39%)	124 (47%)
Less than 30mins away (%)	30 (32%)	85 (50%)	115 (44%)
More than 30mins away (%)	5 (5%)	19 (11%)	24 (9%)
Receipt of benefit			
Carer's benefit (%)	5 (5%)	0 (0%)	5 (2%)
Other benefit (%)	8 (9%)	3 (2%)	11 (4%)
No benefit or other support (%)	80 (86%)	165 (98%)	245 (94%)

Appendix Table 4.5: Sex, ethnic group and age comparisons of formal and informal carers

	Formal carer	Informal carer	P-Value
Sex (% female)	91%	72%	0.040
Ethnic group (% Māori)	48%	26%	0.028
Age (mean)	49.6	66.4	<0.0001

Appendix Table 4.6: Sex of informal carers by ethnic group and sex

	Māori		Non-Māori		P-Values
CR2: Sex	Women	Men	Women	Men	
Female	34 (65%)	33 (87%)	56 (64%)	64 (80%)	0.011
Male	18 (35%)	5 (13%)	32 (36%)	16 (20%)	

Note: Differences in patterns tested for each type of carer were tested using Fisher Exact Test, p-values displayed in final column.

Appendix Table 4.7: Ethnic group of informal carers by ethnic group and sex

Which ethnic group(s) do you belong to?	Māori		Non-Māori		P-Values
	Women	Men	Women	Men	
Māori	39 (74%)	24 (67%)	2 (2%)	1 (1%)	<0.0001
Non-Māori	14 (26%)	12 (33%)	83 (98%)	78 (99%)	

Note: Differences in patterns tested for each type of carer were tested using Fisher Exact Test, p-values displayed in final column. Numbers do not add completely to total of informal carers due to missing data on sex for 2 carers.

Appendix Table 4.8: Ethnic group of carers by ethnic group and sex of LiLACS NZ participants

Carer		LiLACS NZ Participant			
		Māori		Non-Māori	
		Women	Men	Women	Men
Māori	Women	28 (54%)	19 (53%)	2 (2%)	1 (1%)
	Men	10 (19%)	5 (14%)	0	0
Non-Māori	Women	6 (12%)	12 (33%)	54 (64%)	62 (78%)
	Men	8 (15%)	0	29 (34%)	16 (20%)

Note: Differences in patterns tested for ethnic group were tested using chi-square test, p-values = 0.000

Appendix Table 4.9: Occupational status of informal carers by ethnic group and sex

CR7: Your occupational status	Māori		Non-Māori	
	Women	Men	Women	Men
Employed full time	17 (31%)	9 (24%)	24 (27%)	29 (36%)
Employed part time	8 (15%)	4 (11%)	24 (27%)	8 (10%)
Retired/full time student	16 (29%)	19 (50%)	34 (39%)	41 (51%)
Not in paid employment	14 (25%)	6 (16%)	6 (7%)	3 (4%)

Appendix Table 4.10: Employment status of informal carers by ethnic group and sex

Employment of any form	Māori		Non-Māori	
	Women	Men	Women	Men
Not employed	30 (55%)	25 (66%)	40 (45%)	44 (54%)
Employed part or full-time	25 (45%)	13 (34%)	48 (55%)	37 (46%)

Note: Differences in patterns tested for employment status were tested using chi-square test, p-values = 0.202. Differences in employment status by ethnic group tested using t-test, p-values = 0.144. Differences in employment status by sex tested using t-test, p-values = 0.146.

Appendix Table 4.11: Location of informal carers by ethnic group and sex of the LiLACS NZ participant

CR8. Where do you live in proximity to participant?	Māori		Non-Māori	
	Women	Men	Women	Men
In the same household	26 (47%)	27 (71%)	24 (27%)	40 (49%)
In a different household but the same property	2 (4%)	3 (8%)	0	2 (2%)
Within walking distance	6 (11%)	0	9 (10%)	6 (7%)
Within 10 minutes' drive/bus journey	9 (16%)	6 (16%)	29 (33%)	14 (17%)

CR8. Where do you live in proximity to participant?	Māori		Non-Māori	
	Women	Men	Women	Men
Between 10 and 30 minutes' drive/bus journey	9 (16%)	0	15 (17%)	12 (15%)
Within 1 hour drive/bus, plane journey	1 (2%)	1 (3%)	2 (2%)	1 (1%)
Over 1 hour drive/bus, plane journey	2 (4%)	1 (3%)	8 (9%)	3 (4%))
In the South Island	0	0	0	2 (2%)
Overseas	0	0	2 (2%)	1 (1%)
Total N	55	38	89	81

Appendix Table 4.12: Summarised location of carers by ethnic group and sex

CR8. Where do you live in proximity to participant?	Māori		Non-Māori	
	Women	**Men**	**Women**	**Men**
In the same household	28 (51%)	30 (79%)	24 (27%)	42 (52%)
Within 30 minutes' drive/bus journey	24 (44%)	6 (16%)	53 (60%)	32 (40%)
Over 30 minutes' drive/bus/plane journey	3 (5%)	2 (5%)	12 (13%)	7 (9%)

Note: Differences in patterns tested for location were tested using chi-square test, p-values = 0.000.

Appendix Table 4.13: Informal carers: characteristics by ethnic group and relationship to LiLACS NZ participants

	LiLACS NZ participant		
	Māori	**Non-Māori**	**All**
Carer/Kaiāwhina			
Spouse n = 74 (29%)			
Age mean	78.2	82.6	81.2
Ethnic group			
Māori	8 (32%)	0	8 (11%)
Non-Māori	17 (68%)	48 (100%)	65 (89%)
% Kaiāwhina participant female	16 (65%)	36 (75%)	52 (72%)
Employment status			
Full time	1 (4%)	0	1 (1%)
Part time	1 (4%)	0	1 (1%)
Not employed	24 (92%)	48 (100%)	72 (98%)
Distance from participant			
Live in the same house	26 (100%)	45 (94%)	71 (96%)
Less than 30mins away	0	3 (6%)	3 (4%)
More than 30mins away	0	0	0
Children n = 142 (55%)			
Age mean	55.0	58.2	57.5
Ethnic group			

	LiLACS NZ participant		
	Māori	**Non-Māori**	**All**
Māori	42 (89%)	2 (2%)	44 (31%)
Non-Māori	5 (11%)	90 (98%)	95 (68%)
% Kaiāwhina participant female	32 (67%)	58 (62%)	90 (63%)
Employment status			
Full time	23 (48%)	47 (50%)	70 (49%)
Part time	8 (17%)	29 (31%)	37 (26%)
Not employed	17 (35%)	18 (19%)	35 (25%)
Distance from participant			
Live in the same house	25 (52%)	13 (14%)	38 (27%)
Less than 30mins away	19 (40%)	63 (67%)	82 (58%)
More than 30mins away	4 (8%)	18 (19%)	22 (15%)
Other family n = 18 (7%)			
Age mean	56.0	58.6	57.6
Ethnic group			
Māori	6 (86%)	0	6 (33%)
Non-Māori	1 (14%)	11 (100%)	12 (67%)
% Kaiāwhina participant female	5 (71%)	6 (55%)	11 (61%)
Employment status			
Full time	1 (14%)	4 (36%)	5 (27%)
Part time	0	3 (27%)	3 (17%)
Not employed	6 (86%)	4 (36%)	10 (56%)
Distance from participant			
Live in the same house	1 (17%)	4 (36%)	5 (28%)
Less than 30mins away	6 (83%)	6 (55%)	12 (67%)
More than 30mins away	0	1 (9%)	1 (6%)
Other n = 22 (9%)			
Age mean	69.7	76.6	75.0
Ethnic group			
Māori	6 (66%)	1 (8%)	7 (32%)
Non-Māori	3 (33%)	12 (92%)	15 (68%)
% Kaiāwhina participant female	7 (78%)	11 (85%)	18 (82%)
Employment status			
Full time	1 (11%)	1 (8%)	2 (9%)
Part time	3 (33%)	0	3 (14%)
Not employed	5 (55%)	12 (92%)	17 (77%)
Distance from participant			
Live in the same house	4 (44%)	2 (15%)	6 (27%)
Less than 30mins away	5 (56%)	11 (85%)	16 (63%)
More than 30mins away	0	0	0

Appendix Table 4.14: Initiation of informal care by ethnic group and sex of LiLACS NZ participant

How long ago did you begin caring …	Māori		Non-Māori	
	Women	Men	Women	Men
Within the last 12 months	5 (9%)	4 (11%)	6 (7%)	7 (9%)
1-2 years ago	7 (13%)	4 (11%)	11 (13%)	10 (13%)
More than 2 years ago	43 (78%)	30 (79%)	71 (81%)	63 (79%)

Appendix Table 4.15: Time since initiation of care by combination of LiLACS NZ participant ethnic group and sex

Time of care	Māori		Non-Māori	
	Women	Men	Women	Men
N	54	38	84	77
Mean	10.83	15.92	9.72	14.56
95% Confidence Interval	(6.80 – 14.86)	(9.06 – 22.78)	(7.37 – 12.07)	(10.00 – 19.13)
P-Value	0.447	0.153	0.075	0.164

Note: Differences in time by ethnic group, tested using t-test, p = 0.681. Differences in time by sex, tested using t-test, p = 0.021. Caring within the last two years coded as midpoint of interval, caring beyond two years ago coded as the difference between 2014 and stated initiation.

Appendix Table 4.16: Comparison between formal and informal carers: Amount of care

	Formal carers	Informal carers	P-Value
Time since caring started	4.4 years	12.6 years	0.021
Hours spent giving care per week			
0-3 hours	5 (20%)	71 (28%)	
4-9 hours	7 (28%)	57 (23%)	
10-19 hours	4 (16%)	41 (16%)	
20-49 hours	7 (28%)	56 (22%)	
50+ hours	2 (8%)	27 (11%)	0.869
Helped in a crisis in the last 3 months	8 (32%)	99 (39%)	0.486
#of crises in the last 3 months (only those who answered Yes)	0.50 (1.71)	0.64 (1.72)	0.545 (0.98)

Note: Differences in patterns tested for each type of carer were tested using Fisher Exact Test, p-values displayed in final column.

Appendix Table 4.17: Hours per week caring by ethnic group and sex of LiLACS NZ participant

What is the total amount of time you spend giving such care in a typical week…	Māori		Non-Māori	
	Women	Men	Women	Men
3 or less hours a week	10 (18%)	3 (8%)	32 (36%)	26 (33%)
4-9 hours a week	14 (25%)	6 (16%)	25 (28%)	15 (19%)
10-19 hours a week	10 (18%)	7 (18%)	15 (15%)	10 (13%)
20-49 hours a week	12 (22%)	15 (39%)	13 (15%)	19 (24%)
50+ hours a week	9 (16%)	7 (18%)	4 (4%)	9 (11%)
Spouse				
3 or less hours a week	0	2 (12%)	0	2 (6%)

What is the total amount of time you spend giving such care in a typical week…	Māori		Non-Māori	
	Women	Men	Women	Men
4-9 hours a week	1 (11%)	1 (6%)	1 (8%)	1 (3%)
10-19 hours a week	3 (33%)	2 (12%)	2 (17%)	7 (21%)
20-49 hours a week	4 (44%)	8 (47%)	5 (42%)	15 (44%)
50+ hours a week	1 (11%)	4 (24%)	4 (33%)	9 (27%)
Child				
3 or less hours a week	6 (19%)	1 (6%)	24 (41%)	21 (58%)
4-9 hours a week	8 (25%)	3 (19%)	19 (33%)	12 (33%)
10-19 hours a week	6 (19%)	5 (31%)	9 (16%)	2 (6%)
20-49 hours a week	5 (16%)	5 (31%)	6 (10%)	1 (3%)
50+ hours a week	7 (22%)	2 (13%)	0	0
Other				
3 or less hours a week	4 (33%)	0	8 (47%)	3 (43%)
4-9 hours a week	4 (33%)	2 (50%)	3 (18%)	2 (29%)
10-19 hours a week	1 (8%)	0	4 (24%)	1 (14%)
20-49 hours a week	3 (25%)	1 (25%)	2 (12%)	1 (14%)
50+ hours a week	0	1 (25%)	0	0

Appendix Table 4.18: Estimated weekly time spent by informal carers in care activities by ethnic group and sex of LiLACS NZ participant

What is the total amount of time you spend giving such care in a typical week…	Māori		Non-Māori	
	Women	Men	Women	Men
Mean	21.91	28.49	12.54	18.23
95% Confidence Interval	(16.33 – 27.49)	(22.10 – 34.87)	(9.36 – 15.73)	(13.89 – 22.58)
N	55	38	89	
Spouse				
Mean	27.56	32.62	37.33	34.37
95% Confidence Interval	(14.81-40.30)	(22.4-42.82)	(25.08-49.58)	(27.82-40.91)
N	9	17	12	34
Child				
Mean	23.14	24.13	8.57	4.81
95% Confidence Interval	(15.05-31.24)	(14.38-33.87)	(5.96-11.18)	(2.72-6.89)
N	32	16	58	36
Other				
Mean	12.5	26.88	9.32	9.5
95% Confidence Interval	(3.76-21.25)	(-14.06-67.81)	(3.74-14.91)	(-1.57-20.57)
N	12	4	17	7
P-Value	0.144	0.001	0.000	0.8546

Note: Midpoint of categories used for all categories other than 50+ hours a week, where 60 hours is used. Differences in time by ethnic group, tested using t-test, p = 0.0231. Differences in time by sex, tested using t-test, p = 0.000.

Appendix Table 4.19: Perceived responsibility of informal carers by ethnic group and sex of LiLACS NZ participant

How much responsibility do you feel you have …	Māori		Non-Māori	
	Women	Men	Women	Men
All responsibility	14 (25%)	14 (37%)	13 (15%)	14 (17%)
Most of the responsibility	21 (38%)	11 (30%)	23 (26%)	14 (17%)
About half responsibility	10 (18%)	8 (22%)	20 (23%)	22 (27%)
Less than half	6 (11%)	2 (5%)	25 (28%)	21 (26%)
Hardly any responsibility	4 (7%)	2 (5%)	7 (8%)	10 (12%)
Spouse				
All responsibility	3 (33%)	6 (28%)	4 (33%)	7 (19%)
Most of the responsibility	3 (33%)	5 (32%)	5 (42%)	6 (17%)
About half responsibility	0	3 (19%)	2 (17%)	14 (39%)
Less than half	2 (22%)	1 (6%)	1 (8%)	5 (14%)
Hardly any responsibility	1 (11%)	1 (6%)	0	4 (11%)
Child				
All responsibility	8 (25%)	6 (38%)	9 (16%)	6 (17%)
Most of the responsibility	15 (47%)	5 (31%)	16 (28%)	5 (14%)
About half responsibility	7 (22%)	3 (19%)	14 (24%)	7 (20%)
Less than half	1 (3%)	1 (6%)	16 (28%)	13 (36%)
Hardly any responsibility	1 (3%)	1 (6%)	3 (5%)	5 (14%)
Other				
All responsibility	2 (17%)	2 (50%)	0	1 (14%)
Most of the responsibility	2 (17%)	1 (25%)	2 (13%)	3 (43%)
About half responsibility	3 (25%)	1 (25%)	2 (13%)	0
Less than half	3 (25%)	0	8 (50%)	1 (29%)
Hardly any responsibility	2 (17%)	0	4 (25%)	1 (14%)

Note: Differences in patterns tested for responsibility were tested using chi square test, p = 0.009.

Appendix Table 4.20: Proportion of carers perceiving that they have 'all responsibility', by ethnic group and sex of LiLACS NZ participant

How much responsibility do you feel you have …	Māori		Non-Māori	
	Women	Men	Women	Men
Mean	26%	37%	15%	17%
95% Confidence Interval	(14 – 37%)	(21 – 53%)	(7 – 22%)	(9% - 26%)
N	55	38	89	81
Spouse				
Mean	33%	35%	33%	19%
95% Confidence Interval	(-5 - 72%)	(10 – 61%)	(2 – 65%)	(6 – 33%)
N	9	17	12	36
Child				
Mean	25%	38%	16%	17%

How much responsibility do you feel you have …	Māori		Non-Māori	
	Women	Men	Women	Men
95% Confidence Interval	(9 - 41%)	(11 – 64%)	(6 – 25%)	(4 – 29%)
N	32	16	58	36
Other				
Mean	17%	50%	0	14%
95% Confidence Interval	(-8 - 41%)	(-41 – 142%)	(0 – 0%)	(-20 – 49%)
N	12	4	17	7

Note: Differences in proportion by ethnic group, tested using t-test, p = 0.007. Differences in proportion by sex tested using t-test, p = 0.345.

Appendix Table 4.21: NEADL scores of LiLACS NZ participant by ethnic group and sex of LiLACS NZ participant

NEADL Summary Scores	Māori		Non-Māori	
	Women	Men	Women	Men
Within group				
Mean	15.0	15.0	16.0	16.1
95% Confidence Interval	(13.1 – 16.8)	(13.5 – 16.4)	(14.9 – 17.1)	(15.3 – 16.9)
N	44	29	83	77
All other groups				
Mean	15.9	15.8	15.5	15.5
95% Confidence Interval	(15.3 – 16.5)	(15.2 – 16.5)	(14.8 – 16.3)	(14.7 – 16.3)
N	189	204	150	156
P-Value	0.237	0.363	0.490	0.358

Notes: Differences in NEADL Scores by ethnic group tested using t-test, p = 0.099. Differences in NEADL Scores by sex tested using t-test, p = 0.791.

Appendix Table 4.22: Personal care given by informal carers, by ethnic group and sex of LiLACS NZ participant

How often have you … provided <u>personal care</u>	Māori		Non-Māori	
	Women	Men	Women	Men
Daily	7 (13%)	9 (24%)	7 (8%)	10 (12%)
Several times a week	6 (11%)	4 (11%)	3 (3%)	4 (5%)
"Occasionally"	9 (16%)	4 (10%)	11 (13%)	12 (14%)
Never	33 (60%)	21 (55%)	67 (76%)	55 (68%)
Total n	55	38	88	81

Note: Differences in patterns tested for personal care could not be computed. Differences in patterns tested for personal care against ethnic group was tested using Fisher Exact test. p = 0.036. Differences in patterns tested for personal care against sex was tested using Fisher Exact test, p = 0.305.

Appendix Table 4.23: Proportions providing any personal care by combination by ethnic group and sex of LiLACS NZ participant

How often have you … provided **personal care**	Māori		Non-Māori	
	Women	Men	Women	Men
Mean	40%	45%	24%	32%
95% Confidence Interval	(27 – 53%)	(28 – 61%)	(15 – 33%)	(22 – 43%)
N	55	38	88	81
Spouse				
Mean	33%	47%	17%	39%
95% Confidence Interval	(-5 – 72%)	(21 – 74%)	(-8 – 41%)	(22 – 56%)
N	9	17	12	36
Child				
Mean	44%	38%	26%	31%
95% Confidence Interval	(26 – 62%)	(11 – 64%)	(15 – 38%)	(15 – 46%)
N	32	16	57	36
Other				
Mean	42%	75%	18%	14%
95% Confidence Interval	(9 – 74%)	(-5 – 155%)	(-2 – 38%)	(-21 – 49%)
N	12	4	17	7

Note: Differences in proportions by ethnic group tested using t-test, p=0.020. Differences in proportions by sex, tested using t-test, p = 0.300.

Appendix Table 4.24: Household assistance given by informal carers by ethnic group and sex of LiLACS NZ participant

How often have you … provided **household assistance**	Māori		Non-Māori	
	Women	Men	Women	Men
Daily	22 (40%)	25 (66%)	18 (20%)	35 (43%)
Several times a week	12 (22%)	4 (11%)	16 (18%)	9 (11%)
Once a week	5 (9%)	1 (3%)	14 (16%)	4 (5%)
"Occasionally"	4 (7%)	3 (8%)	17 (19%)	12 (15%)
Never	12 (22%)	5 (13%)	24 (27%)	21 (26%)
Total	55	38	89	81

Note: Differences in patterns tested for household assistance could not be computed. Differences in patterns tested for household assistance against ethnic group (p = 0.020) and sex (p = 0.002) were tested separately using Fisher Exact test.

Appendix Table 4.25: Proportions providing any assistance, including occasional, by ethnic group and sex of LiLACS NZ participant

How often have you … provided **household assistance - Any**	Māori		Non-Māori	
	Women	**Men**	**Women**	**Men**
Mean	78.2%	86.8%	73.0%	74.1%
95% Confidence Interval	(66.9 – 89.4%)	(75.6 – 98.1%)	(63.6 – 82.4%)	(64.3 – 83.8%)
N	55	38	89	182

How often have you … provided household assistance - Any	Māori		Non-Māori	
	Women	**Men**	**Women**	**Men**
Spouse				
Mean	89%	82%	100	92%
95% Confidence Interval	(63 – 115%)	(62 – 103%)	(100 – 100%)	(82 – 101%)
N	9	17	12	36
Child				
Mean	81%	88%	72%	56%
95% Confidence Interval	(67 – 96%)	(69 – 106%)	(61 – 84%)	(39 – 73%)
N	32	16	58	36
Other				
Mean	58%	100%	53%	71%
95% Confidence Interval	(26 – 91%)	(100 – 100%)	(26 – 79%)	(26 – 117%)
N	12	4	17	7

Note: Differences in proportions by ethnic group, tested using t-test, p = 0.136. Differences in proportions by sex, tested using t-test, p = 0.551.

Appendix Table 4.26, Proportions providing specified household assistance at least several times a week by ethnic group and sex of LiLACS NZ participant

	N	Māori		Non-Māori		P-Values
		Women	Men	Women	Men	
Food choices	263	15 (27%)	24 (63%)	19 (22%)	34 (43%)	0.000
Food shopping	263	15 (27%)	13 (34%)	7 (8%)	19 (24%)	0.001
Food preparation	263	26 (47%)	28 (74%)	21 (24%)	40 (50%)	0.000
Cooking of meals	263	24 (44%)	27 (71%)	21 (24%)	40 (50%)	0.000
Preparing drinks and snacks	263	16 (29%)	19 (50%)	17 (19%)	31 (39%)	0.002
Sharing in the eating of meals	263	30 (55%)	29 (76%)	23 (26%)	40 (50%)	0.000

Note: Differences in patterns tested within each question using Fisher Exact Test, p-values displayed in final column.

Appendix Table 4.27: Proportions of informal carers providing any other types of support assistance by ethnic group and sex of LiLACS NZ participant

	N	Total	Māori		Non-Māori		P-Values
			Women	Men	Women	Men	
Administrative/legal support	263	127 (49%)	29 (53%)	22 (58%)	45 (51%)	31 (39%)	0.139
Social and Emotional Support	263	256 (98%)	54 (98%)	38 (100%)	88 (100%)	76 (95%)	0.101
Cultural support	263	56 (22%)	14 (26%)	5 (13%)	19 (22%)	18 (23%)	0.553
Spiritual support	263	79 (30%)	24 (44%)	15 (39%)	25 (28%)	15 (19%)	0.008
Family support	263	181 (69%)	41 (75%)	31 (82%)	56 (64%)	53 (66%)	0.185
Transport to health services	263	140 (54%)	35 (64%)	18 (47%)	49 (56%)	38 (48%)	0.279
Māori cultural activities	263	30 (12%)	16 (31%)	13 (34%)	0 (0%)	1 (1%)	0.000
Any of above (except Social and Emotional Support)	263	241 (92%)	53 (96%)	38 (100%)	80 (91%)	70 (88%)	0.810

Note: Differences in patterns tested within each question using Fisher Exact Test, p-values displayed in final column.

Appendix Table 4.28: Impact of caring on employment of informal carers by ethnic group and sex of LiLACS NZ participant

Impact on employment	N	Total	Māori		Non-Māori		P-Values
			Women	Men	Women	Men	
Taken annual leave	121	18 (15%)	3 (13%)	3 (23%)	4 (8%)	8 (22%)	0.248
Taken leave without pay	121	17 (14%)	4 (17%)	3 (23%)	4 (8%)	6 (16%)	0.405
Used your own sick leave	121	12 (10%)	2 (9%)	3 (23%)	1 (2%)	6 (16%)	0.029
Taken "domestic" leave	121	2 (2%)	0 (0%)	1 (8%)	0 (0%)	1 (3%)	0.153
Taken time in lieu, or worked flexitime in consultation with supervisor/colleagues	121	22 (18%)	4 (18%)	5 (39%)	5 (10%)	8 (22%)	0.116
Arranged with another family member to provide the care you normally provide	121	48 (40%)	11 (48%)	7 (54%)	18 (38%)	12 (32%)	0.442
Paid someone else to provide care which you would have preferred to provide yourself	121	9 (7%)	1 (4%)	1 (8%)	4 (8%)	3 (8%)	1.000
Made phone calls or provided care yourself in work time	121	75 (62%)	16 (70%)	4 (46%)	28 (58%)	25 (68%)	0.442

Appendix Table 4.29: General health rating by carer relationship to LiLACS NZ participant

	Fair or worse than fair	Good	Very good
All informal carers	31 (12%)	105 (41%)	120 (47%)
Spouse	15 (20%)	31 (42%)	28 (38%)
Child	11 (8%)	60 (42%)	71 (50%)
Other	5 (13%)	14 (35%)	21 (53%)

Note: Differences in patterns tested across all three groups within this question using Fisher Exact Test, p-values = 0.091. Differences in patterns tested for spouse vs. other groups using Fisher Exact Test, p-values = 0.033. Differences in patterns tested for children vs. other groups using Fisher Exact Test, p-values = 0.046.

Appendix Table 4.30: Comparison between formal and informal carers: health

	Formal carer	Informal carer	P-Value
Would you say your health is:			
Very good	14 (56%)	119 (47%)	-
Good	8 (32%)	104 (41%)	-
Fair	3 (12%)	29 (11%)	-
Poor	0	1 (0.4%)	-
Very Poor	0	1 (0.4%)	0.695

Appendix Table 4.31: General health status by ethnic group and sex of LiLACS NZ participant

	Māori		Non-Māori	
	Women	Men	Women	Men
Very good	29 (53%)	11 (29%)	41 (46%)	41 (51%)
Good	17 (31%)	20 (53%)	39 (44%)	33 (41%)
Fair or worse than fair	9 (17%)	7 (18%)	9 (10%)	7 (8%)
Total	55	38	89	81

Note: No significant differences between groups differences in score by ethnic group tested using t-test, p = 0.419. Differences in score by sex tested using t-test, p = 0.428.

Appendix Table 4.32: COPE Subscale scores by type of carer

	Positive	Negative	Quality of Support
All informal carers	15.0 (14.8-15.2)	9.0 (8.7-9.3)	12.4 (12.1-12.8)
Spouse	15.0 (14.6-15.4)	8.9 (8.3-9.5)	13.2 (12.5-13.8)
Child	14.9 (14.6-15.2)	9.1 (8.7-9.5)	12.3 (11.8-12.8)
Other	15.1 (14.6-15.6)	8.7 (7.8-9.5)	11.7 (10.7-12.8)

Appendix Table 4.33: Negative Impact Component of COPE by ethnic group and sex of LiLACS NZ participant

	Māori		Non-Māori	
	Women	**Men**	**Women**	**Men**
Negative scores				
Mean	9.00	9.70	8.74	8.88
95% Confidence Interval	(8.21, 9.79)	(8.61, 10.79)	(8.25, 9.23)	(8.38, 9.37)
N	55	37	89	81
P-Value	0.932	0.065	0.301	0.687

Note: Differences in score by ethnic group tested using t-test, p = 0.156. Differences in score by sex tested using t-test, p = 0.361.

Appendix Table 4.34: Simplified regression predicting whether carer had a more negative experience (COPE Negative Impact Score > 8) of caring according to demographic information and support variables

Predicting whether COPE Negative Impact Score > 8	Coefficient	95% Confidence Interval	P-Value
Carer			
Māori women	-0.16	(-0.57 – 0.26)	0.46
Māori men	0.49	(-0.23 – 1.21)	0.18
Non-Māori women	(Baseline)		
Non-Māori men	0.38	(-0.04 – 0.79)	0.07
Support variables (all descriptions vs. not)			
Any personal care in the last 3 months	-0.36	(-0.70 – -0.03)	0.03
Constant	0.24	(0.00 – 0.48)	0.05

Note: Probit regression. Positive coefficients indicate aa better experience (lower chance of a person responding that they have had a more negative experience), negative coefficients show a more negative experience. Those not providing regular care were more likely to report a negative experience.

Appendix Table 4.35: Proportions indicating a more negative experience (COPE Negative Impact Score > 8) by whether personal care was provided in the last 3 months

	Did not provide care in the last 3 months	Provided care in the last 3 months
Within group		
Mean	63.6%	47.1%
95% Confidence Interval	(56.5 – 70.8%)	(36.2 – 57.9%)
N	176	85
P-value	0.0108	

Appendix Table 4.36: Positive Value Score component of COPE by ethnic group and sex of LiLACS NZ participant

	Māori		Non-Māori	
	Women	Men	Women	Men
Within group				
Mean	14.91	14.65	15.13	15.05
95% Confidence Interval	(14.32, 15.50)	(13.92, 15.37)	(14.85, 15.40)	(14.73, 15.37)
N	55	37	88	81
All other groups				
Mean	15.01	15.04	14.92	14.96
95% Confidence Interval	(14.80, 15.22)	(14.83, 15.26)	(14.64, 15.20)	(14.70, 15.23)
N	206	224	173	180
P-Value	0.697	0.189	0.355	0.698

Note: Differences in score by ethnic group tested using t-test, p = 0.197. Differences in score by sex tested using t-test, p = 0.576.

Appendix Table 4.37: Quality of Support component of COPE by ethnic group and sex of LiLACS NZ participant

	Māori		Non-Māori	
	Women	Men	Women	Men
Within group				
Mean	12.31	13.24	12.25	12.35
95% Confidence Interval	(11.52, 13.10)	(12.20, 14.28)	(11.58, 12.91)	(11.68, 13.01)
N	55	38	89	81
All other groups				
Mean	12.47	12.30	12.53	12.47
95% Confidence Interval	(12.04, 12.89)	(11.90, 12.70)	(12.08, 12.98)	(12.02, 12.93)
N	208	225	174	182
P-Value	0.736	0.081	0.482	0.757

Note: Differences in score portions by ethnic group tested using t-test, p = 0.320. Differences in score by sex tested using t-test, p = 0.345.

Appendix Table 4.38: Proportions of carers reporting less than full health on each EQ-5D-3L dimensions, by dimension and type of carer

	Mobility	Self-care	Usual activities	Pain and discomfort	Anxiety and depression
All informal carers	43 (17%)	6 (2%)	38 (15%)	79 (31%)	29 (11%)
Spouse	22 (30%)	3 (4%)	20 (27%)	28 (38%)	12 (16%)
Child	15 (11%)	3 (2%)	14 (10%)	39 (28%)	14 (10%)
Other	6 (16%)	0	4 (11%)	12 (32%)	3 (8%)

Appendix Table 4.39: EQ-5D-3L Thermometer Score by Carer Type

	All Kaiāwhina	Spouse	Child	Other
Mean	79.7	72.2	82.5	83.0
95% Confidence Interval	(77.7, 81.6)	(68.6, 75.7)	(79.9, 85.1)	(78.5, 87.5)
N	261	74	143	44
P-Value	NA	0.000	0.002	0.132

Appendix Table 4.40: EQ-5D-3L Utility Score by ethnic group and sex of LiLACS NZ participant

	Māori		Non-Māori	
	Women	Men	Women	Men
Within group				
Mean	0.895	0.815	0.848	0.873
95% Confidence Interval	(0.848, 0.941)	(0.746, 0.884)	(0.808, 0.889)	(0.831, 0.916)
N	55	37	88	81
All other groups				
Mean	0.852	0.869	0.868	0.856
95% Confidence Interval	(0.825, 0.879)	(0.844, 0.893)	(0.839, 0.896)	(0.828, 0.884)
N	206	224	173	180
P-Value	0.144	0.113	0.443	0.489

Note: Differences in score by ethnic group tested using t-test, p = 0.929. Differences in score by sex tested using t-test, p = 0.641.

Estimation of costs

Multiple imputation was used to estimate the costs for those LiLACS NZ participants who did not have carers included in the sample. A total of 25 imputations (ie, alternative, complete data) were estimated for each observation with missing data in the LiLACS NZ sample.

- Data was complete across the whole sample only on ethnic group and sex, with one age observation missing and imputed based on these characteristics using a linear regression.

- Where missing, the types of informal carers a participant might nominate (child, sibling, spouse, other family, others) were then estimated using ethnic group, sex, age and previous types estimated using chained logit equations.

- Where missing, LiLACS NZ participants with high on the Nottingham Expanded Activities of Daily Living were then estimated based on ethnic group, sex, age and carer types using chained logit equations.

- Where missing, LiLACS NZ participants indicating that they did not need or did not have help with daily tasks/social and emotional support were then estimated based on all prior information, using chained logit equations.

- At this point, log-costs were estimated using a linear regression under the various assumptions including the main estimate and the lowest and highest cost estimates.

Appendix Table 4.41: Average estimated yearly informal care costs by ethnic group and sex

Informal care: all carer costs	Māori		Non-Māori	
	Women	Men	Women	Men
Within group				
Mean	$19,197	$24,960	$10,992	$16,382
95% Confidence Interval	($14,308-$24,085)	($19,368-$30,552)	($8,199-$13,785)	($12,520-$20,243)
N	55	38	89	79
All other groups				
Mean	$15,635	$14,925	$19,177	$16,388
95% Confidence Interval	($13,393-$17,878)	($12,776-$17,074)	($16,516-$21,837)	($13,605-$18,810)
N	208	225	174	182
P-Value	0.161	0.001	0.000	0.8546

Note: Weekly typical carer hours analysed by taking midpoint of categories used for all categories. For 50+ hours a week, where 60 hours is used. Weekly figures multiplied by 52 weeks/year and $16.85 median caregiver wage. Differences in time by ethnic group tested using t-test, p = 0.000. Differences in time by sex tested using t-test, p = 0.015.

Appendix Table 4.42: Estimated yearly informal care costs by carer retirement status, by ethnic group and sex

Informal care: non-retired carer costs	Māori		Non-Māori	
	Women	Men	Women	Men
Within group				
Mean	$20,523	$23,381	$7,213	$4,753
95% Confidence Interval	($14,242-$26,805)	($15,285-$31,477)	($4,998-$9,428)	($2,637-$6,870)
N	39	19	56	40
Informal care: retired carers				
Mean	$15,963	$26,540	$17,405	$28,308
95% Confidence Interval	($8,238-$23,689)	($18,087-$34,992)	($11,280-$23,529)	($22,915-$33,701)
N	16	19	33	39
P-Value	0.400	0.574	0.000	0.000

Note: Weekly typical carer hours analysed by taking midpoint of categories used for all categories. For 50+ hours a week, where 60 hours is used. Weekly figures multiplied by 52 weeks/year and $16.85 median caregiver wage. Differences in time by ethnic group tested using t-test, p = 0.000. Differences in time by sex tested using t-test, p = 0.4343.

Appendix Table 4.43: Estimated yearly informal care costs by non-retired carers, by ethnic group and sex

Informal care: non-retired carer costs	Māori		Non-Māori	
	Women	Men	Women	Men
Within group				
Mean	$20,523	$23,381	$7,213	$4,753
95% Confidence Interval	($14,242-$26,805)	($15,285-$31,477)	($4,998-$9,428)	($2,637-$6,870)
N	39	19	56	40
All other groups				
Mean	$9,029	$10,329	$14,641	$14,461
95% Confidence Interval	($6,883-$11,174)	($7,978-$12,681)	($11,249-$18,033)	($11,489-$17,434)
N	115	135	98	114
P-Value	0.000	0.000	0.003	0.000

Note: Weekly typical carer hours analysed by taking midpoint of categories used for all categories. For 50+ hours a week, where 60 hours is used. Weekly figures multiplied by 52 weeks/year and $16.85 median caregiver wage. Differences in time by ethnic group tested using t-test, p = 0.000. Differences in time by sex tested using t-test, p = 0.4343.

Appendix Table 4.44: Average estimated yearly informal care costs by working carers, by ethnic group and sex

Informal care: working carer costs	Māori		Non-Māori	
	Women	Men	Women	Men
Within group				
Mean	$17,191	$19,175	$5,732	$4,251
95% Confidence Interval	($9,558-$24,823)	($12,542-$25,808)	($3,852-$7,612)	($2,471-$6,031)
N	25	13	48	37
All other groups				
Mean	$6,956	$7,838	$11,151	$11,095
95% Confidence Interval	($5,287-$8,625)	($5,690-$9,985)	($7,965-$14,337)	($8,268-$13,922)
N	98	110	75	86
P-Value	0.000	0.001	0.012	0.003

Note: Weekly typical carer hours analysed by taking midpoint of categories used for all categories. For 50+ hours a week, where 60 hours is used. Weekly figures multiplied by 52 weeks/year and $16.85 median caregiver wage. Differences in time by ethnic group tested using t-test, p = 0.000. Differences in time by sex tested using t-test, p = 0.4841.

Appendix Table 4.45: Average estimated yearly informal care costs by carer using alternative time estimates, by ethnic group and sex

Informal care: all carer costs	Māori		Non-Māori	
	Women	Men	Women	Men
Average time within category	$19,197	$24,960	$10,992	$16,382
95% confidence interval	($14,308-$24,085)	($19,368-$30,552)	($8,199-$13,785)	($12,520-$20,243)
Minimum time within category	$13,476	$17,155	$6,990	$10,980
95% confidence interval	($9,463-$17,492)	($12,485-$21,825)	($4,886- $9,094)	($7,923-$14,038)
Maximum time within category	$26,350	$34,379	$15,388	$22,781
95% confidence interval	($19,783-$32,917)	($26,840-$41,918)	($11,598-$19,177)	($19,948-$25,453)
N	55	38	89	79

Note: Weekly typical carer hours analysed by taking alternative values from response categories. Weekly figures multiplied by 52 weeks/year and $16.85 median caregiver wage.

Appendix Table 4.46: Total estimated yearly informal care costs using alternative assumptions, by ethnic group and sex

Informal care: all carer costs	Māori		Non-Māori	
	Women	Men	Women	Men
Main estimate				
Average	$19,197	$24,960	$10,992	$16,382
N	55	38	89	79
Total costs	$1,055,821	$948,486	$978,277	$1,294,147
95% confidence interval	($786,958-$1,324,684)	($735,995-$1,160,978)	($729,711-$1,226,844)	($989,093-$1,599,201)
Minimum cost estimate				
Average	$10,677	$10,148	$2,844	$1,907
N	25	13	48	37
Total costs	$266,916	$131,924	$136,526	$70,564
95% confidence interval	($129,179-$404,653)	($90,313-$173,535)	($84,529-$188,523)	($32,609-$108,519)
Maximum cost estimate				
Average	$35,701	$46,580	$20,849	$30,866
N	55	38	89	79
Total costs	$1,963,563	$1,770,056	$1,855,531	$2,438,427
95% confidence interval	($1,474,194-$2,452,931)	($1,381,910-$2,158,201)	($1,398,586-$2,312,475)	($1,881,245-$2,995,608)

Appendix Table 4.47: Total estimated yearly informal care costs using alternative assumptions, by LiLACS NZ participant ethnic group and sex

Informal care: all carer costs	Kaiāwhina sample	Rest of LiLACS NZ	Total
Main estimates	$4,276,732	$1,667,788	$5,944,521
Non-retired only	$1,838,706	$1,223,864	$3,062,570
Working only	$1,111,460	$1,396,741	$2,508,201
Minimum cost estimate	$605,930	$1,788,279	$2,394,209
Maximum cost estimate	$8,027,575	$3,303,838	$11,331,415

Appendix 5.1: Section 5 technical tables

The following tables provide detailed data for the key indicators presented in this section. The tables present the prevalence and number of people by sex and ethnic group and 95 percent confidence intervals for all estimates. Generalised linear models were used for analysis of potentially significant predictors of outcomes and controlled for age, sex, socioeconomic decile and ethnic group.

Significance tests were performed by constructing multivariate generalised linear regression models, all models contained as covariates sex, ethnicity, age, wave of interview and socioeconomic status of the participant's meshblock of residence (NZDep). In relation to sex, ethnicity and decile: where interaction terms between them and the variable of interest were found to be significant, separate results are presented for subgroups, for example in the case of sex, a separate model for men and a separate model for women. These interactions were investigated in the order: sex, ethnicity and decile. In this cohort study, anyone identifying themselves as Māori was classed as Māori whether other ethnicities were reported as well or not, and anyone not classing themselves as Māori was classed as non-Māori, meaning that Māori classification was prioritised. Data for this section were not imputed, those where the value of the variable was unknown were not used, hence the varying numbers in Table 5.1.

Generalised linear models were used for analysis of potentially significant predictors of outcomes and controlled for age, sex, socioeconomic decile and ethnic group.

Comparisons between those with and without three common chronic conditions and depression over time were calculated using generalised linear models controlled for age, sex, socioeconomic decile and ethnic group.

Comparisons between those with and without chronic illness and depression over time were calculated using generalised linear models controlled for age, sex, socioeconomic decile and ethnic group.

Appendix Table 5.1: Number of LiLACS NZ participants with data on each indicator

	Māori women	Non-Māori women	Māori men	Non-Māori men
NEADL				
Wave 1	154	212	102	188
Wave 2	132	195	92	175
Wave 3	97	156	58	149
Wave 4	75	129	42	117
Fried				
Wave 1	134	187	94	173
Wave 2	102	172	68	163
Wave 3	73	124	47	130
Wave 4	55	105	35	107
Physical HRQOL				
Wave 1	148	205	103	183
Wave 2	129	180	91	170
Wave 3	96	149	56	146
Wave 4	72	122	40	117

	Māori women	Non-Māori women	Māori men	Non-Māori men
Mental HRQOL				
Wave 1	148	205	103	183
Wave 2	129	180	91	170
Wave 3	96	149	56	146
Wave 4	72	122	40	117
GP Visits more than four times a year (%)				
Wave 1	155	211	101	188
Wave 2	132	193	91	175
Wave 3	96	156	57	149
Wave 4	74	128	42	117
Hospitalisations				
Wave 1	218	265	162	233
Wave 2	197	253	146	214
Wave 3	111	175	72	159
Wave 4	101	161	65	144

Note: NEADL – Nottingham Extended Activities of Daily Living Scale; HRQOL from the SF-12® summary scales

Appendix Table 5.2: LiLACS NZ participants with and without depression by ethnic group and sex, Waves 1-4

	N	Depressive Symptomatology	Māori women	Non-Māori women	Māori men	Non-Māori men
Wave 1	930 (99%)	No Depression	158 (66%)	170 (62%)	116 (66%)	161 (68%)
		Depression	83 (34%)	106 (38%)	60 (34%)	76 (32%)
Wave 2	837 (89%)	No Depression	138 (66%)	158 (61%)	99 (64%)	149 (69%)
		Depression	70 (34%)	101 (39%)	55 (36%)	67 (31%)
Wave 3	538 (57%)	No Depression	79 (65%)	112 (62%)	47 (62%)	111 (69%)
		Depression	42 (35%)	69 (38%)	29 (38%)	49 (31%)
Wave 4	491 (52%)	No Depression	73 (66%)	107 (64%)	45 (65%)	103 (71%)
		Depression	37 (34%)	59 (36%)	24 (35%)	43 (29%)

Note: Neither ethnic group nor sex are significant predictors of depression (p = 0.24 and 0.70 respectively). Numbers add to greater than participants as hospital data are included after participants dropped out.

Appendix Table 5.3: Depression and functional status, frailty, quality of life and GP visits by ethnic group and sex, Waves 1-4

	Māori women	Non-Māori women	Māori men	Non-Māori men
NEADL mean score (CI) Participants with no depression				
Wave 1	18.1 (17.3, 18.9)	18.4 (17.7, 19.1)	17.3 (16.4, 18.3)	18.6 (18.1, 19)
Wave 2	18.1 (17.4, 18.8)	18.1 (17.5, 18.7)	16.7 (15.8, 17.6)	17.5 (16.9, 18)
Wave 3	18.4 (17.6, 19.2)	17.7 (16.9, 18.5)	15.9 (14.6, 17.3)	17 (16.4, 17.7)
Wave 4	18 (17, 18.9)	17.8 (17, 18.6)	15.4 (14.1, 16.6)	17 (16.4, 17.7)
NEADL mean score (CI) Participants with depression				
Wave 1	15.8 (14.2, 17.4)	16.3 (15.3, 17.3)	16.2 (14.5, 18)	15.6 (14.3, 16.9)
Wave 2	14.9 (13.3, 16.6)	14.1 (12.6, 15.5)	13.3 (11.3, 15.2)	14.3 (13, 15.6)
Wave 3	14.9 (12.6, 17.1)	15.1 (13.7, 16.4)	14 (11.5, 16.4)	14.7 (13.3, 16.1)
Wave 4	12.6 (9.7, 15.4)	14.3 (12.6, 16)	15.3 (13, 17.6)	15.1 (13.6, 16.7)
Adjusted for sex, ethnicity, age, wave, socioeconomic decile; the NEADL score is significantly associated with depression				
Fried frailty mean score (CI) Participants with no depression				
Wave 1	0.71 (0.52, 0.91)	0.86 (0.66, 1.05)	0.66 (0.41, 0.91)	0.67 (0.49, 0.84)
Wave 2	1.17 (0.98, 1.37)	1 (0.83, 1.17)	1.11 (0.86, 1.37)	0.97 (0.81, 1.14)
Wave 3	1.1 (0.88, 1.32)	1.17 (0.98, 1.36)	0.84 (0.48, 1.19)	0.74 (0.57, 0.91)
Wave 4	1.21 (0.88, 1.53)	1.06 (0.81, 1.3)	1 (0.64, 1.36)	1.09 (0.88, 1.3)
Fried mean score (CI) Participants with depression				
Wave 1	0.98 (0.67, 1.28)	1.32 (1.03, 1.61)	1.41 (1.07, 1.76)	1.42 (1.09, 1.74)
Wave 2	1.12 (0.77, 1.47)	1.4 (1.08, 1.71)	1.58 (1.06, 2.11)	1.55 (1.26, 1.85)
Wave 3	1.18 (0.78, 1.58)	1.15 (0.83, 1.47)	0.94 (0.48, 1.39)	1.39 (1.06, 1.73)
Wave 4	1.13 (0.65, 1.6)	1.06 (0.71, 1.4)	1.08 (0.62, 1.54)	1.54 (1.12, 1.95)
Adjusted for sex, ethnicity, age, wave, socioeconomic decile; the Fried score is significantly associated with depression				
Physical HRQOL SF-12® PHC mean score (CI) Participants with no depression				
Wave 1	44.7 (42.5, 46.8)	41.9 (39.9, 43.8)	45.9 (43.2, 48.6)	44.5 (42.5, 46.5)
Wave 2	46.1 (44, 48.2)	42.4 (40.3, 44.6)	46.9 (44.1, 49.8)	46 (44.3, 47.8)
Wave 3	44.1 (41.8, 46.4)	41.9 (39.5, 44.2)	46 (43.3, 48.8)	44.9 (42.8, 46.9)
Wave 4	46.2 (43.8, 48.7)	43.5 (41.2, 45.8)	41.7 (38.1, 45.3)	44.8 (42.7, 46.9)
Physical HRQOL SF-12® PHC mean score (CI) Participants with depression				
Wave 1	37.1 (33.8, 40.4)	36.1 (33.3, 38.9)	42.7 (39.4, 45.9)	39.7 (36.3, 43)
Wave 2	40.3 (37.1, 43.5)	37.8 (34.7, 40.9)	37.7 (33.9, 41.4)	40 (36.6, 43.5)
Wave 3	38 (34.3, 41.6)	36.1 (33.1, 39.2)	40.9 (35.7, 46.1)	40.8 (37.1, 44.4)
Wave 4	39.3 (35.3, 43.2)	34.9 (31.5, 38.3)	43.5 (38.7, 48.3)	38.9 (35.5, 42.2)
Adjusted for sex, ethnicity, age, wave, socioeconomic decile; the SF-12® PHC score is significantly associated with depression				
Mental HRQOL SF-12® MHC mean score (CI) Participants with no depression				
Wave 1	54.7 (53.2, 56.2)	56.8 (55.7, 58)	54.8 (53, 56.6)	57 (55.9, 58.1)
Wave 2	54.5 (52.5, 56.4)	57.4 (56.3, 58.5)	55 (52.9, 57)	55.7 (54.6, 56.7)
Wave 3	56.1 (54.3, 58)	57.2 (55.8, 58.5)	56.1 (53.4, 58.7)	56.9 (55.7, 58.1)
Wave 4	57.2 (55.4, 59)	57.3 (55.8, 58.7)	57.3 (55.2, 59.3)	56.4 (55, 57.8)

	Māori women	Non-Māori women	Māori men	Non-Māori men
Mental HRQOL SF-12® MHC mean score (CI) Participants with depression				
Wave 1	51.1 (48, 54.2)	51.7 (49.3, 54.1)	49 (45.4, 52.6)	51.1 (48.5, 53.8)
Wave 2	51.1 (48.2, 54)	49.8 (46.9, 52.6)	50 (47.4, 52.7)	52.6 (50.2, 55)
Wave 3	53.8 (50.4, 57.3)	51.7 (48.9, 54.4)	47.4 (41.9, 52.9)	52.8 (50.2, 55.3)
Wave 4	52.9 (49.2, 56.7)	54.1 (51.5, 56.7)	49.6 (43.9, 55.2)	52.5 (49.6, 55.4)
Adjusted for sex, ethnicity, age, wave, socioeconomic decile; the SF-12® MHC score is significantly associated with depression				
GP Visits more than four times a year Percentage of participants with no depression				
Wave 1	15 (9, 23)	10 (5, 16)	22 (13, 33)	15 (9, 23)
Wave 2	17 (10, 27)	13 (8, 21)	15 (7, 28)	8 (4, 15)
Wave 3	16 (8, 28)	20 (12, 29)	13 (4, 28)	11 (5, 18)
Wave 4	12 (5, 24)	13 (6, 22)	4 (0, 19)	17 (9, 26)
GP Visits more than four times a year Percentage of participants with depression				
Wave 1	26 (14, 40)	10 (5, 19)	44 (26, 62)	26 (14, 40)
Wave 2	31 (18, 45)	27 (18, 39)	31 (17, 48)	27 (16, 41)
Wave 3	26 (13, 44)	27 (16, 40)	32 (13, 57)	26 (14, 41)
Wave 4	25 (10, 47)	19 (9, 33)	40 (16, 68)	18 (7, 35)
Adjusted for sex, ethnicity, age, wave, socioeconomic decile; visiting a GP more than four times a year is significantly associated with depression				

Note: For all variables in this table depression is significantly associated (p < 0.0001).

Appendix Table 5.4: Depression and hospital admissions per person year by ethnic group and sex, Waves 1-4

		W1 - W2	W2 - W3	W3 - W4	W4 + one year
Māori women	No Depression	0.66 (0.54, 0.79)	0.5 (0.39, 0.61)	0.69 (0.56, 0.82)	1.04 (0.88, 1.2)
	Depression	1.25 (1.01, 1.49)	0.9 (0.69, 1.1)	0.97 (0.76, 1.18)	1.2 (0.97, 1.44)
Non-Māori women	No Depression	0.47 (0.37, 0.58)	0.62 (0.5, 0.73)	0.6 (0.49, 0.72)	0.6 (0.48, 0.71)
	Depression	0.79 (0.62, 0.96)	0.87 (0.69, 1.05)	1.16 (0.95, 1.36)	0.87 (0.7, 1.05)
Māori men	No Depression	0.71 (0.55, 0.86)	0.79 (0.62, 0.95)	0.93 (0.76, 1.11)	1.04 (0.85, 1.22)
	Depression	1.29 (1, 1.58)	1.37 (1.07, 1.67)	1 (0.75, 1.26)	1.43 (1.12, 1.73)
Non-Māori men	No Depression	1.03 (0.87, 1.19)	0.91 (0.76, 1.05)	0.91 (0.76, 1.06)	0.99 (0.83, 1.14)
	Depression	1.35 (1.09, 1.61)	1.23 (0.98, 1.47)	1.5 (1.23, 1.78)	1.14 (0.9, 1.38)

Note: Total number of hospital admissions per person year. Depression is a significant predictor (p < 0.0001).

Appendix Table 5.5: Depression and length of stay in hospital by ethnic group and sex, Waves 1-4

		W1 - W2	W2 - W3	W3 - W4	W4 + one year
Māori women	No Depression	5.04 (4.69, 5.39)	3.24 (2.96, 3.52)	3.45 (3.16, 3.74)	4.79 (4.45, 5.13)
	Depression	7.35 (6.77, 7.94)	3.89 (3.46, 4.31)	4.33 (3.88, 4.77)	4.71 (4.24, 5.18)
Non-Māori women	No Depression	2.03 (1.82, 2.25)	2.19 (1.96, 2.41)	4.52 (4.2, 4.84)	3.89 (3.59, 4.18)
	Depression	5.83 (5.37, 6.29)	4.23 (3.84, 4.62)	6.65 (6.16, 7.15)	6.1 (5.63, 6.57)
Māori men	No Depression	3.29 (2.96, 3.62)	2.58 (2.29, 2.87)	3.07 (2.75, 3.39)	3.31 (2.97, 3.64)
	Depression	6.84 (6.17, 7.5)	6.64 (5.99, 7.3)	3.05 (2.61, 3.49)	9.05 (8.29, 9.81)
Non-Māori men	No Depression	7.82 (7.38, 8.25)	5.48 (5.12, 5.84)	4.01 (3.7, 4.32)	3.22 (2.94, 3.5)
	Depression	7.57 (6.95, 8.19)	11.45 (10.69, 12.21)	6.72 (6.14, 7.3)	5.61 (5.08, 6.15)

Note: Total number of nights in hospital per person year. Depression is a significant predictor ($p < 0.0001$).

Appendix Table 5.6: Depression and hospitalisation costs by participants with and without depression

	W1 - W2	W2 - W3	W3 - W4	W4 + one year
No Depression	$5,042.65	$3,640.09	$4,743.40	$4,291.40
Depression	$6,824.25	$6,403.81	$6,473.16	$5,883.58

Note: Calculations based on 2015 NZ dollar costs per person per year. Depression is a significant predictor ($p < 0.0001$).

Appendix Table 5.7: Cardiovascular disease and depression by ethnic group and sex, Waves 1-4

		Wave 1	Wave 2	Wave 3	Wave 4
Māori women	Neither	65 (27%)	62 (30%)	36 (30%)	36 (33%)
	CVD only	91 (38%)	74 (36%)	43 (36%)	37 (34%)
	Depression only	13 (5%)	12 (6%)	7 (6%)	6 (6%)
	Both	69 (29%)	57 (28%)	34 (28%)	30 (28%)
Non-Māori women	Neither	65 (24%)	62 (24%)	49 (27%)	48 (29%)
	CVD only	104 (38%)	95 (37%)	63 (35%)	59 (36%)
	Depression only	28 (10%)	27 (10%)	18 (10%)	18 (11%)
	Both	78 (28%)	74 (29%)	51 (28%)	41 (25%)
Māori men	Neither	39 (23%)	32 (21%)	18 (24%)	18 (26%)
	CVD only	74 (43%)	64 (42%)	29 (38%)	27 (39%)
	Depression only	17 (10%)	15 (10%)	7 (9%)	5 (7%)
	Both	43 (25%)	40 (26%)	22 (29%)	19 (28%)
Non-Māori men	Neither	61 (26%)	57 (26%)	46 (29%)	46 (32%)
	CVD only	100 (42%)	92 (43%)	65 (41%)	57 (39%)
	Depression only	17 (7%)	14 (6%)	11 (7%)	9 (6%)
	Both	59 (25%)	53 (25%)	38 (24%)	34 (23%)

Note: Neither ethnic group nor sex are significant predictors of CVD:depression ($p = 0.56$ and 0.92 respectively).

Appendix Table 5.8: Cardiovascular disease, depression and functional status, frailty, quality of life and GP visits, by ethnic group and sex, Waves 1-4

	Māori women	Non-Māori women	Māori men	Non-Māori men
NEADL mean score (CI) Neither CVD nor depression				
Wave 1	19.1 (18, 20.2)	18.8 (17.7, 19.8)	18.8 (17.2, 20.4)	19 (18.2, 19.8)
Wave 2	19.3 (18.7, 20)	18.3 (17.2, 19.3)	17.5 (15.9, 19)	17.9 (17.2, 18.7)
Wave 3	19.3 (18.5, 20.1)	17.9 (16.6, 19.1)	16.7 (12.7, 20.7)	17 (16.2, 17.9)
Wave 4	18.5 (17.4, 19.6)	17.7 (16.5, 18.9)	16.8 (14.9, 18.8)	17.2 (16.2, 18.3)
NEADL mean score (CI) CVD only				
Wave 1	17.4 (16.2, 18.6)	18.1 (17.2, 19.1)	17 (16, 17.9)	18.3 (17.8, 18.9)
Wave 2	17.1 (15.9, 18.2)	17.9 (17.2, 18.7)	16.4 (15.2, 17.5)	17.2 (16.4, 18)
Wave 3	17.5 (16.2, 18.9)	17.6 (16.6, 18.6)	15.6 (14.5, 16.8)	17 (16.2, 17.9)
Wave 4	17.4 (15.8, 18.9)	17.9 (16.8, 19)	15 (13.4, 16.5)	16.8 (16, 17.7)
NEADL mean score (CI) Participants with depression only				
Wave 1	15.9 (11.5, 20.2)	17.3 (15.6, 19)	15.3 (11, 19.6)	16.3 (13.1, 19.4)
Wave 2	14.1 (7.3, 20.9)	15.5 (12.7, 18.2)	14.5 (11.5, 17.6)	14.8 (12.3, 17.4)
Wave 3	14.8 (8, 21.6)	16.8 (14.4, 19.2)	15.2 (12.5, 17.9)	15.1 (11.7, 18.5)
Wave 4	15.7 (0.5, 30.8)	14.8 (11.6, 17.9)	14 (12.7, 15.3)	16.6 (12.3, 20.8)
NEADL mean score (CI) Participants with CVD and depression				
Wave 1	15.8 (14, 17.5)	15.9 (14.6, 17.1)	16.6 (14.7, 18.6)	15.4 (14, 16.9)
Wave 2	15 (13.3, 16.8)	13.5 (11.7, 15.4)	12.8 (10.3, 15.2)	14.1 (12.6, 15.7)
Wave 3	14.8 (12.2, 17.3)	14.4 (12.8, 16)	13.5 (10.3, 16.8)	14.6 (13, 16.2)
Wave 4	11.7 (8.6, 14.9)	14.1 (12, 16.2)	15.8 (12.6, 19.1)	14.7 (13, 16.5)
Adjusted for sex, ethnicity, age, wave, socioeconomic decile; the NEADL score is significantly associated with CVD:depression				
Fried mean score (CI) Neither CVD nor depression				
Wave 1	0.43 (0.17, 0.7)	0.73 (0.47, 0.99)	0.43 (0.06, 0.8)	0.52 (0.24, 0.81)
Wave 2	1.28 (1.02, 1.54)	1.04 (0.77, 1.32)	1.13 (0.7, 1.55)	1.11 (0.84, 1.39)
Wave 3	1 (0.65, 1.35)	1.22 (0.89, 1.56)	0.57 (0.08, 1.07)	0.79 (0.52, 1.06)
Wave 4	1 (0.41, 1.59)	1.09 (0.72, 1.46)	0.8 (-0.24, 1.84)	1.08 (0.75, 1.4)
Fried mean score (CI) CVD only				
Wave 1	0.91 (0.64, 1.18)	0.94 (0.66, 1.22)	0.77 (0.45, 1.1)	0.74 (0.52, 0.97)
Wave 2	1.08 (0.79, 1.37)	0.97 (0.74, 1.2)	1.11 (0.77, 1.45)	0.89 (0.69, 1.09)
Wave 3	1.19 (0.89, 1.48)	1.13 (0.9, 1.35)	0.92 (0.47, 1.36)	0.7 (0.47, 0.94)
Wave 4	1.38 (1.01, 1.75)	1.03 (0.68, 1.37)	1.06 (0.63, 1.48)	1.1 (0.81, 1.39)
Fried mean score (CI) Participants with depression only				
Wave 1	1.25 (0.28, 2.22)	0.71 (0.27, 1.14)	1.11 (0.3, 1.92)	1 (0.28, 1.72)
Wave 2	0.25 (-0.55, 1.05)	0.75 (0.29, 1.21)	1.22 (0.15, 2.29)	1.42 (0.73, 2.11)
Wave 3	0.75 (-0.05, 1.55)	0.73 (0.2, 1.26)	0 (0, 0)	1.13 (0.08, 2.17)
Wave 4	1.67 (-1.2, 4.54)	1.08 (0.5, 1.65)	0.67 (-0.77, 2.1)	1.29 (0.41, 2.17)

	Māori women	Non-Māori women	Māori men	Non-Māori men
Fried mean score (CI) Participants with CVD and depression				
Wave 1	0.91 (0.59, 1.24)	1.52 (1.18, 1.86)	1.55 (1.16, 1.94)	1.54 (1.17, 1.9)
Wave 2	1.24 (0.87, 1.62)	1.62 (1.24, 2)	1.8 (1.17, 2.43)	1.6 (1.26, 1.94)
Wave 3	1.28 (0.8, 1.75)	1.3 (0.91, 1.69)	1.25 (0.77, 1.73)	1.47 (1.1, 1.83)
Wave 4	1.08 (0.58, 1.59)	1.05 (0.58, 1.51)	1.2 (0.64, 1.76)	1.62 (1.11, 2.13)
Adjusted for sex, ethnicity, age, wave, socioeconomic decile; the Fried score is significantly associated with CVD:depression				
Physical HRQOL SF-12® PHC mean score (CI) Neither CVD nor depression				
Wave 1	50.5 (48, 53)	44.6 (41.5, 47.6)	47.8 (42.9, 52.7)	48.8 (46, 51.5)
Wave 2	49.8 (47, 52.7)	45.5 (42.3, 48.7)	50 (44.7, 55.4)	48.9 (46.5, 51.4)
Wave 3	48.1 (45.6, 50.6)	45.5 (42.4, 48.5)	48.1 (42.5, 53.7)	47.4 (44.5, 50.4)
Wave 4	48.1 (45, 51.2)	45.8 (42.7, 48.8)	44.8 (38.6, 50.9)	46.2 (43.1, 49.4)
Physical HRQOL SF-12® PHC mean score (CI) Participants with CVD only				
Wave 1	40.5 (37.7, 43.3)	40.1 (37.5, 42.6)	44.7 (41.4, 48.1)	42.1 (39.5, 44.7)
Wave 2	42.9 (40, 45.8)	40.3 (37.5, 43.2)	45.5 (42.1, 49)	44.3 (42, 46.6)
Wave 3	40.3 (36.9, 43.7)	39 (35.7, 42.3)	45.1 (41.8, 48.4)	43.1 (40.4, 45.9)
Wave 4	44.2 (40.4, 48.1)	41.5 (38.1, 44.8)	40.8 (36.2, 45.3)	43.6 (40.6, 46.5)
Physical HRQOL SF-12® PHC mean score (CI) Participants with depression only				
Wave 1	37 (27.7, 46.3)	38.1 (32.9, 43.2)	44.9 (39.2, 50.6)	45 (38.7, 51.4)
Wave 2	37.2 (26.1, 48.3)	37.1 (30.1, 44.1)	42.1 (36.5, 47.8)	44.6 (37.1, 52.1)
Wave 3	32 (16.5, 47.5)	35.4 (29, 41.8)	48.9 (44.8, 53.1)	46 (36.5, 55.4)
Wave 4	46.5 (29.6, 63.4)	34.4 (26.5, 42.2)	46.8 (38.6, 54.9)	42.8 (34.7, 50.8)
Physical HRQOL SF-12® PHC mean score (CI) Participants with CVD and depression				
Wave 1	37.1 (33.4, 40.9)	35.4 (31.9, 38.8)	41.7 (37.4, 45.9)	37.9 (33.9, 41.9)
Wave 2	40.7 (37.1, 44.2)	38.1 (34.5, 41.6)	36 (31.3, 40.7)	38.8 (34.8, 42.8)
Wave 3	39.5 (35.6, 43.3)	36.4 (32.8, 40)	38 (31.6, 44.4)	39.4 (35.3, 43.4)
Wave 4	37.9 (33.4, 42.3)	35.2 (31.4, 39)	42.2 (35.6, 48.9)	37.8 (33.9, 41.7)
Adjusted for sex, ethnicity, age, wave, socioeconomic decile; the SF-12® PHC score is significantly associated with CVD:depression				
Mental HRQOL SF-12® MHC mean score (CI) Neither CVD nor depression				
Wave 1	54 (52, 56)	56.4 (54.4, 58.3)	54 (51.3, 56.6)	57.6 (56.2, 59.1)
Wave 2	55.4 (53, 57.7)	57.5 (55.9, 59.1)	53.3 (49.2, 57.4)	55.7 (54.1, 57.4)
Wave 3	55.4 (52.2, 58.5)	56.9 (55.2, 58.6)	57 (54.1, 59.9)	56.4 (54.4, 58.3)
Wave 4	56.2 (53.7, 58.7)	56.7 (54.4, 59)	56.6 (51, 62.2)	57.7 (56.2, 59.1)
Mental HRQOL SF-12® MHC mean score (CI) Participants with CVD only				
Wave 1	55.3 (53.1, 57.4)	57.1 (55.7, 58.6)	55.1 (52.7, 57.5)	56.7 (55.2, 58.2)
Wave 2	53.7 (50.7, 56.7)	57.3 (55.7, 58.9)	55.7 (53.3, 58.1)	55.6 (54.2, 57.1)
Wave 3	56.8 (54.6, 59)	57.4 (55.4, 59.4)	55.7 (52, 59.3)	57.2 (55.6, 58.8)
Wave 4	58.1 (55.4, 60.9)	57.7 (55.9, 59.6)	57.4 (55, 59.9)	55.3 (52.9, 57.7)

	Māori women	Non-Māori women	Māori men	Non-Māori men
Mental HRQOL SF-12® MHC mean score (CI) Participants with depression only				
Wave 1	52.9 (45.6, 60.1)	50 (44.9, 55.1)	48.8 (40, 57.6)	52.2 (48.5, 55.9)
Wave 2	55.9 (46.6, 65.2)	50.9 (44.5, 57.3)	50.1 (44.5, 55.7)	50.6 (42.9, 58.2)
Wave 3	58.5 (49.4, 67.7)	53.8 (47.8, 59.7)	50.1 (42, 58.2)	53.4 (47.2, 59.6)
Wave 4	55.1 (49.5, 60.7)	54.5 (50.4, 58.6)	47.7 (41.4, 54)	51.9 (44.8, 59)
Mental HRQOL SF-12® MHC mean score (CI) Participants with CVD and depression				
Wave 1	50.8 (47.3, 54.4)	52.3 (49.5, 55.1)	49.1 (45, 53.2)	50.8 (47.5, 54.1)
Wave 2	51 (48, 54)	49.4 (46.1, 52.7)	50 (46.8, 53.2)	53.1 (50.7, 55.5)
Wave 3	52.6 (48.7, 56.5)	50.9 (47.7, 54.2)	46.5 (39.1, 53.8)	52.6 (49.7, 55.5)
Wave 4	52.7 (48, 57.3)	54 (50.5, 57.4)	50.3 (42.1, 58.5)	52.7 (49.3, 56.1)
Adjusted for sex, ethnicity, age, wave, socioeconomic decile; the SF-12® MHC score is significantly associated with CVD:depression				
GP Visits more than four times a year Percentage of participants with neither CVD nor depression				
Wave 1	2 (0, 12)	6 (1, 16)	13 (3, 34)	2 (0, 12)
Wave 2	8 (2, 21)	13 (5, 25)	6 (0, 29)	2 (0, 12)
Wave 3	10 (2, 27)	17 (7, 31)	100 (72, 100)	5 (1, 16)
Wave 4	4 (0, 20)	5 (1, 18)	100 (54, 100)	10 (3, 24)
GP Visits more than four times a year Percentage of participants with CVD only				
Wave 1	24 (14, 36)	13 (6, 22)	26 (14, 41)	24 (14, 36)
Wave 2	24 (13, 40)	14 (7, 24)	20 (8, 37)	12 (6, 21)
Wave 3	22 (9, 40)	22 (12, 35)	19 (6, 38)	15 (7, 26)
Wave 4	21 (7, 42)	19 (9, 34)	5 (0, 24)	22 (11, 37)
GP Visits more than four times a year Percentage of participants with depression only				
Wave 1	13 (0, 53)	9 (1, 29)	40 (12, 74)	13 (0, 53)
Wave 2	29 (4, 71)	25 (9, 49)	27 (6, 61)	42 (15, 72)
Wave 3	100 (48, 100)	6 (0, 30)	100 (48, 100)	20 (3, 56)
Wave 4	33 (1, 91)	13 (2, 38)	25 (1, 81)	14 (0, 58)
GP Visits more than four times a year Percentage of participants with CVD and depression				
Wave 1	28 (15, 45)	11 (4, 22)	45 (24, 68)	28 (15, 45)
Wave 2	32 (18, 48)	28 (17, 42)	32 (16, 52)	23 (12, 39)
Wave 3	32 (16, 52)	35 (21, 51)	43 (18, 71)	28 (14, 45)
Wave 4	25 (9, 49)	22 (9, 40)	45 (17, 77)	19 (7, 39)
Adjusted for sex, ethnicity, age, wave, socioeconomic decile; visiting a GP more than four times a year is significantly associated with CVD:depression				

Note: For all variables in this table CVD-depression is a significant predictor (p < 0.0001).

Appendix Table 5.9: Cardiovascular disease, depression and hospital admissions per person year by ethnic group and sex, Waves 1-4

		W1 - W2	W2 - W3	W3 - W4	W4 + one year
Māori women	Neither	0.3 (0.16, 0.43)	0.22 (0.11, 0.34)	0.58 (0.39, 0.76)	0.91 (0.68, 1.14)
	CVD only	0.92 (0.72, 1.11)	0.63 (0.47, 0.8)	0.79 (0.61, 0.97)	1.15 (0.93, 1.37)
	Depression only	0.37 (0.04, 0.7)	0.25 (-0.02, 0.52)	0.14 (-0.06, 0.35)	0.45 (0.09, 0.82)
	Both	1.45 (1.17, 1.73)	1.05 (0.8, 1.29)	1.17 (0.92, 1.43)	1.41 (1.13, 1.69)
Non-Māori women	Neither	0.37 (0.22, 0.51)	0.49 (0.32, 0.66)	0.29 (0.16, 0.42)	0.61 (0.42, 0.79)
	CVD only	0.55 (0.4, 0.69)	0.71 (0.55, 0.87)	0.85 (0.68, 1.03)	0.59 (0.45, 0.74)
	Depression only	0.7 (0.39, 1.01)	0.85 (0.51, 1.2)	0.89 (0.54, 1.24)	1.2 (0.8, 1.61)
	Both	0.83 (0.63, 1.03)	0.88 (0.67, 1.08)	1.26 (1.01, 1.51)	0.74 (0.55, 0.93)
Māori men	Neither	0.45 (0.24, 0.65)	0.67 (0.42, 0.93)	0.43 (0.22, 0.63)	0.63 (0.38, 0.88)
	CVD only	0.88 (0.67, 1.09)	0.87 (0.66, 1.09)	1.24 (0.99, 1.5)	1.3 (1.04, 1.56)
	Depression only	0.55 (0.2, 0.9)	1.14 (0.63, 1.65)	1.54 (0.95, 2.13)	1.4 (0.84, 1.96)
	Both	1.58 (1.2, 1.95)	1.48 (1.11, 1.84)	0.87 (0.59, 1.15)	1.43 (1.08, 1.79)
Non-Māori men	Neither	0.64 (0.44, 0.84)	0.76 (0.54, 0.98)	0.9 (0.66, 1.13)	0.64 (0.44, 0.84)
	CVD only	1.27 (1.05, 1.49)	1 (0.8, 1.19)	0.92 (0.73, 1.11)	1.26 (1.04, 1.48)
	Depression only	1.35 (0.8, 1.9)	0.55 (0.2, 0.9)	1.41 (0.84, 1.97)	0.27 (0.02, 0.51)
	Both	1.35 (1.06, 1.65)	1.39 (1.09, 1.69)	1.53 (1.21, 1.84)	1.4 (1.09, 1.7)

Note: CVD;depression is a significant predictor for hospital admissions (p < 0.0001).

Appendix Table 5.10: Cardiovascular disease, depression and length of stay in hospital by ethnic group and sex, Waves 1-4

Days in hospital		W1 - W2	W2 - W3	W3 - W4	W4 + one year
Māori women	Neither	1.36 (1.07, 1.64)	1.18 (0.92, 1.45)	4.36 (3.86, 4.87)	5.59 (5.02, 6.16)
	CVD only	7.63 (7.06, 8.19)	4.1 (3.69, 4.52)	2.59 (2.26, 2.92)	4.14 (3.72, 4.56)
	Depression only	2.81 (1.9, 3.72)	0.41 (0.06, 0.76)	1.57 (0.89, 2.25)	4.96 (3.75, 6.17)
	Both	8.39 (7.7, 9.07)	4.67 (4.16, 5.18)	5.04 (4.51, 5.57)	4.88 (4.36, 5.41)
Non-Māori women	Neither	0.64 (0.45, 0.84)	1.4 (1.12, 1.69)	3.37 (2.93, 3.81)	2.77 (2.36, 3.17)
	CVD only	2.96 (2.63, 3.29)	2.74 (2.42, 3.05)	5.44 (4.99, 5.89)	4.79 (4.37, 5.21)
	Depression only	5 (4.17, 5.83)	4.43 (3.65, 5.2)	3.81 (3.09, 4.53)	4.74 (3.94, 5.55)
	Both	6.13 (5.58, 6.68)	4.16 (3.71, 4.61)	7.73 (7.11, 8.34)	6.64 (6.07, 7.21)

Days in hospital		W1 - W2	W2 - W3	W3 - W4	W4 + one year
Māori men	Neither	2.07 (1.62, 2.52)	3.77 (3.16, 4.38)	2.41 (1.93, 2.9)	0.92 (0.62, 1.22)
	CVD only	4.11 (3.64, 4.57)	1.96 (1.64, 2.28)	3.47 (3.04, 3.89)	4.88 (4.38, 5.38)
	Depression only	6.68 (5.45, 7.91)	6.33 (5.13, 7.52)	5.77 (4.63, 6.91)	3.5 (2.61, 4.39)
	Both	6.9 (6.11, 7.68)	6.79 (6.01, 7.57)	2.37 (1.91, 2.83)	10.76 (9.78, 11.74)
Non-Māori men	Neither	7.15 (6.48, 7.82)	1.71 (1.38, 2.04)	3.99 (3.49, 4.5)	1.48 (1.17, 1.79)
	CVD only	8.23 (7.67, 8.79)	7.85 (7.3, 8.4)	4.02 (3.63, 4.42)	4.6 (4.18, 5.02)
	Depression only	6.35 (5.15, 7.55)	5 (3.94, 6.07)	3.76 (2.84, 4.68)	0.27 (0.02, 0.51)
	Both	7.9 (7.18, 8.62)	13.05 (12.12, 13.97)	7.54 (6.84, 8.24)	7.17 (6.49, 7.86)

Note: CVD:depression is a significant predictor for length of stay in hospital (p < 0.0001).

Appendix Table 5.11: Cardiovascular disease, depression and hospitalisation costs, Waves 1-4

	W1 - W2	W2 - W3	W3 - W4	W4 + one year
Neither	$3,201.61	$2,297.63	$4,351.22	$3,846.31
CVD only	$6,277.73	$4,394.12	$5,051.06	$4,638.03
Depression only	$6,171.23	$4,181.77	$4,459.75	$4,093.81
Both	$7,051.40	$7,120.53	$7,110.04	$6,506.50

Note: CVD:depression is a significant predictor for hospitalisation costs (p < 0.0001).

Appendix Table 5.12: Chronic lung disease and depression by ethnic group and sex, Waves 1-4

		Wave 1	Wave 2	Wave 3	Wave 4
Māori women	Neither	108 (48%)	99 (49%)	55 (48%)	51 (49%)
	CLD only	43 (19%)	35 (17%)	19 (17%)	18 (17%)
	Depression only	42 (19%)	36 (18%)	20 (17%)	17 (16%)
	Both	34 (15%)	32 (16%)	21 (18%)	19 (18%)
Non-Māori women	Neither	122 (45%)	117 (46%)	81 (45%)	77 (47%)
	CLD only	43 (16%)	40 (16%)	30 (17%)	29 (18%)
	Depression only	71 (26%)	68 (26%)	48 (27%)	43 (26%)
	Both	34 (13%)	32 (12%)	20 (11%)	16 (10%)
Māori men	Neither	77 (45%)	69 (45%)	34 (45%)	33 (48%)
	CLD only	37 (22%)	30 (20%)	13 (17%)	12 (17%)
	Depression only	32 (19%)	30 (20%)	18 (24%)	16 (23%)
	Both	25 (15%)	23 (15%)	11 (14%)	8 (12%)
Non-Māori men	Neither	123 (53%)	116 (54%)	86 (54%)	81 (56%)
	CLD only	36 (15%)	32 (15%)	24 (15%)	21 (14%)
	Depression only	54 (23%)	47 (22%)	37 (23%)	33 (23%)
	Both	21 (9%)	19 (9%)	12 (8%)	10 (7%)

Note: Neither ethnic group nor sex are significant predictors of CLD:depression (p = 0.25 and 0.20 respectively).

Appendix Table 5.13: Chronic lung disease, depression and functional status, frailty, quality of life and GP visits, by ethnic group and sex, Waves 1-4

	Māori women	Non-Māori women	Māori men	Non-Māori men
NEADL mean score (CI) Participants with neither CLD nor depression				
Wave 1	18.5 (17.4, 19.5)	18.7 (17.9, 19.5)	17 (15.6, 18.4)	18.7 (18.2, 19.2)
Wave 2	18.4 (17.6, 19.1)	18.6 (17.9, 19.2)	16.5 (15.2, 17.7)	17.6 (17, 18.2)
Wave 3	18.2 (17.2, 19.2)	18.1 (17.2, 19)	15.3 (13.6, 17.1)	17.4 (16.8, 18)
Wave 4	17.7 (16.6, 18.9)	18.1 (17.2, 19)	15.2 (13.4, 17)	17.2 (16.5, 17.9)
NEADL mean score (CI) Participants with CLD only				
Wave 1	17.1 (15.5, 18.6)	17.5 (16.1, 18.9)	17.8 (16.8, 18.9)	18.2 (17.2, 19.2)
Wave 2	17.9 (16.6, 19.2)	16.8 (15.3, 18.2)	17.2 (15.9, 18.6)	17 (15.6, 18.5)
Wave 3	18.7 (17.1, 20.2)	16.7 (15.1, 18.3)	17.5 (16.1, 18.8)	15.9 (14.2, 17.6)
Wave 4	18.3 (16.6, 20)	17 (15.2, 18.7)	15.9 (14.6, 17.2)	16.2 (14.2, 18.3)
NEADL mean score (CI) Participants with depression only				
Wave 1	15.8 (13.5, 18.1)	16.7 (15.5, 17.9)	18.6 (17.5, 19.7)	15.4 (13.9, 16.9)
Wave 2	15.5 (13.4, 17.6)	14.2 (12.3, 16)	16 (14.3, 17.7)	14 (12.4, 15.6)
Wave 3	15.9 (13.3, 18.6)	15.5 (13.8, 17.1)	15 (12.2, 17.8)	14 (12.3, 15.7)
Wave 4	13.5 (9, 18)	13.9 (11.8, 16.1)	14.8 (11.8, 17.8)	14.5 (12.4, 16.5)
NEADL mean score (CI) Participants with both CLD and depression				
Wave 1	16 (13.4, 18.5)	15.3 (13.5, 17.2)	13.3 (9.9, 16.7)	16.2 (13.5, 18.9)
Wave 2	14.3 (11.5, 17.1)	14.1 (11.3, 16.9)	9.1 (5.9, 12.4)	15.4 (13.1, 17.6)
Wave 3	13.6 (9.7, 17.5)	14.1 (11.9, 16.2)	12 (6.6, 17.4)	16.7 (14.4, 18.9)
Wave 4	10.9 (6.7, 15.1)	15.4 (12.8, 18)	16.8 (11.7, 21.8)	16.9 (15.4, 18.4)
Adjusted for sex, ethnicity, age, wave, socioeconomic decile; the NEADL score is significantly associated with CLD:depression				
Fried mean score (CI) Participants with neither CLD nor depression				
Wave 1	0.61 (0.4, 0.82)	0.75 (0.54, 0.95)	0.6 (0.3, 0.89)	0.57 (0.38, 0.76)
Wave 2	1.14 (0.91, 1.37)	0.88 (0.7, 1.06)	1.23 (0.89, 1.56)	0.98 (0.79, 1.16)
Wave 3	1.16 (0.91, 1.42)	1.21 (0.99, 1.43)	0.87 (0.39, 1.35)	0.73 (0.53, 0.92)
Wave 4	1.27 (0.88, 1.66)	0.94 (0.65, 1.23)	1.06 (0.61, 1.52)	1.08 (0.84, 1.31)
Fried mean score (CI) Participants with CLD only				
Wave 1	1 (0.53, 1.47)	1.15 (0.7, 1.59)	0.78 (0.3, 1.27)	0.97 (0.57, 1.37)
Wave 2	1.28 (0.87, 1.69)	1.28 (0.88, 1.68)	0.85 (0.51, 1.18)	0.96 (0.59, 1.33)
Wave 3	0.92 (0.34, 1.49)	1.05 (0.63, 1.47)	0.75 (0.36, 1.14)	0.77 (0.36, 1.18)
Wave 4	1 (0.23, 1.77)	1.33 (0.83, 1.84)	0.83 (0.04, 1.62)	1.13 (0.58, 1.68)
Fried mean score (CI) Participants with depression only				
Wave 1	0.74 (0.32, 1.16)	1.13 (0.85, 1.4)	0.93 (0.45, 1.41)	1.38 (1, 1.76)
Wave 2	1 (0.55, 1.45)	1.38 (1, 1.76)	1.25 (0.54, 1.96)	1.63 (1.25, 2)
Wave 3	1.09 (0.46, 1.73)	1.1 (0.72, 1.48)	0.5 (-0.01, 1.01)	1.41 (0.99, 1.82)
Wave 4	1 (0.62, 1.38)	1.09 (0.64, 1.54)	1.11 (0.51, 1.71)	1.74 (1.18, 2.29)

	Māori women	Non-Māori women	Māori men	Non-Māori men
Fried mean score (CI) Participants with both CLD and depression				
Wave 1	1.23 (0.75, 1.7)	1.76 (1.06, 2.47)	1.79 (1.38, 2.19)	1.5 (0.83, 2.17)
Wave 2	1.27 (0.66, 1.88)	1.44 (0.82, 2.06)	2.25 (1.66, 2.84)	1.4 (0.9, 1.9)
Wave 3	1.27 (0.67, 1.88)	1.27 (0.59, 1.95)	1.67 (1.12, 2.21)	1.36 (0.67, 2.05)
Wave 4	1.5 (0.21, 2.79)	1 (0.39, 1.61)	1 (-0.3, 2.3)	1.11 (0.51, 1.71)
Adjusted for sex, ethnicity, age, wave, socioeconomic decile; the Fried score is significantly associated with CLD:depression				
Physical HRQOL SF-12® PHC mean score (CI) Participants with neither CLD nor depression				
Wave 1	45.8 (43.2, 48.3)	43.2 (41, 45.4)	46.9 (43.4, 50.3)	45.7 (43.5, 48)
Wave 2	47.3 (45.2, 49.4)	43.1 (40.6, 45.6)	48.2 (44.5, 51.9)	46.7 (44.7, 48.7)
Wave 3	44.9 (42.2, 47.5)	43.6 (41, 46.2)	46.3 (42.9, 49.6)	46.4 (44.2, 48.6)
Wave 4	46 (43, 48.9)	43.7 (41.1, 46.4)	41.1 (36.8, 45.5)	45.6 (43.2, 48)
Physical HRQOL SF-12® PHC mean score (CI) Participants with CLD only				
Wave 1	41.1 (37.2, 45.1)	38.4 (34.1, 42.6)	43.5 (38.8, 48.2)	40.5 (36.3, 44.7)
Wave 2	43.7 (38.1, 49.3)	40.5 (36, 45.1)	44.6 (40, 49.3)	43.8 (40.3, 47.2)
Wave 3	40 (34.4, 45.5)	36.9 (31.9, 41.8)	45.3 (39.6, 51)	40 (35.1, 44.8)
Wave 4	46.5 (40.4, 52.6)	42.4 (37.6, 47.2)	43 (34.6, 51.3)	41.7 (36.7, 46.8)
Physical HRQOL SF-12® PHC mean score (CI) Participants with depression only				
Wave 1	37.8 (32, 43.6)	37.7 (34.3, 41)	46 (41.3, 50.8)	40.1 (36.2, 44)
Wave 2	43.6 (38.8, 48.5)	39.2 (35.5, 42.9)	42.4 (37.8, 47)	40.6 (36.4, 44.8)
Wave 3	39.2 (33, 45.4)	39.1 (35.6, 42.6)	45.8 (40.2, 51.4)	40 (35.9, 44.1)
Wave 4	41.9 (35.6, 48.2)	35.6 (31.4, 39.8)	43.8 (37, 50.7)	36.6 (32.7, 40.4)
Physical HRQOL SF-12® PHC mean score (CI) Participants with both CLD and depression				
Wave 1	36.7 (32.1, 41.2)	32.2 (26.9, 37.4)	39 (34.5, 43.5)	38.6 (30.9, 46.2)
Wave 2	36.8 (32.6, 41)	34 (27.9, 40.1)	30.6 (25.6, 35.6)	40 (33.1, 46.8)
Wave 3	37.5 (32.6, 42.4)	29.2 (24.3, 34)	32.4 (24.4, 40.5)	42.7 (33.6, 51.7)
Wave 4	36.2 (30.4, 42)	33.2 (27, 39.4)	42.7 (34.8, 50.7)	45.1 (39.2, 51)
Adjusted for sex, ethnicity, age, wave, socioeconomic decile; the SF-12® PHC score is significantly associated with CLD:depression				
Mental HRQOL SF-12® MHC mean score (CI) Participants with neither CLD nor depression				
Wave 1	54.9 (53.3, 56.5)	56.2 (54.8, 57.7)	55 (52.9, 57.1)	56.9 (55.7, 58.2)
Wave 2	55.8 (54, 57.5)	57.4 (56.1, 58.7)	54.7 (52.3, 57.1)	55.3 (54, 56.5)
Wave 3	57.2 (55.5, 58.9)	57 (55.6, 58.5)	55.8 (52.2, 59.3)	56.5 (55.2, 57.8)
Wave 4	57.2 (55, 59.4)	57.1 (55.3, 58.9)	57.9 (55.4, 60.4)	56.7 (55.3, 58.2)
Mental HRQOL SF-12® MHC mean score (CI) Participants with CLD only				
Wave 1	54 (50.3, 57.7)	58 (56.1, 59.9)	54.6 (50.9, 58.3)	57.2 (54.9, 59.5)
Wave 2	51.2 (45.5, 56.8)	57.2 (54.8, 59.7)	55.5 (51.5, 59.4)	57 (54.7, 59.2)
Wave 3	54.6 (49, 60.3)	57.5 (54.3, 60.7)	56.7 (53.1, 60.4)	58 (55.1, 61)
Wave 4	56 (51.6, 60.5)	57.5 (55.1, 60)	55.9 (51.4, 60.4)	55 (50.6, 59.4)

	Māori women	Non-Māori women	Māori men	Non-Māori men
Mental HRQOL SF-12® MHC mean score (CI) Participants with depression only				
Wave 1	52.6 (48.3, 56.9)	52 (49.4, 54.6)	49.6 (46.3, 52.8)	49.8 (46.6, 53)
Wave 2	51.8 (47.2, 56.3)	49.9 (46.5, 53.2)	49.2 (45.5, 52.8)	52.1 (49.4, 54.8)
Wave 3	56.2 (52.6, 59.8)	52.1 (48.9, 55.3)	47.9 (40.8, 55)	52.3 (49.6, 55.1)
Wave 4	54.4 (49.7, 59.2)	52.9 (49.8, 56)	48.3 (40.9, 55.7)	53.1 (50.2, 55.9)
Mental HRQOL SF-12® MHC mean score (CI) Participants with both CLD and depression				
Wave 1	50 (45.2, 54.8)	50.8 (45, 56.6)	47.7 (39.8, 55.6)	54.5 (50.1, 58.9)
Wave 2	51.5 (47.8, 55.1)	49.5 (43.3, 55.7)	51.4 (47.2, 55.6)	53.5 (47.9, 59.1)
Wave 3	50.9 (44.9, 57)	50.7 (44.7, 56.7)	46.6 (34.9, 58.4)	53.8 (47.5, 60.2)
Wave 4	51.6 (44.4, 58.7)	57.5 (52.4, 62.5)	52.7 (39.3, 66.1)	51 (42.2, 59.9)
Adjusted for sex, ethnicity, age, wave, socioeconomic decile the SF-12®; MHC score is significantly associated with CLD:depression				
GP Visits more than four times a year Percentage of participants with neither CLD nor depression				
Wave 1	11 (5, 20)	13 (7, 21)	18 (8, 32)	11 (5, 20)
Wave 2	12 (5, 23)	12 (6, 21)	18 (7, 35)	6 (2, 14)
Wave 3	16 (7, 30)	21 (12, 32)	11 (2, 29)	8 (3, 16)
Wave 4	11 (3, 25)	9 (3, 20)	5 (0, 26)	16 (8, 27)
GP Visits more than four times a year Percentage of participants with CLD only				
Wave 1	27 (12, 46)	3 (0, 15)	30 (13, 53)	27 (12, 46)
Wave 2	30 (12, 54)	18 (7, 35)	11 (1, 35)	15 (4, 34)
Wave 3	14 (2, 43)	18 (6, 37)	18 (2, 52)	21 (7, 42)
Wave 4	20 (3, 56)	22 (7, 44)	100 (63, 100)	18 (4, 43)
GP Visits more than four times a year Percentage of participants with depression only				
Wave 1	23 (8, 45)	6 (1, 15)	47 (23, 72)	23 (8, 45)
Wave 2	29 (13, 51)	21 (11, 35)	26 (10, 48)	24 (12, 41)
Wave 3	24 (7, 50)	24 (12, 40)	33 (10, 65)	32 (17, 51)
Wave 4	33 (10, 65)	23 (10, 40)	55 (23, 83)	21 (7, 42)
GP Visits more than four times a year (%). Both CLD and depression				
Wave 1	30 (13, 53)	21 (7, 42)	43 (18, 71)	30 (13, 53)
Wave 2	33 (16, 55)	45 (23, 68)	38 (15, 65)	35 (14, 62)
Wave 3	31 (11, 59)	33 (13, 59)	29 (4, 71)	8 (0, 38)
Wave 4	18 (2, 52)	8 (0, 36)	100 (40, 100)	11 (0, 48)
Adjusted for sex, ethnicity, age, wave, socioeconomic decile; the SF-12® MHC score is significantly associated with CLD:depression				

Note: All variables in above table CLD:depression is a significant predictor (p < 0.0001).

Appendix Table 5.14: Chronic lung disease, depression and hospital admissions per person year by ethnic group and sex, Waves 1-4

		W1 - W2	W2 - W3	W3 - W4	W4 + one year
Māori women	Neither	0.51 (0.37, 0.64)	0.57 (0.43, 0.72)	0.65 (0.49, 0.8)	0.72 (0.56, 0.88)
	CLD only	1.21 (0.88, 1.53)	0.39 (0.21, 0.58)	1 (0.7, 1.3)	2.17 (1.73, 2.61)
	Depression only	1.54 (1.17, 1.92)	0.85 (0.57, 1.13)	1.05 (0.74, 1.36)	1.23 (0.9, 1.57)
	Both	1.15 (0.79, 1.51)	1.11 (0.76, 1.47)	0.94 (0.62, 1.27)	1.27 (0.89, 1.65)
Non-Māori women	Neither	0.45 (0.33, 0.57)	0.62 (0.48, 0.76)	0.58 (0.45, 0.72)	0.56 (0.43, 0.69)
	CLD only	0.59 (0.36, 0.82)	0.67 (0.43, 0.92)	0.67 (0.43, 0.92)	0.72 (0.47, 0.98)
	Depression only	0.77 (0.56, 0.97)	0.78 (0.58, 0.99)	0.99 (0.76, 1.22)	1.03 (0.79, 1.26)
	Both	0.88 (0.56, 1.19)	1.09 (0.74, 1.44)	1.66 (1.23, 2.09)	0.52 (0.28, 0.77)
Māori men	Neither	0.64 (0.46, 0.82)	0.71 (0.52, 0.9)	0.75 (0.56, 0.95)	1.04 (0.81, 1.27)
	CLD only	0.88 (0.58, 1.19)	1.03 (0.71, 1.36)	1.43 (1.04, 1.81)	1.03 (0.7, 1.35)
	Depression only	0.97 (0.63, 1.31)	1.18 (0.8, 1.56)	0.9 (0.57, 1.23)	1.14 (0.77, 1.51)
	Both	1.9 (1.36, 2.44)	1.8 (1.28, 2.33)	1.19 (0.76, 1.61)	2.16 (1.59, 2.74)
Non-Māori men	Neither	0.87 (0.7, 1.03)	0.74 (0.59, 0.89)	0.88 (0.71, 1.04)	0.88 (0.71, 1.04)
	CLD only	1.66 (1.24, 2.08)	1.57 (1.16, 1.98)	1.08 (0.74, 1.42)	1.47 (1.07, 1.86)
	Depression only	1.22 (0.93, 1.51)	1.19 (0.89, 1.48)	1.55 (1.22, 1.89)	0.73 (0.5, 0.96)
	Both	1.78 (1.21, 2.35)	1.41 (0.9, 1.92)	1.35 (0.85, 1.84)	2.63 (1.93, 3.32)

Note: CLD:depression is a significant predictor (p < 0.0001).

Appendix Table 5.15: Chronic lung disease, depression and length of stay by ethnic group and sex, Waves 1-4

Days in hospital		W1 - W2	W2 - W3	W3 - W4	W4 + one year
Māori women	Neither	2.8 (2.49, 3.12)	4.07 (3.69, 4.45)	4.24 (3.85, 4.63)	3.9 (3.52, 4.27)
	CLD only	12.06 (11.02, 13.1)	1.44 (1.08, 1.79)	2.16 (1.72, 2.6)	8.34 (7.48, 9.21)
	Depression only	6.21 (5.46, 6.97)	1.73 (1.33, 2.13)	4.95 (4.28, 5.62)	6.89 (6.1, 7.69)
	Both	10.36 (9.28, 11.44)	7 (6.11, 7.89)	3.92 (3.25, 4.58)	3.27 (2.67, 3.88)
Non-Māori women	Neither	1.37 (1.16, 1.57)	2.4 (2.13, 2.68)	3.72 (3.38, 4.06)	3.1 (2.79, 3.41)
	CLD only	4.18 (3.57, 4.79)	1.81 (1.4, 2.21)	6.8 (6.02, 7.58)	6.04 (5.3, 6.77)
	Depression only	5.67 (5.11, 6.22)	3.84 (3.38, 4.3)	5.69 (5.13, 6.24)	7.95 (7.3, 8.61)
	Both	6.36 (5.51, 7.21)	5.23 (4.46, 6)	9.48 (8.45, 10.52)	1.57 (1.15, 1.99)
Māori men	Neither	2.34 (2, 2.68)	2.72 (2.35, 3.09)	1.87 (1.56, 2.17)	3.19 (2.79, 3.59)
	CLD only	5.47 (4.72, 6.22)	2.4 (1.9, 2.9)	6.3 (5.49, 7.11)	3.65 (3.03, 4.26)
	Depression only	6.71 (5.81, 7.61)	5.41 (4.6, 6.22)	3.25 (2.63, 3.88)	5.02 (4.24, 5.8)
	Both	7.89 (6.79, 8.99)	9.16 (7.98, 10.35)	2.69 (2.05, 3.34)	19.47 (17.74, 21.2)

Non-Māori men					
	Neither	7.5 (7.01, 7.98)	5.38 (4.97, 5.78)	4.04 (3.69, 4.4)	2.56 (2.28, 2.85)
	CLD only	9.4 (8.39, 10.4)	6.21 (5.39, 7.02)	4.07 (3.41, 4.73)	5.87 (5.08, 6.66)
	Depression only	5.36 (4.74, 5.98)	12.76 (11.8, 13.71)	7.47 (6.74, 8.2)	3.76 (3.24, 4.28)
	Both	13.8 (12.21, 15.38)	8.57 (7.31, 9.82)	4.37 (3.48, 5.27)	12.3 (10.8, 13.8)

Note: CLD:depression is a significant predictor (p < 0.0001).

Appendix Table 5.16: Chronic lung disease, depression and hospitalisation costs, Waves 1-4

	W1 - W2	W2 - W3	W3 - W4	W4 + one year
Neither	$4,579.35	$3,882.35	$4,723.75	$3,814.55
CLD only	$6,882.53	$3,336.94	$5,195.66	$6,068.49
Depression only	$6,797.23	$6,105.52	$6,452.74	$5,467.59
Both	$7,636.73	$7,608.51	$6,740.71	$7,038.97

Note: 2015 dollars per person per year are shown. CLD:depression is a significant predictor for hospitalisation costs (p < 0.0001)

Appendix Table 5.17: Diabetes mellitus and depression by ethnic group and sex, Waves 1-4

		Wave 1	Wave 2	Wave 3	Wave 4
Māori women	Neither	108 (47%)	97 (47%)	60 (51%)	57 (53%)
	DM only	46 (20%)	40 (20%)	17 (14%)	14 (13%)
	Depression only	51 (22%)	45 (22%)	29 (25%)	26 (24%)
	Both	27 (12%)	23 (11%)	12 (10%)	10 (9%)
Non-Māori women	Neither	139 (51%)	131 (51%)	95 (53%)	91 (55%)
	DM only	28 (10%)	26 (10%)	16 (9%)	15 (9%)
	Depression only	92 (34%)	88 (34%)	63 (35%)	55 (33%)
	Both	13 (5%)	12 (5%)	<5	<5
Māori men	Neither	85 (49%)	73 (48%)	36 (47%)	33 (48%)
	DM only	30 (17%)	26 (17%)	11 (14%)	12 (17%)
	Depression only	39 (23%)	36 (24%)	23 (30%)	20 (29%)
	Both	19 (11%)	18 (12%)	6 (8%)	<5
Non-Māori men	Neither	140 (59%)	131 (61%)	98 (62%)	91 (63%)
	DM only	20 (8%)	17 (8%)	12 (8%)	11 (8%)
	Depression only	56 (24%)	50 (23%)	38 (24%)	34 (23%)
	Both	20 (8%)	17 (8%)	11 (7%)	9 (6%)

Note: Neither sex or ethnic group are significant predictors of DM:depression (p = 0.16 and 0.22 respectively).

Appendix Table 5.18: Diabetes mellitus, depression and functional status, frailty, quality of life and GP visits, by ethnic group and sex, Waves 1-4

	Māori women	Non-Māori women	Māori men	Non-Māori men
NEADL mean score (CI) Participants with neither DM nor depression				
Wave 1	18.2 (17.3, 19.2)	18.4 (17.6, 19.1)	17.6 (16.7, 18.6)	18.6 (18.1, 19)
Wave 2	18.6 (17.9, 19.3)	18.1 (17.4, 18.8)	16.8 (15.8, 17.9)	17.4 (16.8, 18)
Wave 3	18.9 (18.3, 19.5)	17.6 (16.8, 18.5)	16.6 (15.5, 17.7)	17 (16.3, 17.7)
Wave 4	18.2 (17.2, 19.1)	17.9 (17, 18.8)	15.7 (14.3, 17)	17.1 (16.3, 17.8)

	Māori women	Non-Māori women	Māori men	Non-Māori men
Fried mean score (CI) Participants with neither DM nor depression				
Wave 1	0.74 (0.5, 0.98)	0.74 (0.54, 0.94)	0.6 (0.31, 0.88)	0.68 (0.49, 0.86)
Wave 2	1.23 (1.01, 1.45)	1.01 (0.83, 1.19)	1.15 (0.84, 1.46)	0.97 (0.8, 1.14)
Wave 3	1.03 (0.76, 1.29)	1.14 (0.95, 1.34)	0.64 (0.26, 1.01)	0.73 (0.55, 0.9)
Wave 4	1.06 (0.7, 1.43)	1.02 (0.75, 1.29)	1 (0.55, 1.45)	1.07 (0.85, 1.29)
Physical HRQOL SF-12® PHC mean score (CI) Participants with neither DM nor depression				
Wave 1	45.2 (42.6, 47.8)	42.8 (40.6, 44.9)	46.7 (43.6, 49.9)	44.4 (42.3, 46.5)
Wave 2	47.3 (44.9, 49.7)	42.4 (40, 44.8)	47.7 (44.2, 51.2)	45.9 (44, 47.8)
Wave 3	45 (42.6, 47.4)	42.2 (39.7, 44.7)	47.7 (45.2, 50.1)	44.9 (42.7, 47.2)
Wave 4	46.5 (43.6, 49.3)	43.4 (40.9, 45.9)	44 (40.4, 47.5)	45 (42.8, 47.2)
Mental HRQOL SF-12® MHC mean score (CI) Participants with neither DM nor depression				
Wave 1	54.4 (52.6, 56.2)	56.7 (55.4, 57.9)	54.1 (52, 56.3)	57.2 (56.1, 58.3)
Wave 2	55.1 (53.2, 57)	57.2 (55.9, 58.5)	54.3 (52, 56.6)	55.9 (54.8, 57)
Wave 3	56.2 (54.1, 58.3)	57.3 (55.9, 58.7)	55.2 (51.9, 58.6)	56.8 (55.6, 58.1)
Wave 4	56.9 (54.9, 58.9)	57.4 (55.9, 59)	56.9 (54, 59.8)	56.1 (54.6, 57.7)
GP Visits more than four times a year Percentage of participants with neither DM nor depression				
Wave 1	14 (7, 24)	9 (4, 16)	20 (10, 33)	14 (7, 24)
Wave 2	17 (8, 29)	12 (6, 20)	13 (4, 28)	8 (4, 15)
Wave 3	21 (10, 35)	17 (10, 27)	11 (2, 29)	11 (5, 19)
Wave 4	10 (3, 23)	7 (2, 17)	100 (81, 100)	14 (7, 23)
NEADL mean score (CI) Participants with DM only				
Wave 1	17.8 (16, 19.6)	18.5 (17, 20)	16.4 (13.9, 18.9)	18.5 (16.7, 20.4)
Wave 2	17 (15, 18.9)	17.8 (16.3, 19.3)	16.4 (14.4, 18.5)	18 (16.2, 19.8)
Wave 3	16.5 (13.3, 19.7)	17.8 (15.7, 20)	14.4 (10.4, 18.3)	17.5 (15.9, 19)
Wave 4	17 (13.4, 20.6)	17.2 (15, 19.4)	14.8 (11.5, 18)	16.7 (14.8, 18.6)
Fried mean score (CI) Participants with DM only				
Wave 1	0.64 (0.28, 1)	1.47 (0.91, 2.04)	0.83 (0.29, 1.38)	0.58 (0.01, 1.16)
Wave 2	1 (0.55, 1.45)	0.94 (0.35, 1.53)	1 (0.48, 1.52)	1 (0.48, 1.52)
Wave 3	1.4 (1.03, 1.77)	1.31 (0.64, 1.98)	1.33 (0.47, 2.19)	0.88 (-0.07, 1.82)
Wave 4	1.75 (1.01, 2.49)	1.3 (0.54, 2.06)	1 (0.12, 1.88)	1.29 (0.41, 2.17)
Physical HRQOL SF-12® PHC mean score (CI) Participants with DM only				
Wave 1	43.2 (39.5, 46.8)	37.3 (32.5, 42.2)	43.7 (38.1, 49.3)	45.7 (38.6, 52.8)
Wave 2	43.4 (38.9, 48.0)	42.5 (37.1, 47.8)	44.9 (39.7, 50.2)	47.2 (43.2, 51.1)
Wave 3	40 (32.9, 47.0)	38.8 (31.8, 45.8)	42.1 (34.5, 49.7)	44.5 (39.0, 50.0)
Wave 4	45.1 (38.5, 51.7)	42.8 (35.9, 49.8)	37.4 (28.7, 46.1)	43.4 (33.9, 52.9)
Mental HRQOL SF-12® MHC mean score (CI) Participants with DM only				
Wave 1	55.7 (52.7, 58.6)	57.6 (54.3, 60.8)	56.5 (53, 59.9)	55.4 (51.5, 59.4)
Wave 2	52.9 (47.6, 58.2)	58.2 (55.4, 61.1)	56.6 (52, 61.1)	53.7 (48.9, 58.6)
Wave 3	58.3 (55.5, 61.2)	56 (51.5, 60.6)	58 (53.3, 62.7)	57.3 (52.2, 62.3)
Wave 4	58.7 (52.6, 64.8)	55.9 (51.3, 60.4)	57.9 (54.6, 61.3)	58.2 (53.6, 62.7)

	Māori women	Non-Māori women	Māori men	Non-Māori men
GP Visits more than four times a year Percentage of participants with DM only				
Wave 1	17 (6, 35)	14 (3, 36)	28 (10, 53)	17 (6, 35)
Wave 2	18 (5, 40)	22 (6, 48)	21 (5, 51)	8 (0, 38)
Wave 3	100 (74, 100)	38 (14, 68)	18 (2, 52)	9 (0, 41)
Wave 4	25 (3, 65)	42 (15, 72)	11 (0, 48)	40 (12, 74)
NEADL mean score (CI) Participants with depression only				
Wave 1	15.6 (13.6, 17.6)	16.5 (15.4, 17.5)	15.9 (14.1, 17.7)	15.7 (14.2, 17.3)
Wave 2	15.8 (14.1, 17.6)	14.4 (12.8, 15.9)	14.1 (12.1, 16.1)	14.6 (13.1, 16.1)
Wave 3	14.7 (11.7, 17.7)	15.2 (13.8, 16.6)	15.1 (12.7, 17.4)	14.5 (12.9, 16.1)
Wave 4	13.3 (9.8, 16.8)	14.5 (12.7, 16.2)	15.8 (13.2, 18.4)	14.9 (13, 16.8)
Fried mean score (CI) Participants with depression only				
Wave 1	1.1 (0.69, 1.51)	1.27 (0.97, 1.58)	1.42 (0.99, 1.86)	1.34 (0.95, 1.73)
Wave 2	1.17 (0.75, 1.6)	1.36 (1.04, 1.69)	1.67 (1.12, 2.21)	1.49 (1.14, 1.83)
Wave 3	1.36 (0.87, 1.84)	0.97 (0.7, 1.24)	0.93 (0.45, 1.41)	1.33 (0.93, 1.74)
Wave 4	1.3 (0.62, 1.98)	1.06 (0.71, 1.4)	1.08 (0.58, 1.59)	1.43 (0.96, 1.9)
Physical HRQOL SF-12® PHC mean score (CI) Participants with depression only				
Wave 1	38.7 (34.8, 42.6)	35.8 (32.8, 38.7)	44.4 (40.6, 48.2)	41.9 (37.8, 46)
Wave 2	41.5 (37.2, 45.9)	37.6 (34.3, 41)	38.6 (34.1, 43.1)	42.1 (37.8, 46.5)
Wave 3	37.9 (33.1, 42.7)	36.5 (33.3, 39.6)	42.3 (36.6, 48)	40.8 (36.1, 45.5)
Wave 4	37.9 (33.2, 42.7)	34.8 (31.3, 38.3)	43.7 (37.9, 49.5)	40.7 (36.6, 44.9)
Mental HRQOL SF-12® MHC mean score (CI) Participants with depression only				
Wave 1	50.7 (46.5, 54.9)	51.4 (48.8, 53.9)	48.5 (43.4, 53.6)	51.8 (48.8, 54.8)
Wave 2	50.8 (47.3, 54.2)	50.7 (47.8, 53.6)	49.9 (46.7, 53.2)	53 (50.1, 55.8)
Wave 3	54.7 (50.2, 59.2)	52.3 (49.5, 55)	46 (39.3, 52.8)	53.6 (50.5, 56.6)
Wave 4	52.3 (47.2, 57.4)	54 (51.4, 56.6)	50.4 (43.8, 57)	51.4 (48, 54.9)
GP Visits more than four times a year Percentage of participants with depression only				
Wave 1	19 (7, 36)	8 (3, 17)	41 (21, 64)	19 (7, 36)
Wave 2	34 (19, 53)	23 (14, 35)	34 (18, 54)	25 (13, 41)
Wave 3	17 (5, 39)	24 (13, 37)	38 (15, 65)	28 (14, 45)
Wave 4	29 (10, 56)	20 (9, 34)	38 (14, 68)	16 (5, 36)
NEADL mean score (CI) Participants with both DM and depression				
Wave 1	16.1 (13.2, 19.1)	14.4 (9.3, 19.6)	16.9 (12.3, 21.5)	15.3 (12.7, 17.9)
Wave 2	13 (9.3, 16.7)	12 (4.5, 19.5)	11.1 (6.2, 16)	13.5 (10.5, 16.4)
Wave 3	14.9 (11.2, 18.7)	13.3 (7.4, 19.1)	9.5 (0, 19)	15.4 (11.8, 19)
Wave 4	9.6 (3.2, 15.9)	11 (-1.7, 23.7)	12.5 (6.1, 18.9)	15.8 (12.5, 19)
Fried mean score (CI) Participants with both DM and depression				
Wave 1	0.71 (0.29, 1.13)	1.71 (0.69, 2.74)	1.4 (0.71, 2.09)	1.6 (0.98, 2.22)
Wave 2	1 (0.25, 1.75)	1.8 (-0.04, 3.64)	1 (-3.3, 5.3)	1.8 (1.24, 2.36)
Wave 3	0.88 (0.05, 1.7)	3.33 (1.9, 4.77)	1 (-11.71, 13.71)	1.63 (1, 2.25)
Wave 4	1 (0.12, 1.88)	---	---	1.86 (0.73, 2.98)

	Māori women	Non-Māori women	Māori men	Non-Māori men
Physical HRQOL SF-12® PHC mean score (CI) Participants with both DM and depression				
Wave 1	33.6 (27, 40.2)	39.7 (28.2, 51.2)	39.3 (32.7, 46)	34.1 (28.5, 39.6)
Wave 2	37.5 (32.9, 42.1)	38.6 (24.9, 52.4)	35.2 (27.5, 42.8)	34.2 (29.8, 38.7)
Wave 3	39.2 (32.4, 46)	31.9 (13.2, 50.5)	35.6 (15.9, 55.2)	40.4 (35.7, 45.2)
Wave 4	42.9 (31.3, 54.5)	38.5 (-46.3, 123.4)	42.5 (29, 56)	33.1 (29.2, 36.9)
Mental HRQOL SF-12® MHC mean score (CI) Participants with both DM and depression				
Wave 1	52.1 (47.9, 56.2)	54.8 (45.8, 63.9)	49.9 (44.6, 55.2)	49.6 (43.8, 55.4)
Wave 2	53.3 (48.1, 58.6)	40.4 (26, 54.8)	50.3 (45.2, 55.5)	51.5 (46.7, 56.4)
Wave 3	51 (44.9, 57.1)	43.6 (21.8, 65.3)	52.6 (42.3, 62.9)	50.2 (45.1, 55.2)
Wave 4	55.3 (50.1, 60.5)	56 (-108.4, 220.4)	44.4 (29.7, 59.1)	56 (50.2, 61.9)
GP Visits more than four times a year Percentage of participants with both DM and depression				
Wave 1	40 (16, 68)	29 (4, 71)	50 (19, 81)	40 (16, 68)
Wave 2	25 (7, 52)	71 (29, 96)	20 (3, 56)	33 (12, 62)
Wave 3	50 (19, 81)	75 (19, 99)	100 (29, 100)	20 (3, 56)
Wave 4	17 (0, 64)	100 (16, 100)	50 (1, 99)	25 (3, 65)

Note: DM:depression is a significant predictor for all variables in this table (p < 0.0001).

Appendix Table 5.19: Diabetes mellitus, depression and hospital admissions per person year by ethnic group and sex, Waves 1-4

		W1 - W2	W2 - W3	W3 - W4	W4 + one year
Māori women	Neither	0.56 (0.42, 0.7)	0.4 (0.28, 0.52)	0.58 (0.44, 0.72)	1.19 (0.98, 1.39)
	DM only	0.95 (0.67, 1.24)	0.79 (0.53, 1.04)	1.17 (0.86, 1.48)	0.5 (0.29, 0.7)
	Depression only	1.35 (1.04, 1.67)	0.86 (0.61, 1.12)	1.01 (0.73, 1.29)	1.2 (0.9, 1.5)
	Both	1.29 (0.86, 1.72)	1.13 (0.73, 1.53)	0.96 (0.59, 1.33)	1.44 (0.99, 1.9)
Non-Māori women	Neither	0.48 (0.37, 0.6)	0.53 (0.41, 0.65)	0.62 (0.49, 0.75)	0.62 (0.49, 0.75)
	DM only	0.47 (0.22, 0.73)	1.15 (0.75, 1.55)	0.55 (0.28, 0.82)	0.52 (0.26, 0.79)
	Depression only	0.69 (0.52, 0.86)	0.8 (0.62, 0.98)	1.12 (0.9, 1.34)	0.89 (0.7, 1.08)
	Both	1.65 (0.95, 2.35)	1.6 (0.91, 2.29)	1.94 (1.18, 2.69)	0.86 (0.36, 1.37)
Māori men	Neither	0.55 (0.39, 0.7)	0.73 (0.55, 0.91)	0.9 (0.7, 1.1)	0.91 (0.71, 1.11)
	DM only	1.17 (0.79, 1.56)	1 (0.64, 1.36)	1.04 (0.67, 1.4)	1.45 (1.02, 1.88)
	Depression only	1.13 (0.8, 1.47)	1.15 (0.81, 1.49)	0.97 (0.66, 1.28)	1.3 (0.94, 1.65)
	Both	1.75 (1.16, 2.35)	2.1 (1.45, 2.75)	1.17 (0.68, 1.66)	1.95 (1.33, 2.58)
Non-Māori men	Neither	1.04 (0.87, 1.21)	0.89 (0.73, 1.04)	0.88 (0.73, 1.04)	1.02 (0.85, 1.19)
	DM only	0.99 (0.55, 1.43)	1.11 (0.65, 1.57)	1.24 (0.75, 1.73)	0.85 (0.45, 1.25)
	Depression only	1.15 (0.87, 1.43)	1.18 (0.89, 1.46)	1.37 (1.06, 1.67)	1.25 (0.96, 1.54)
	Both	1.92 (1.32, 2.53)	1.38 (0.86, 1.89)	1.96 (1.34, 2.57)	0.72 (0.35, 1.1)

Note: DM:depression is a significant predictor for hospital admissions (p < 0.0001).

Appendix Table 5.20: Diabetes mellitus, depression and length of stay by ethnic group and sex, Waves 1-4

Days in hospital		W1 - W2	W2 - W3	W3 - W4	W4 + one year
Māori women	Neither	3.44 (3.09, 3.79)	1.6 (1.37, 1.84)	2.38 (2.09, 2.66)	5.68 (5.23, 6.13)
	DM only	9.14 (8.27, 10.01)	7.39 (6.61, 8.18)	7.87 (7.06, 8.69)	1.29 (0.96, 1.62)
	Depression only	6.55 (5.85, 7.26)	2.07 (1.68, 2.47)	3.47 (2.96, 3.98)	4.49 (3.91, 5.08)
	Both	10.19 (8.99, 11.39)	8.68 (7.57, 9.79)	6.97 (5.97, 7.96)	6.25 (5.31, 7.19)
Non-Māori women	Neither	2.35 (2.1, 2.6)	2.03 (1.79, 2.27)	4.63 (4.27, 4.99)	4.19 (3.85, 4.53)
	DM only	0.69 (0.38, 1)	3.25 (2.58, 3.91)	4.1 (3.35, 4.84)	2.19 (1.64, 2.73)
	Depression only	5.18 (4.72, 5.65)	3.56 (3.17, 3.94)	6.37 (5.85, 6.88)	6.27 (5.76, 6.78)
	Both	11.16 (9.34, 12.97)	10.78 (9, 12.57)	12.05 (10.17, 13.94)	5.17 (3.93, 6.4)
Māori men	Neither	2.65 (2.31, 3)	2.32 (2, 2.65)	3.38 (2.99, 3.77)	1.35 (1.1, 1.6)
	DM only	5.18 (4.37, 5.99)	3.53 (2.85, 4.2)	2.15 (1.63, 2.68)	9.79 (8.67, 10.91)
	Depression only	4.96 (4.26, 5.66)	4.51 (3.84, 5.17)	2.59 (2.09, 3.1)	9.42 (8.46, 10.38)
	Both	11.36 (9.85, 12.88)	12.81 (11.21, 14.42)	5.38 (4.34, 6.42)	7.54 (6.31, 8.77)
Non-Māori men	Neither	8.61 (8.12, 9.09)	2.8 (2.53, 3.08)	4.28 (3.93, 4.62)	3.42 (3.12, 3.73)
	DM only	2.61 (1.9, 3.31)	26.47 (24.22, 28.73)	2.15 (1.5, 2.79)	1.94 (1.33, 2.55)
	Depression only	7.07 (6.37, 7.76)	13.11 (12.16, 14.06)	5.18 (4.59, 5.78)	6.7 (6.02, 7.38)
	Both	9.02 (7.7, 10.34)	6.39 (5.29, 7.5)	11.92 (10.4, 13.43)	1.45 (0.92, 1.98)

Note: DM:depression is a significant predictor for length of stay in hospital (p < 0.0001).

Appendix Table 5.21: Diabetes mellitus, depression and hospitalisation costs, Waves 1-4

	W1 - W2	W2 - W3	W3 - W4	W4 + one year
Neither	$4,984.62	$2,949.38	$4,748.24	$4,238.72
DM only	$5,636.57	$6,739.50	$5,048.51	$4,939.07
Depression only	$5,762.74	$5,571.50	$5,538.72	$6,063.40
Both	$10,758.70	$10,078.69	$11,438.62	$5,475.73

Note: DM:depression is a significant predictor for hospitalisation costs (p < 0.0001).