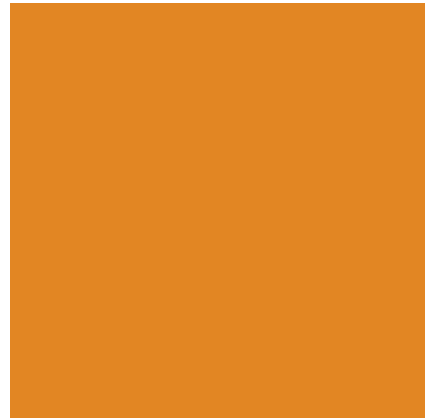


Alzheimers New Zealand

Awareness and understanding of dementia in
New Zealand

Final report

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Objectives and method

1.1 Background and objectives

Alzheimers New Zealand is a non-profit organisation focused on supporting all people affected by dementia; people with dementia, their home-based carers, families/ whānau and friends. They do this by raising awareness, providing advocacy, information services and resources to the public generally, as well as health professionals and health providers in the dementia sector/ community.

Although a benchmark survey was first conducted in 2013, the survey was completed by an all-female panel predominately aged over 35 years and as such the results were not representative of the general population.

This survey aims to record a new benchmark measuring the current levels of awareness and understanding of dementia that is representative of the general population. Specifically, the objectives are to:

- Measure understanding and awareness of dementia in New Zealand.
- Provide greater insights into awareness and understanding of dementia in New Zealand.
- Measure understanding, knowledge and experiences of the services and support provided by Alzheimers NZ, among those that have accessed services.
- Set benchmarks for Alzheimers NZ to measure the success of its awareness raising activity in the future.

1.2 Method

These results have been gathered from two sources:

- An initial standalone telephone survey among a nationwide sample of those aged 18 years and over. To ensure the sample is as representative as possible, data has been rim weighted by age, gender, region and ethnicity.

The sample size was n=750 and fieldwork was carried out from the 26th May to the 8th of June 2014.

- Follow up questions in the UMR Research nation-wide omnibus survey. This is a telephone survey of a nationally representative sample of 750 New Zealanders, 18 years of age and over. These questions were added to enable international comparison with the findings from an international survey by the Alzheimer's Association (2014)¹ for the Alzheimer's and Brain Awareness Month, which were released after the interviewing for the initial survey had been

¹ The Alzheimer's and Brain Awareness Month International Survey; a 12 country survey, including a total of 6,037 adults aged 18+ surveyed in local languages.

completed and gain better insight and understanding of some of the attitudinal findings from the standalone survey.

Fieldwork was conducted from the 24th of July to the 29th July 2014 at UMR Research's national interview facility in Auckland.

The margin of error for a 50% figure at the 95% confidence level for a sample size of 750 is plus or minus 3.6%

■ Maori booster

As Alzheimers NZ were particularly interested in the views and knowledge of those of Maori ethnicity, an additional booster survey was carried out, also via telephone. To give an overall sample of n=150 Maori, another n=76 Maori had to be surveyed in the booster. This sample was also weighted by age, gender and region to ensure an accurate representation.

Fieldwork was carried out on the 8th of June 2014.

The margin of error for a 50% figure at the 95% confidence level for a sample size of 150 is plus or minus 8%.

Results have been reported for both the general public sample and the combined Maori sample.

1.3 Reporting notes

■ International studies

Results from this study will be compared to those found in international studies whenever such international results are available. As the UMR survey is not based on any one international study and is intended for a New Zealand audience there are differences between questions, such as the language used. Due to these differences, any such comparison is intended to place New Zealand in a broader perspective rather than be used as statistically robust comparison.

■ Terms used

When referring to 'respondents' in the report, the term is referring to respondents in the general public sample only. When referring to only Maori respondents (those surveyed in both the general public sample and Maori booster), the term Maori or Maori respondents is used.

■ Standalone telephone survey or omnibus findings

Unless specifically stated, the findings in this report relate to the initial standalone telephone survey.

Executive summary

2.1 Key findings

- *Awareness and perceived knowledge about dementia is high but, in reality specific knowledge is more limited and more information is needed.*
 - Unprompted, over half of New Zealanders and 38% of Maori declare they know 'a lot' or 'a fair amount' about dementia.
 - Only one-fifth is able to accurately guess the estimated number of people in New Zealand that have dementia though there is a strong belief that the number of people with dementia will increase.
 - Memory loss is the most highly recalled symptom (unprompted), followed by changes in mood and behaviour.
 - Unprompted, many people cannot recall any other symptoms.
 - When prompted, the most commonly recalled symptoms are related to memory loss, indicating that more education is required to enable people to recognise and act in response to the symptoms of dementia.
- *Dementia touches a large proportion of New Zealanders' lives and may affect an even larger proportion as the number of people with dementia increases.*
 - Two out of every three New Zealanders are touched by dementia;
 - For 64% of those that know / have known someone with dementia, it is a family member;
 - A third of those that know / have known someone with dementia have been involved in their direct care.
- *Perceptions of dementia are by and large accurate. New Zealanders are generally aware that:*
 - Dementia gets worse over time.
 - Things can be done to reduce the risk of dementia.
 - People with dementia can continue their regular life activities.
 - There are places to go for advice or support.
 - Memory loss is not the only symptom of dementia.
 - It is not just old people who get dementia.
 - Dementia is not a normal part of the aging process.
 - You do not need a family history to be at risk of Alzheimer's.

They are also aware that the number of people with dementia will increase, even if they are less sure of the exact number of people with dementia in New Zealand currently.

However, there is one significant misconception, with 61% of people not believing dementia is a fatal condition; 31% think it is definitely false.

And, some perceptions are more polarised and are dependent on the progression of the disease; 36% believe people with dementia need to be cared for in a rest home (11% think this is definitely true) and 56% believe that people with dementia don't know what is going on around them (16% think this is definitely true).

■ *New Zealanders' attitudes towards dementia are generally more positive than might have been assumed when compared with international research findings. Respondents' declared intentions² suggest that most:*

- Are willing to include those with dementia in their social activities.
- Would help those in public.
- Would take those close to them exhibiting symptoms to the Doctor.
- Would be able assist someone with dementia.
- Would not be reluctant to tell others if a close family member had Alzheimer's.

Though there are some misgivings about being in public with someone with dementia.

■ *Personal feelings about dementia are more polarised:*

- A marginally larger proportion of New Zealanders disagree dementia is one of the things they fear most about getting older.
- A much higher proportion would rather care for someone with dementia than be diagnosed with dementia.
- Two-thirds would take a test to determine if they were likely to get dementia in future.
- Cancer is a bigger fear than dementia, though this is less marked for older respondents.

■ *New Zealanders are, apparently, less fearful of dementia than their international counterparts:*

- Compared with the global average, New Zealander's are less concerned about Alzheimer's,
- More New Zealanders claim they would be likely to take a test to determine if they were likely to get dementia in future; and,
- They are more misinformed regarding Alzheimer's being a fatal disease.

■ *The doctor or GP is top of mind for advice or support, though among those who have approached an organisation for help; their local Alzheimer's Association was most commonly approached.*

² The scope of this survey did not enable an observation of respondents' actual (real life) responses to these statements, but our experience indicates declared intentions generally present a more idealistic scenario than would be found in practice.

- *Maori are by and large quite similar to the general public across most measures concerning dementia, though some clear differences exist. Maori are:*
 - Less likely to declare having 'a lot' or 'fair amount' of knowledge (unprompted).
 - More likely to cite a family member as someone they knew with dementia.
 - Less likely to be directly involved in the care of that person.
 - More likely to name medical centres as somewhere to approach for advice or support.
 - Less likely to mention violence or aggression as a symptom of dementia and more likely to mention shaking.
 - Less likely to believe there are things you can do to reduce the risk of developing dementia.
 - Less likely to say dementia is one of the things they fear most about getting older.
 - More willing to take a test to determine if they might get dementia in future.
 - Less likely to be worried about being seen in public with someone with dementia.
- *Impact of demographics and experience of dementia;*

Eighty five percent of respondents 60 years or over know (or have known) someone with dementia and, of those, 42% are, or have been involved in caring for that person;

Those over 60 are more likely to fear Alzheimer's; a quarter chose it as the disease or condition they were most afraid of getting (a third chose cancer);

Females generally claim (and findings confirm) they are more knowledgeable, likely to have more accurate perceptions of dementia and more likely to declare they would be willing help those in need than males.

2.2 Detailed findings

■ Knowledge of dementia

Over half of the general public declared knowing 'a lot' or 'fair amount' about dementia (53%), placing public knowledge of dementia below relatively common and treatable conditions such as asthma or diabetes, but above other conditions such as Parkinson's disease or Muscular Dystrophy. Self-declared knowledge was lower among Maori (38%) and significantly higher among those that know someone with dementia (71%).

Two out of three respondents (67%) said they know or have known someone with dementia and 64% of these respondents reported this person to be a family member, highlighting the wide spread of those affected or touched by dementia. This also shows that, given the number of people with dementia is projected to rise significantly in the future; dementia will continue to be a real and increasing concern for all New Zealanders.

53% know 'a lot' or 'fair amount' about dementia
67% know a person with dementia - for 64% of these it is a family member

The symptom of dementia most people could recall without prompting was memory loss. Large proportions could only recall other symptoms when prompted with forgetting things regularly, getting lost, forgetting people's names and misplacing things regularly. These were all recalled by over nine in ten respondents when prompted.

There was a wide range of estimations for the number of people in New Zealand that have dementia with less than one in five giving the estimate that Alzheimers NZ calculated of 50,000. There was a strong belief that the number of people in with dementia would increase over the next 35 years.

■ Perceptions of and attitudes toward dementia

Most perceptions of dementia were accurate with the vast majority agreeing that dementia gets worse over time and large proportions agreeing that things can be done to reduce the risk of developing dementia and that people with dementia can continue their regular life activities after being diagnosed.

The vast majority refuted the statement there is nowhere to go for advice or support and that memory loss is the only symptom of dementia. Large proportions also disagreed that only old people get dementia and that it is a normal part of the aging process. Internationally, New Zealanders appear to be more informed about this last belief when compared with results from 12 nations. Furthermore, most recognise that you do not need a family history to be at risk of Alzheimer's.

Only 27%
believe
dementia is
fatal

Over twice as many respondents believe that dementia is not fatal (61%) compared to those that believe it is (27%). Only 10% believe this is definitely true compared to 31% who believe it is definitely false. The omnibus findings also show that the majority (54%) believe Alzheimer's disease is not a fatal condition.

Two other statements tested did not have a clear true or false answer; partly because the answer may depend on another factor such as the level of progression of the disease. The two most conflicting statements were; 'people with dementia need to be cared for in a rest home' and 'people with dementia don't understand what is going on around them'.

■ Most willing to include and help those with dementia

Attitudes towards dementia were generally fairly positive in New Zealand, with the vast majority declaring they would be willing to include those with dementia in their social activities, even if they said they would be worried being in public with someone with dementia. Respondents also declared they would be very willing to help those they saw in public that looked like they had dementia and needed help and to take those close to them who exhibited symptoms of dementia to the doctor.

A much larger proportion agreed they felt they would be able to assist someone with dementia that needed help than those that disagreed.

■ Personal feelings about dementia

Findings indicate that New Zealanders do fear dementia; more than a third (34%) of New Zealanders state that dementia is one of the things they fear most about getting older and 15% fear getting dementia more than any other condition; second only to cancer.

Even though levels of fear are divided, most agree that they would rather care for someone with dementia than be diagnosed with it. Again, these findings were replicated in the Omnibus survey where half of respondents disagreed they would rather be diagnosed with Alzheimer's disease than care for someone with the disease.

Over two-thirds agreed they would certainly take a test to see if they were likely to get dementia in the future and would not be reluctant to tell people if a close family member was diagnosed with dementia. Only 11% of respondents in the Omnibus survey would be reluctant to tell other people if a close family member was diagnosed with Alzheimer's.

■ Sources of advice

The doctor or GP was the source of advice most respondents said they would go to for help if they suspected someone they knew had dementia; the internet, a foundation or society to do with dementia (including the Alzheimer's society) and a family member were also mentioned by smaller proportions.

Just over one in ten had already approached an organisation or group for support or advice about dementia and when asked where they had gone the results were fairly different to where respondents had said they would go if they suspected someone they knew had dementia. In practice, the local Alzheimer's organisation was the place most respondents had approached for advice, followed by their GP or doctor - the reverse was true for Maori, with their GP or doctor being the most likely source of advice.

75% said they would go to the doctor for advice

In practice, 24% of these did; 31% went to the local dementia organisation

Respondents that had sought advice were significantly more likely to have a parent with dementia and, positively, most of those that had sought advice also rated the source as helpful.

■ Caring for those with dementia

A third of those that know someone with dementia are involved in the direct care of that person. Those who had a spouse, parent, patient or client with dementia were far more likely to be involved and those who know a grandparent or friend with dementia were less likely.

33% that know someone with dementia care for them

■ Fear of dementia when compared to cancer

Fear of dementia is second only to cancer. In the omnibus research, 15% of respondents selected Alzheimer's as the disease or condition they were most afraid of getting; 45% selected cancer. Respondents over 60 were more likely than other age ranges to express concern about Alzheimer's with a quarter choosing it as the disease or condition they were most afraid of getting (a third chose cancer).

There was a similar pattern when asked which disease respondents were most afraid of a loved one getting with 17% stating Alzheimer's disease, again, behind only cancer (54%).

These findings are similar to international studies, where being diagnosed with cancer was generally a greater concern than being diagnosed with dementia. However, when compared to the global average (23%) reported in the Alzheimer's Association survey (2014) New Zealanders are less concerned about Alzheimer's.

■ Differences in the knowledge of Maori and targeting

Maori were generally quite similar to the general public across most measures that were tested, though some clear differences did exist. Notably, they were less likely to declare having 'a lot' or 'fair amount' of knowledge about dementia at the beginning of the survey, but when prompted with a brief description they were comparable to the general public results.

The same proportion of Maori and the general public know a person with dementia and although Maori were more likely to report it being a family member (49%), they were less likely to be directly involved in the care of that person.

The main sources of advice cited were similar for Maori and the general public (the doctor, the Internet); however, there were slight differences in the sources of advice cited by low proportions with Maori slightly more likely to cite medical centres. This suggests that working with doctors and keeping the Alzheimers New Zealand website up-to-date and relevant in search results would be most effective in targeting information to both the general public and Maori, and that medical centres and support groups are additional channels that have potential to reach a wider Maori audience.

In practice, Maori that had actually approached an organisation for advice were more likely than the general public to have approached a doctor and their second most frequented source was the local Alzheimer's organisation, giving further weight to the importance of working with doctors who appear to be top of mind when it comes to advice concerning those affected by dementia.

■ Maori perceptions of dementia

As mentioned above, Maori were similar to the general public for most measures. Similar proportions were able to cite symptoms of dementia unprompted and when prompted with symptoms, they were also very similar to the general public for those that were most well-known. Some differences were evident though and Maori were less likely to cite violence or aggression as a symptom and more likely to cite shaking.

Perceptions of dementia were also mostly similar for Maori and the general public - the main difference was that Maori were less likely to believe there are things you can do to reduce the risk of developing dementia.

Attitudes toward dementia were an area that Maori differed a bit more from the general public - they were less likely to say dementia is one of the things they fear most about getting older and more likely to be willing to take a test to determine if they might get it in the future. They were also less likely to be worried about being in public with someone with dementia.

■ Age as a factor

Respondents 60 years of age and over were more likely to declare knowing 'a lot' or 'fair amount' about dementia (68%). This is not surprising considering that 85% of them also know or knew someone with dementia and 42% are or were involved in directly caring for that person. They are also more likely to have cited the local Alzheimer's organisation as a place they have gone to for advice.

Interestingly, even though they think they know more about dementia than other age groups and even with their higher level of personal experience, there were almost no significant differences recorded between age groups for awareness of prompted symptoms of dementia, statements testing perceptions of dementia and statements concerning their beliefs and attitudes towards dementia.

■ Gender as a factor

There was a fair amount of difference between genders concerning knowledge and attitudes towards dementia, with females generally being more knowledgeable about dementia and more willing to help those in need.

Females were more likely to declare knowing 'a lot' or 'fair amount' about dementia (60% and 70% after a brief description) and this was confirmed throughout the survey with females answering questions more accurately. They were more likely to agree, when prompted, that changes in personality (92%), violence or aggression (72%) and language problems (69%) are symptoms of dementia.

They were also more likely to have accurate perceptions of dementia with a significantly higher number disagreeing that only old people get dementia and that it is a normal part of the aging process.

Lastly, females were more willing to assist those with dementia - most of them agreed that they would help someone in public if they thought they had dementia and needed help and that they would accompany a person to the doctor. A larger proportion also said they would be able to assist someone with dementia. In practice, females were more likely to be involved in directly caring for the person they know that has dementia (39%).

Section one: Awareness and understanding of dementia (and Alzheimer's disease)

3.1 Unprompted awareness and understanding

■ General public

Knowledge of dementia was middle of the field when it came to the general public's knowledge of a selection of illnesses.

Over half of respondents reported knowing 'a lot' or 'fair amount' about Alzheimer's disease overall (54%), with a third of these respondents reporting they knew 'a lot'. The numbers were very similar for dementia (53%), which is to be expected given the link between the two.

Respondents were far more likely to say they know 'a lot' or 'fair amount' about depression (76%), asthma and diabetes (both at 72%) - illnesses that people of any age commonly suffer from and are perhaps more widely discussed.

They were less likely to say they know about other neurological or muscular conditions such as Parkinson's disease (35%) and muscular dystrophy (21%).

■ Maori booster

Maori were generally less likely to declare knowledge across the various illnesses tested, though results were similar for asthma, diabetes and muscular dystrophy. They were significantly less likely to report knowledge of dementia at 38%, though this is still a large minority. Interestingly, this lower result is accounted for by males, of whom only 28% said they knew 'a lot' or 'fair amount', females were more comparable to the general public at 47%.

Results were similar for Alzheimer's with 37% of those in the Maori booster reporting knowing 'a lot' or 'fair amount' compared to 54% of the general public. Again, males were significantly less likely to declare knowledge (29%) compared to females (43%). Age was another area where differences were highlighted this time, with younger Maori under 44 years of age also less likely to declare knowledge (31%) compared to Maori over 44 (47%).

■ International studies

The results of an American survey conducted by Harris Interactive for the MetLife Foundation (2010)³ shows that although a larger proportion in the United States knows little about Alzheimer's disease than those in New Zealand, those that declare knowledge may have a deeper understanding⁴.

In the United States study, 62% said they knew 'little' or 'nothing at all' compared to 46% of respondents in New Zealand that knew 'not that much' or 'hardly anything', suggesting that those in the United States know less about Alzheimer's. However, 38% of those in the United States declared they know 'a lot' compared to only 18% in New Zealand which may suggest a deeper level of knowledge - the remaining 36% in New Zealand said they knew 'a fair amount', which was not an option in the United States based study.

■ Demographics (general public)

Females were more likely to declare knowing 'a lot' or 'fair amount' about three of the illnesses tested including depression (80%), dementia (60%), Alzheimer's (58%). Respondents 60 years of age and over were also significantly more likely to declare knowledge of dementia (68%) and Alzheimer's (70%), as were older couples with no children living at home (66% declared knowledge of each illness). Those between 30 and 44 years of age were less likely (42% declared knowledge of dementia and 45% Alzheimer's)⁵.

Although the sample size is very small for those of Pacific and Asian ethnicity and must be interpreted cautiously, there is some evidence they are more likely to report knowing 'hardly anything' about Alzheimer's (29% and 28% respectively)⁶.

■ By experiences and views of dementia

Respondents that had approached an organisation for support or advice about dementia reported very strong levels of knowledge. They were significantly more likely to say they know 'a lot' or 'fair amount' about dementia (87%) and Alzheimer's (84%), with over half of respondents reporting their level of knowledge to be 'a lot'.

Those that know a person with dementia are also significantly more likely to say they know 'a lot' or 'fair amount' about dementia (71%) and Alzheimer's (68%). When involved in the direct care of this person declared knowledge is even greater (83% for dementia, 81% for Alzheimer's).

Those that did not know someone with dementia were significantly more likely to say they knew 'not that much' or 'hardly anything' with 83% of those that didn't know someone with dementia reporting this.

³ Harris Interactive. (2011). What America Thinks: MetLife Foundation Alzheimer's Survey.

⁴ Comparison of these results can only be suggestive and not taken as fact due to the differences in the scales used for this question between surveys and the time delay between the American (2010) and New Zealand based survey (2014).

⁵ Although results for those under 30 were similar to those 30-44, the sample size was not large enough to determine whether the differences were significant.

⁶ For those of Asian ethnicity, results were similar to the general public when combining knowing 'not that much' and 'hardly anything'.

Levels of knowledge about the disease may have some effect on respondents' level of concern about the disease with those that were more concerned about being diagnosed with dementia rather than cancer in the future also more likely to say they know 'a lot' or 'fair amount' about dementia (60%) compared to those that selected cancer (52%), though the difference is not significant.

Declared knowledge of illnesses – summary

Total know 'a lot' + 'a fair amount'

How much do you feel you know about each of the following conditions? A lot, a fair amount, not that much or hardly anything?

	General public %	Maori booster %
<i>Base: n=</i>	750	150
Depression	76	64
Asthma	72	74
Diabetes	72	70
Alzheimer's disease	54	37
Dementia	53	38
Parkinson's disease	35	29
Muscular dystrophy	21	17

Base: All respondents

3.2 Prompted awareness and understanding

■ General public and Maori booster

After giving the respondents a brief, yet detailed description of dementia, the proportion that said they knew 'a lot' or 'fair amount' increased by 12% to 65%. The increase was a result of more respondents reporting knowing 'a fair amount' rather than 'a lot'.

Maori had a far greater increase, by 22% to 60%, with their overall results becoming much more comparable to the general public. Again, the increase can be attributed to more Maori saying they know 'a fair amount', rather than 'a lot'.

It is difficult to say why this increase occurred with data from the quantitative survey and qualitative research would be needed to give an accurate idea; however, it could be as simple as Maori knowing about the condition, but not being able to remember its name or knowing it by a different name.

Giving Maori a description of dementia also evened out levels of declared knowledge across demographics, with the former differences around gender and age no longer being statistically significant.

■ Demographics (general public)

Females were still significantly more likely than males to declare a greater knowledge of dementia, even after all respondents were given a brief description. Overall, 70% of females said they know 'a lot' or fair amount' about dementia (up 10%), compared to 59% of males (up 15%). Those between the ages of 30 and 44 years of age continue to be less likely to declare knowledge at 56% (up 14%), with a relatively large proportion of them (44%) knowing 'not that much' or 'hardly anything'.

■ By experiences and views of dementia

Results that were significantly higher for levels of unprompted knowledge about dementia were also significantly higher for prompted levels of knowledge and generally had small increases.

Ninety-three percent of those that had approached an organisation for support or advice about dementia said they know 'a lot' or 'fair amount' (up 6%), as did 75% that know a person with dementia (up 4%) and 91% involved in the direct care of this person (up 8%).

Although those that did not know someone with dementia were still significantly more likely to say they knew 'not that much' or 'hardly anything', there was a large decrease in this figure after providing a description (58%, down 24%).

Prompted declared knowledge of dementia

As you may be aware, the term "dementia" describes a group of conditions which can affect memory, thinking, behaviour, personality and emotion. It is caused by physical changes in the brain. Because dementia is a progressive condition, symptoms will gradually worsen. There are many different types of dementia, the most common of which is Alzheimer's disease.

Based on that description, would you say you know a lot, a fair amount, not that much or hardly anything about dementia?

	General public %	Maori booster %
Base: n=	750	150
A lot	19	13
A fair amount	46	47
TOTAL 'A LOT' + 'A FAIR AMOUNT'	65	60
Not that much	27	29
Hardly anything	8	11
TOTAL 'NOT THAT MUCH' + 'HARDLY ANYTHING'	35	40
Unsure	-	-

Base: All respondents

Section two: Recognising symptoms of dementia

These questions help us to understand what symptoms or behaviour respondents associated with dementia and where misunderstandings and misconceptions exist. These questions were asked twice; the first time they were asked open-ended and unprompted, the second time respondents were asked which ones they thought were common symptoms from a randomised list.

4.1 Unprompted awareness and understanding

■ General public

When asking respondents unprompted which sort of symptoms or behaviour would make them suspect someone they knew had dementia, memory loss was by far the most commonly cited symptom of dementia; cited by four in five respondents (79%). Most people that referred to memory loss did so through short statements, saying things like “forgetfulness”, “forgetting things” or “loss of memory”. A notable proportion also referred to problems recognising or remembering people they should know.

“Forgetting things, getting people mixed up, forgetting who your kids are - a whole range of things that start gradually”.

The next most cited symptom was changes in mood or behaviour, cited by a quarter.

“Becoming forgetful and not remembering where they put things, forgetting familiar people’s names, being confused, maybe getting distressed about not being able to remember things - mood changes which may fluctuate.”

Other symptoms had much lower rates of recollection. General comments about being confused or disorientated were cited by 13%, followed by repeating things at 10% and being disorientated specifically about time or the person’s current location at 9%. Other symptoms cited by at least 5% included changes in personality (6%), problems with language and difficulty performing regular tasks (both 5%).

■ Maori booster

The Maori booster had similar results to the general public in the overall context. Memory loss was the most cited symptom by a large margin, also cited by four in five (81%) and was followed by changes in mood or behaviour (21%).

Repeating things was the third most recalled symptom, cited by 9%. Maori were more likely to cite disorientation specifically with time and place (7%) than they were to generally comment on confusion or disorientation (5%), a reversal from general public results. Other symptoms cited by at least 5% were problems with language (6%) and changes in personality (5%).

■ Demographics

Overall, females were more likely than males to be able to name symptoms of dementia - only 4% of general public females and 3% of Maori females said they were unsure or didn't know any symptoms compared to 10% of general public males and 11% of Maori males. This frequently showed in results with females having slightly higher levels of recollection across most symptoms, it was more obvious for memory loss with 84% of general public females citing it compared to 73% of males.

There was also a division by age with 11% of those in the general public under 44 unsure and 10% of Maori under 44 unsure compared to 3% of those over 44 (both general public and Maori). Those over 44 were more likely to cite disorientation of time and place (13% general public and Maori). When looking at higher results specific to the general public, 7% of those over 44 cited difficulty performing regular tasks as a symptom. Specific to Maori, 14% of those over 44 cited problems with language.

“Constant forgetfulness, not being aware of words and their associations or losing those kind of word associations.”

Another 8% of Maori over 44 cited 'living in the past' as a symptom - referring to talking about events from the past, even from childhood and sometimes confusing them with present.

“Forgetting the date and forgetting people they have known for a long time like family. Remembering people that aren't in their lives, from a long time ago...”

A quarter (26%) of younger respondents that lived alone was unable to give any symptoms of dementia, which is far higher than those in any other household situation.

Those of Pacific and Asian ethnicities were also more likely to not be able to cite symptoms (32% of Pacific and 25% of Asian peoples). Though it was still the most cited symptom for them, they were significantly less likely to cite memory loss as a symptom (55% of Pacific and 50% of Asian peoples). Perhaps due to the larger proportion of Asian ethnicities living there, those in Auckland were also more likely to not know any symptoms (13%).

■ By experiences and views of dementia

As you would expect, those that said they know 'a lot' or 'fair amount' about dementia before hearing a description were more likely to cite any given symptom, even if only slightly; 85% of them cited memory loss as a symptom. This also held true for those that said they know 'a lot' or 'fair amount' about dementia after hearing the description, though the proportion of this group able to recall any given symptom was lower.

Those that know someone with dementia were also slightly more likely to be able to name most symptoms; the symptom with the biggest increase in recollection compared to the general public was memory loss at 84% (5% higher). The symptom that stood out the most for those involved in the direct care of a person with dementia was changes in mood or behaviour- cited by 32% (up 7% on the general public); the recollection of this symptom was also higher among those that had approached an organisation for advice or support regarding dementia at 38%. These figures might suggest that mood swings do have a memorable impact on those caring for people with dementia and that some may be prompted to seek advice or support because of them.

Unprompted symptoms of dementia

What sort of symptoms or behaviour would make you suspect someone you knew had dementia?

	General public %	Maori booster %
<i>Base: n=</i>	750	150
Memory loss	79	81
Changes in mood or behaviour	25	21
Confusion (general comment)	13	5
Repeating things	10	9
Disorientation of time and place	9	7
Changes in personality	6	5
Problems with language	5	6
Difficulty performing regular tasks	5	1
Loss of initiative	3	-
Misplacing things	3	1
Poor judgement	2	1
Lose control of bodily functions	1	2
Hallucinations	1	1
Poor concentration	1	1
Living in the past	1	4
Loss of coordination	1	1
Other	1	2
Don't know/unsure	7	7

Base: All respondents

4.2 Prompted awareness and understanding

■ General public

Knowledge of symptoms of dementia was much higher when respondents were prompted. When asked about 11 symptoms of dementia, over 90% thought four of them were true. The symptom that most respondents believe to be true is 'forgetting things regularly' with 96% saying this is a symptom - a result consistent with this symptom being the most cited when unprompted.

Other symptoms cited as being true by the vast majority of respondents were getting lost (95%), forgetting people's names and misplacing things regularly (both 93%).

A slightly lower, but still very large proportion, believed changes in personality (87%), difficulty performing everyday tasks and forgetting what things are used for (85% each) are common symptoms.

Symptoms that were less commonly believed (yet still believed by the majority) included loss of initiative (70%), language problems (63%) and violence or aggression (60%). Language problems and violence or aggression also had relatively large minorities state they were not symptoms (27% and 31% respectively).

■ Maori booster

Maori had a very similar overall trend to the general public and agreement that symptoms were common to dementia was within 5% of the general public for all but two of the symptoms. Forgetting things regularly continued to be the most agreed with symptom with 95% of Maori believing it is common to dementia. This was closely followed by forgetting people's names (93%) and getting lost (92%).

Other symptoms agreed to be common to dementia by almost 90% of Maori include forgetting what things are used for, misplacing things regularly, changes in personality and difficulty performing everyday tasks.

Similar to the general public, loss of initiative, language problems and violence or aggression were agreed to be symptoms by relatively lower proportions that were still majorities. The view towards the last symptom - shaking - was far more polarised for Maori than the general public with 41% believing it is a common symptom of dementia and almost the same proportion (43%) believing it is not.

■ International studies

Like the Robert J. Blendon, et al. (2012) study⁷, the UMR survey tested common perceptions of symptoms of dementia. There are three symptoms of dementia that can be compared between the two surveys, with two of these symptoms recording very similar results for international and New Zealand respondents.

Getting lost was seen as a symptom by 95% of New Zealanders and 'wandering and getting lost' was seen as a symptom by 88% to 95% of respondents in the five countries tested internationally.

Difficulty performing everyday tasks was seen as a symptom by 85% of New Zealanders and 83% to 88% of respondents in the five countries tested internationally.

New Zealanders were more likely to believe that violence or aggression is a symptom with 60% reporting this. The United States is the most comparable to New Zealand with 53% reporting anger and violence is a symptom. Under half of the respondents in the four other countries were likely to believe violence to be a symptom; Poland was the least likely, with only 35% believing it to be a symptom.

■ Demographics

The largest difference between males and females was for the symptom 'violence or aggression' with only 46% of general public males and 37% of Maori males believing aggression is a symptom compared to 72% of general public females and 66% of Maori females. Those between 30 and 44 years of age were also more likely to believe aggression is a symptom (67%).

⁷ Blendon, R.J., Benson J.M., Wikler, E.M., Weldon K.J., Georges, J., Baumgart, M., & Kallmyer B.A. (2012). The impact of experience with a family member with Alzheimer's disease on views about the disease across five countries. *International Journal of Alzheimer's Disease*, vol. 2012.

Pacific peoples were less likely to believe that getting lost is a symptom (73% compared to 95% of the general public). Those of Asian ethnicity also had a few differences when compared to the general public. They were less likely to believe forgetting things regularly (88%), forgetting people's names (84%) and misplacing things regularly (82%) are symptoms (between 8% to 11% less Asian respondents cited these as symptoms compared to the general public) and they were more likely to believe shaking is a symptom (57% compared to 34% of the general public).

■ By experiences and views of dementia

Those that said they knew 'a lot' or 'fair amount' about dementia, both before the description of dementia was given and after it was given, were significantly more likely to believe most of the symptoms tested are common to dementia.

Respondents that know a person with dementia were more likely to believe four of the symptoms tested are common to dementia compared to those that do not know someone. Almost all of those that know someone with the illness said that getting lost is a symptom (98%) compared to 89% that do not know someone. 89% of those that know someone said difficulty performing everyday tasks is a symptom (compared to 78% that do not), 76% said loss of initiative is a symptom (compared to 59% that do not) and 62% say that violence or aggression is a symptom (compared to 55% that do not).

The differences were more pronounced for respondents involved in directly caring for someone with dementia, with 95% agreeing that changes in personality is a symptom, 84% agreeing that loss of initiative is a symptom and 74% agreeing that violence or aggression is a symptom.

Prompted symptoms of dementia - summary

Total 'yes'

Please tell me which of the following you think are common symptoms of dementia?

	General public	Maori booster
	%	%
<i>Base: n=</i>	750	150
Forgetting things regularly	96	95
Getting lost	95	92
Forgetting people's names	93	93
Misplacing things regularly	93	88
Changes in personality	87	88
Difficulty performing everyday tasks	85	87
Forgetting what things are used for e.g. car keys	85	90
Loss of initiative	70	72
Language problems	63	67
Violence or aggression	60	53
Shaking	34	41

Base: All respondents

Section three: Perceptions of and attitudes toward dementia – Statement testing

Statement testing was undertaken to learn more about respondents' understanding of dementia, including any misconceptions people may hold.

Notes to reader:

1. In our experience, some respondents may give answers they deem socially appropriate and that reflect how they would like to see themselves, rather than answers that may reflect reality and position them in a bad light. Following this, it would be rational to presume some results may present a more idealistic scenario than would be found in practice.
2. Findings are reported at a **total** true/ false or agree/ disagree **and a definitely** true/ false or **strongly** agree/ disagree level. In our experience, respondents are sometimes reluctant to provide strong or definite answers i.e. stating that something is definitely true or false or scoring a 0 or a 10 on a 0-10 point scale. So, while 'total' scores give a good indication of perceptions and beliefs the extremes give a much more accurate picture of the strength of feeling toward a particular issue.

5.1 Statement testing

■ General public: Accurate perceptions of dementia

The statement that most respondents agreed is true is that for someone with dementia, their condition gets worse over time, which had 94% agree is true overall and 59% agree is definitely true.

There were two more statements which large proportions answered accurately; 88% said it is false there is nowhere to go for advice or support (69% said this is definitely false) and 86% said it is false that memory loss is the only symptom of dementia (61% said this is definitely false).

These three statements all had clear majorities answer them accurately with low proportions giving the inaccurate answer, giving them high net ratings⁸ between 75% and 91%.

Four more statements had over half of respondents answer accurately, though they also had slightly larger proportions give inaccurate answers or state they were unsure giving them comparatively lower, but still strong, net ratings. Of these four statements:

⁸ The net rating is calculated by subtracting the proportion that answered inaccurately from the proportion that answered accurately; a positive result shows more respondents were accurate and a negative result shows that more were inaccurate.

- The largest population (77%) disagreed that only old people can get dementia and 17% agreed, giving it a net rating of 60% (46% said this was definitely false).
- The statement 'there are things you can do to reduce your risk of developing dementia' had a similar net rating of 58% with 72% agreeing (26% said this is definitely true) and 14% disagreeing (4% said it is definitely false); this was also the statement most respondents were unsure of (13%).
- The statement 'it is a normal part of the aging process' got a net rating of 45% (70% disagreed and 25% agreed). 6% said it was definitely true and 37% said it was definitely false.
- The statement 'people with dementia can continue with their regular life activities after being diagnosed' got a net rating of 43% (66% agreed and 23% disagreed). 24% said this was definitely true and 5% said it was definitely false.

■ Less accurate perceptions of dementia

Only one statement tested had a negative net rating indicating that the majority of people are misled about one facet of dementia tested. The statement 'dementia is a fatal condition' was reported to be false by a much larger proportion (61%) than those which reported it as true (27%), giving it a negative net rating of -34%. 11% said this is definitely true and 31% said it was definitely false.

■ Other perceptions of dementia

Some statements did not have an objective true or false answer, partly because the answer may depend on another factor such as the level of progression of the disease.

The statement 'people with dementia need to be cared for in a rest home' was the most conflicting statement tested, being reported as false by the slim majority of respondents (51%), though a relatively large proportion (36%) agreed with it and another 10% of respondents said it depends. However, 13% said it was definitely true and 20% that it was definitely false.

The statement 'people with dementia don't understand what's going on around them' was predominately reported as being true (56%), though a relatively large minority (31%) reported it to be false. 16% said this was definitely true and 11% that it was definitely false.

■ Maori booster

Results for the Maori booster were generally fairly similar to those of the general public and there were no statistically significant differences. The biggest difference was for the belief that dementia is a fatal condition with Maori less likely to say this statement is false (10% less) and being slightly more likely to say they were unsure. However, results are almost identical at a 'definitely' true level; 10% of Maori said it was definitely true compared with 11% of the general public.

■ International studies

Two international studies tested statements about Alzheimer's being a fatal condition. As we tested 'dementia' in our standalone telephone survey these results are not comparable; however, we did test beliefs about Alzheimer's being fatal in the omnibus survey and these results are compared later in this section in the omnibus survey section (Section 5.3).

■ Demographics

Females were far more adamant that dementia is not a normal part of the aging process with 46% saying the statement 'it is a normal part of the aging process' is definitely false compared to only 30% of males that stated it is definitely false. Additionally, 52% of females said the statement 'only old people get dementia' is definitely false compared to 40% of males.

Females were also more likely to give the answer 'it depends' when asked whether people with dementia need to be cared for in a rest home (13%).

When looking at perceptions of dementia by age group, only one trend stood out. Younger respondents were far more likely to say that the statement 'people with dementia don't understand what is going on around them' is false (44% of those 18-29 and 37% of those 30-44) compared to older respondents (26% of those 45-59 and 19% of those 60 and over).

Pacific and Asian peoples were far more likely to say that some of the statements about dementia tested are true. Pacific peoples were more likely to say that dementia is a fatal condition (61%), that it is a normal part of the aging process (50%) and that memory loss is the only symptom of dementia (30%). Asian ethnicities were also more likely to say that dementia is a fatal condition (44%); other statements they were more likely to agree with were that people with dementia need to be cared for in a rest home (53%), only old people get dementia (33%) and there is nowhere to go for advice or support (21%).

■ By experiences and views of dementia

Those that declared they know 'a lot' or 'fair amount' about dementia before being given a description were more likely to agree the condition gets worse over time (97%) and that things can be done to reduce the risk of developing dementia (75%). They were less likely to agree that only old people get dementia (12%).

They were also more likely to say that three statements depended on something else. Specifically, that people with dementia need to be cared for in a rest home (13%), that they don't understand what's going on around them (11%) and that they can continue with their regular life activities (10%).

Those that know someone with dementia were more likely to agree the condition gets worse over time (97%); they were also less likely to agree that only old people get dementia (12%).

Those that said they were more concerned about being diagnosed with cancer than dementia were also less likely to believe dementia is a fatal condition, with 21% reporting that statement to be true (compared to 33% that were more concerned about dementia and 27% overall).

5.2 Attitudes towards dementia – Standalone telephone survey

■ Including people with dementia

The large majority agreed that if someone they knew had dementia they would continue to include them in their social activities (86% general public, 85% Maori). Over half (52%) of the general public and 61% of Maori strongly agreed (rated 10 on a 0-10 point scale where 0 means strongly disagree and 10 means strongly agree). However, there was far more division when respondents were asked how comfortable they would be in public with a person with dementia.

Just over a third (36%) disagreed (15% strongly disagreed) they would be worried being in public with someone with dementia due to how they might act and 32% agreed they would be worried (7% strongly agreed). 31% gave a neutral rating⁹. Maori were less likely to say they would be worried with 41% disagreeing (19% strongly) and only 24% agreeing (7% strongly), 35% gave a neutral rating.

A cross tabulation of these two questions shows that being worried about how someone with dementia might act in public when you are with them did not stop people from saying they would continue to include them in their social activities; 84% of those that said they would get worried being in public with a person with dementia also said they would continue to include them in social activities.

■ Helping people with dementia

Statements to do with helping people with dementia received high agreeable ratings for both the general public and Maori.

The large majority agreed that if they saw someone in public who they thought had dementia and needed help they would help them (83% general public, 85% Maori). 49% of general public and 59% of Maori strongly agreed. A very large proportion agreed that if someone close to them exhibited confusion and memory loss, they would accompany them to the doctor to determine if the cause was dementia (77% general public, 80% Maori). 42% of general public and 54% of Maori strongly agreed.

A slightly lower, but still large proportion agreed that if someone with dementia needed help they would feel able to assist them (62% general public, 63% Maori), the remaining respondents were more likely to give a neutral rating for this statement, with only a very small proportion disagreeing that they would feel able to help (10% general public, 5% Maori). 30% of general public and 39% of Maori strongly agreed with this statement.

■ Personal feelings about dementia

Most respondents claim they would not hesitate to take a simple test to find out if they were likely to get dementia in the future (69% general public, 76% Maori). 46% of general public and 53% of Maori strongly agreed they would take a simple test.

⁹ A neutral rating is defined by selecting a middle rating of 4-6 on a scale from 0-10.

Part of the reason for this lack of hesitation may be due to another result which shows more people disagreed than agreed that dementia is one of the things they fear most about getting older; 39% of the general public disagreed that they feared it and 27% gave a neutral rating. Nevertheless, a third (34%) agreed it was one of the things they feared most. 15% strongly disagreed and 14% strongly agreed dementia is one of the things they fear most about getting older.

Maori were even less likely to agree it was one of the things they feared most (25%), with almost three quarters disagreeing or giving a neutral rating (46% disagreed and 27% gave a neutral rating). 22% of Maori strongly disagreed and 11% strongly agreed dementia is one of the things they fear most about getting older.

Respondents were far more likely to say they would rather care for someone with dementia than be diagnosed with it. Only 18% of the general public agreed that they would rather be diagnosed with dementia than care for someone with it, with the far larger proportion disagreeing (45%) and 30% gave a neutral rating); results for this statement were almost identical for Maori. 9% of the general public strongly agreed they would rather be diagnosed with dementia than care for someone with dementia, while a quarter (25%) strongly disagreed.

The only other statement to get very low levels of agreement was one regarding whether respondents would be reluctant to tell others about a family member with dementia. Only 19% agreed they would be reluctant to tell others if a close family member was diagnosed, with over three times that many (67%) disagreeing. 9% strongly agreed they would be reluctant and 32% strongly disagreed.

Maori were slightly less likely to agree (14%; 9% strongly agreed) or disagree (64%; 33% strongly disagreed) and were more likely to give a neutral rating (22%).

■ International studies

The Blendon et al., (2012) study asked a similar question to UMR; testing interest in early diagnostic testing, though for Alzheimer's rather than dementia. The UMR study also used slightly stronger wording. New Zealanders claimed to be more likely to take a test than any of the five countries tested in the international report. Between 23% and 30% of those in France, Germany, Poland and the United States said they were very likely to get a diagnostic test if one were available and 39% were likely in Spain. In New Zealand, 46% strongly agreed¹⁰ they would almost certainly take a test.

The MetLife Foundation survey found that nearly a quarter (23%) of adults were extremely or very concerned that they may someday have to provide care for a loved one with Alzheimer's; an increase from 18% in 2006.

¹⁰ Chose '10' on a scale of 0 to 10, where '0' meant strongly disagree and '10' meant strongly agree.

■ Demographics

Most differences in agreement across statements were differences by gender, with females generally stating they were more likely to help people with dementia. Females were more likely to agree they would be able to assist someone with dementia (69% vs. 54% of males) and help someone in public if they thought they had dementia and needed it (91% vs. 75% of males). They were also more likely to disagree that they would be reluctant to tell others if a close family member had been diagnosed with dementia (74% vs. 60% of males).

Males were less likely to say they would accompany a person close to them to the doctor to check if they had dementia (72%).

Younger respondents 18-29 were more likely to agree they would be reluctant to tell others if a close family member was diagnosed with dementia - 30% compared to 13% of those 30-59 and 18% of those 60 and over.

Pacific peoples were more likely to agree that they would be able to assist someone with dementia (89%); they were also more likely to agree that they would be reluctant to tell others if a close family member was diagnosed with dementia (53%).

Those of an Asian ethnicity were also more likely to agree they would be reluctant to tell others if a close family member was diagnosed with dementia (43%) and more likely to agree that they would rather be diagnosed with dementia than care for someone with dementia (36%).

■ By experiences and views of dementia

Those that said they had 'a lot' or 'fair amount' of knowledge about dementia unprompted were more likely to disagree that they would be reluctant to tell others if a close family member had been diagnosed with dementia (74%). After being given a description of dementia, those that said they knew a reasonable amount about it were more likely to say they would be able to assist someone with dementia (68%).

Respondents that know or knew someone with dementia were more likely to disagree that they would be reluctant to tell others if a close family member was diagnosed with dementia (73%); they were also less likely to agree that they would be worried about being in public with someone with dementia (27%). Those involved in the direct care of this person were significantly more likely to agree that they would be able to assist someone with dementia (74%).

Those that could list changes in personality as a symptom of dementia unprompted were more likely to disagree they would accompany a person close to them to the doctor to check if they had dementia (22%).

Respondents that said they were more concerned about being diagnosed with dementia rather than cancer were far more likely to agree it was one of the things they feared most about aging - almost two-thirds (64%) of those that were more concerned about dementia said it was one of the things they feared most compared to only 28% that were more concerned about cancer. They were also more likely to agree that they would be worried being in public with someone with dementia (46%).

Statement testing – summary

Total true

For each of the following statements about dementia, please tell me whether you think they are definitely true, probably true, probably false, definitely false or if you are not sure.

	General public %	Maori booster %
<i>Base: n=</i>	750	150
For someone with dementia, their condition gets worse over time.	94	92
There are things you can do to reduce your risk of developing dementia.	72	63
People with dementia can continue with their regular life activities after being diagnosed.	66	62
People with dementia don't understand what's going on around them.	56	62
People with dementia need to be cared for in a rest home.	36	34
Dementia is a fatal condition.	27	30
It is a normal part of the aging process.	25	25
Only old people get dementia.	18	18
Memory loss is the only symptom of dementia.	12	12
There is nowhere to go for advice and support.	7	5
Base: All respondents		

Statement testing – summary

Total agree (7-10)

Using a 0 to 10 scale where 0 means strongly disagree and 10 means strongly agree, how strongly do you agree or disagree with the following statements?

	General public %	Maori booster %
<i>Base: n=</i>	750	150
If someone I knew was diagnosed with dementia I would continue to include them in our regular social activities.	86	85
If I saw someone in public who I thought had dementia and needed help, I would help them.	83	85
If someone close to me was exhibiting confusion and memory loss, I would ask them if I could accompany them to their Doctor to determine if the cause was dementia.	77	80
If it was possible to take a simple test to find out if I was likely to get dementia in the future, I would almost certainly take it.	69	76
If someone with Dementia needed help I would feel able to assist them.	62	63
Dementia is one of the things I fear most about getting older	34	25
If I was out in public with someone who had dementia, I would be worried about how they would act.	32	24
If a close family member was diagnosed with dementia, I would be reluctant to tell other people about it.	19	14
I would rather be diagnosed with dementia than care for someone with dementia.	18	17

Base: All respondents

5.3 Omnibus survey – International comparisons

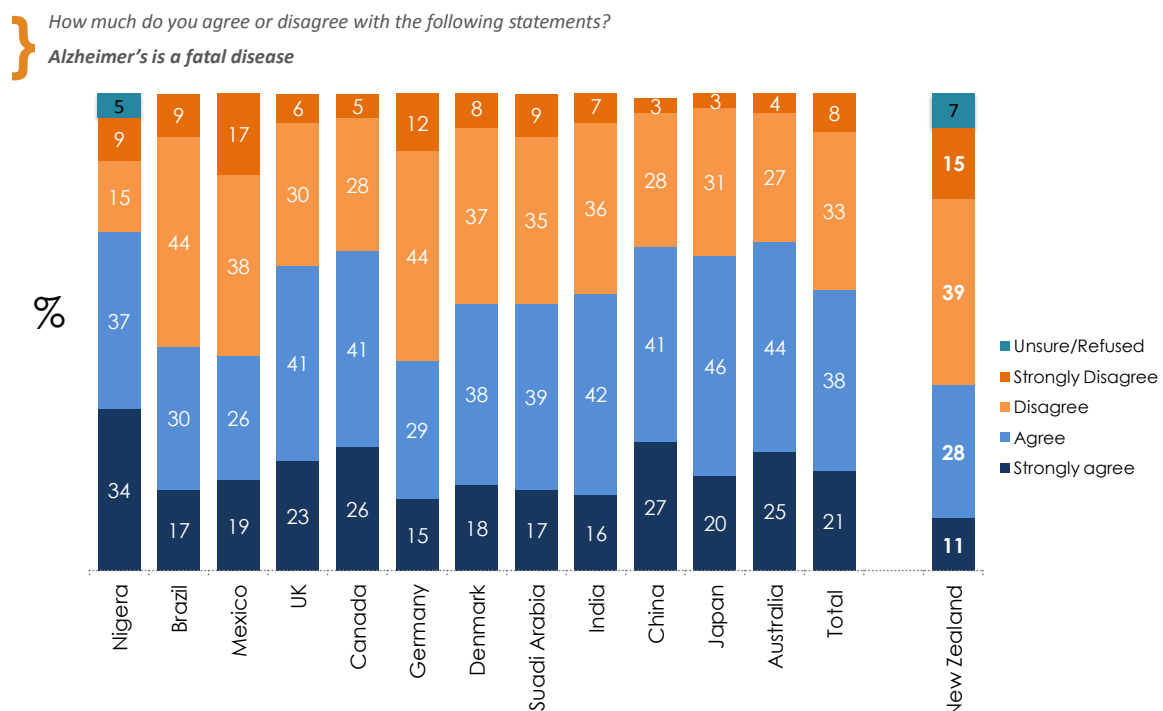
■ Majority do not believe Alzheimer's is fatal

The belief that most respondents hold an inaccurate view of; is regarding the statement “Alzheimer's is a fatal disease”, with the majority (54%) disagreeing it is fatal and 39% agreeing it is.

Internationally, New Zealanders appear to be more misinformed than many of the countries surveyed by the Alzheimer's Association (2014) report in an overall context. However, the New Zealand results are similar to those recorded in Germany, Mexico and Brazil.

A second international study by Blendon et al., (2012) showed that large proportions in four of the five countries they tested do not believe Alzheimer's is a fatal disease. New Zealand was in the middle ground of the Blendon results which showed smaller proportions believe Alzheimer's is fatal in Germany and Poland (33% and 34% respectively) and slightly larger proportions believe it to be fatal in Spain and France (42% and 44% respectively). The United States was the one nation to have a much larger proportion believe Alzheimer's is fatal according to their results (61%)¹¹

Agreement – Fatal disease



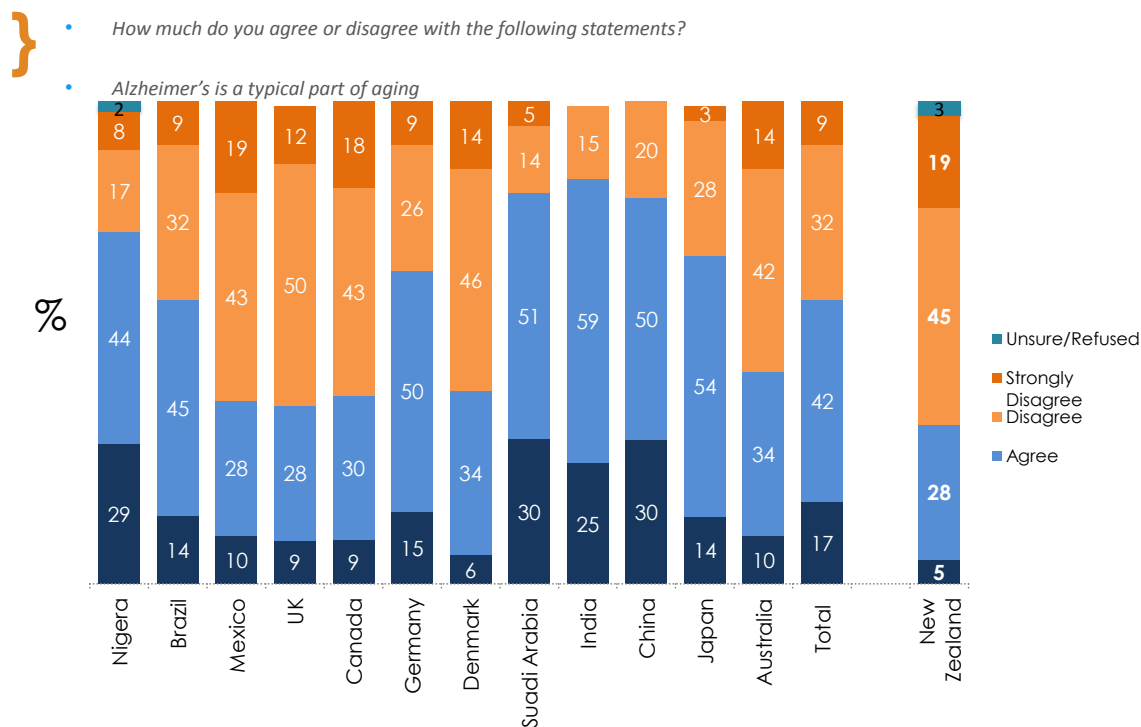
¹¹ Findings are not directly comparable as the New Zealand results include Unsure/Refused responses; the Nigerian results also appear to but the other countries do not; suggesting that the findings for these countries have been recalculated excluding Unsure/Refused responses.

- Most recognise Alzheimer's is not a typical part of aging although a large minority think it is

Almost two-thirds (64%) disagreed that Alzheimer's disease is a typical part of the aging process, though a large minority (33%) still agreed that it is.

Internationally, New Zealanders appear to be more informed about this belief when compared to results from all 12 nations which showed 59% of respondents believe it to be a typical part of aging. New Zealand's results were most similar to those from Mexico, Canada, Denmark and the UK.

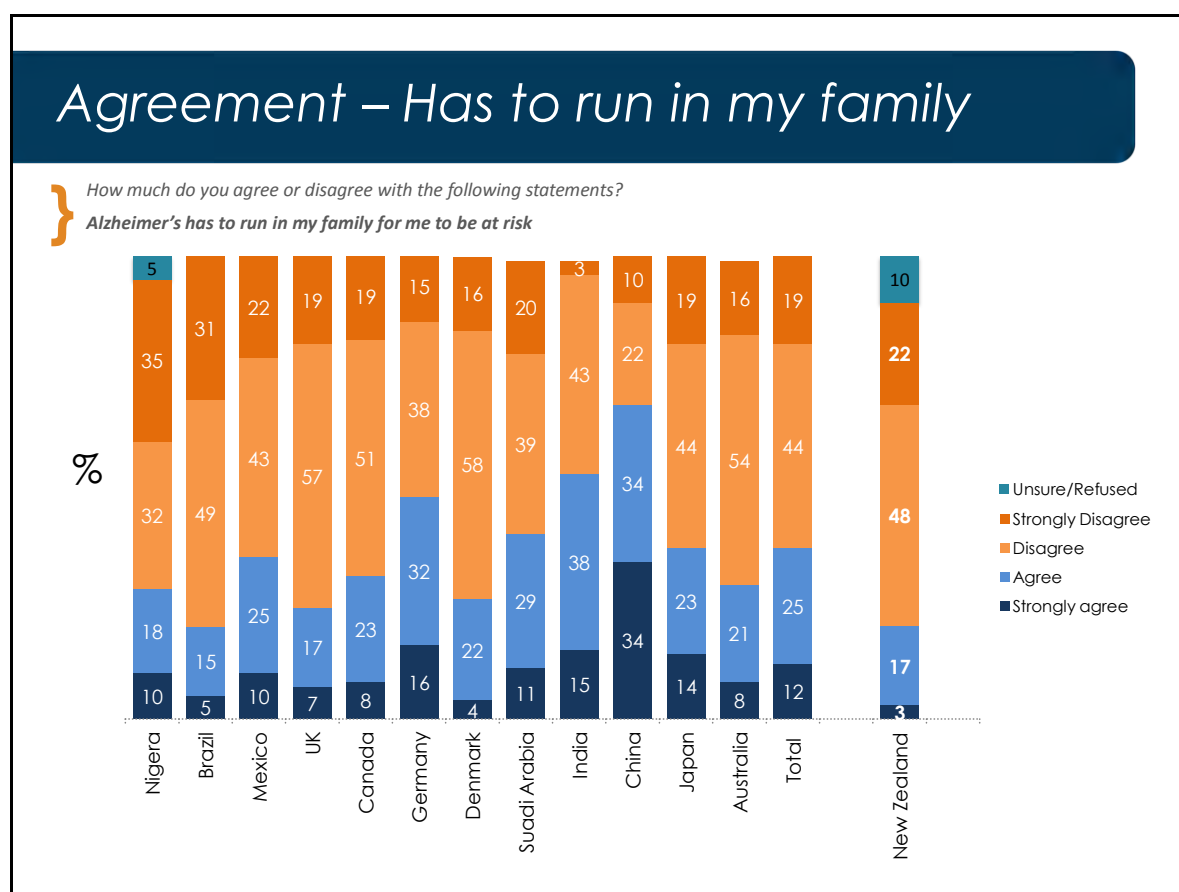
Agreement – Typical part of aging



■ Most recognise you do not need a family history to be at risk of Alzheimer's

A large proportion of respondents rightly assume that Alzheimer's does not have to run in the family for them to be at risk; 70% disagree. Only 20% agree this is the case. We also note that 10% of New Zealanders were unsure; findings which were not available for most other countries.

Again, New Zealanders appear to be slightly more informed internationally with a lower proportion of respondents than across the 12 nations agreeing with this statement (20% compared with 37% internationally). Internationally, New Zealand results were most similar to Brazil and the UK.



■ Majority disagree Alzheimer's is one of the things to be feared most about aging

Over half (55%) disagreed that Alzheimer's is one of the things they fear most about getting older, though a large minority still agreed that for them it was something to be feared (41%).

Looking at the extremes, we note also that 13% strongly agreed that Alzheimer's is one of the things they fear most about getting older; the same proportion strongly disagreed (13%).

Levels of self-declared knowledge had no significant impact on whether they feared it for this question; however, those that had personal experience through knowing someone with Alzheimer's were more likely to say it was one of the things they feared most about getting older (45%, compared to 33% that did not know someone with Alzheimer's).

■ Majority would rather care for someone with Alzheimer's than have it

Half of respondents disagreed that they would rather be diagnosed with Alzheimer's disease than care for someone with the disease and a lower proportion (37%) agreed that they would rather have Alzheimer's.

Looking at the extremes; 10% strongly agreed and 17% strongly disagreed they would rather be diagnosed with Alzheimer's than care for someone with it. However, findings in the MetLife Foundation survey indicate that nearly a quarter (23%) of adults is extremely or very concerned that they may someday have to provide care for a loved one with Alzheimer's.

Those who claimed to know 'a lot' or 'a fair amount' about Alzheimer's are slightly less likely (34%) to prefer being diagnosed with Alzheimer's than care for someone with it compared to those with lower levels of knowledge on 40% (46% of those that know 'hardly anything').

■ Vast majority are not reluctant to talk about family with Alzheimer's

The vast majority of respondents disagreed that they would be reluctant to tell other people if a close family member was diagnosed with Alzheimer's (87%) with only 11% of respondents in agreement.

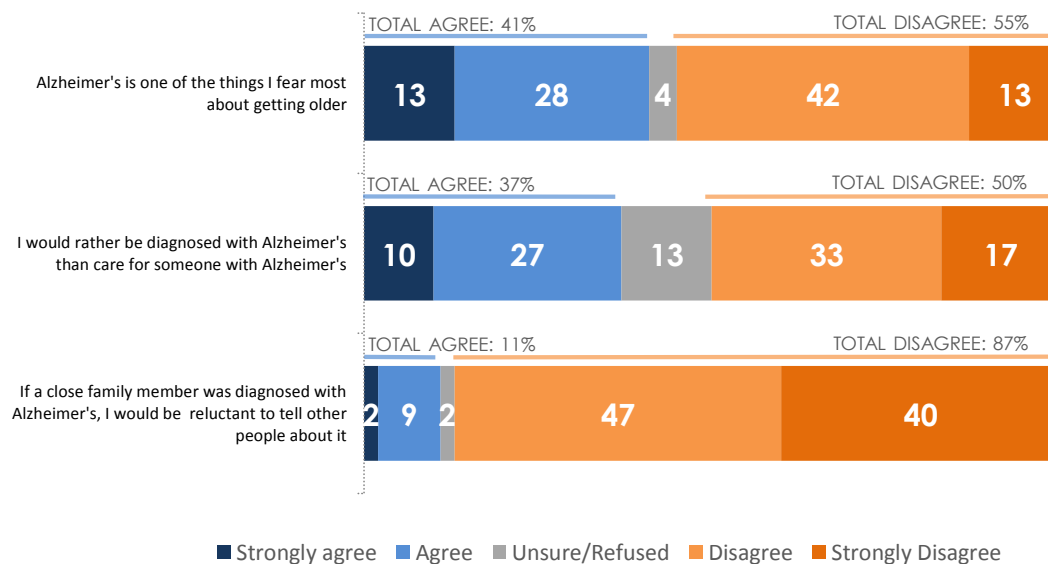
Looking at the extremes; 2% strongly agreed and 40% strongly disagreed they would be reluctant to talk to others about a family member with Alzheimer's.

People who don't know anyone with Alzheimer's claim they are more reluctant than people who do know someone with Alzheimer's to talk about a family member with the disease (16% compared to 8% respectively). Those that knew 'hardly anything' about Alzheimer's disease are far more likely to be reluctant to talk to others about a family member with the disease (32%) compared to those with any greater amount of knowledge. (7% to 10% of those that knew 'not that much' to 'a lot' were reluctant.

Level of agreement



How much do you agree or disagree with the following statements? Strongly agree, Agree, Disagree, Strongly Disagree



Section four: Seeking help for someone with dementia

6.1 Potential sources of help and advice

■ General public

Three-quarters of the general public said they would approach the doctor or their GP if they suspected someone they knew may have dementia, making them the most popular source of help and advice by a significant margin.

The Internet was the only other source of advice to be cited by a notably larger proportion than other sources with one in five (19%) reporting it as the place they would go to.

Other sources of advice cited by 10% or less of the general public included family members (10%), a foundation or society to do with dementia (other than the Alzheimer's society, 7%), the Alzheimer's society (5%), a hospital or support groups (also 5%). Friends, a specialist and a medical centre were also mentioned by lower proportions.

■ Maori booster

Maori results were similar to the general public overall with 70% citing the doctor or their GP as a source of advice about dementia; again, this was the most popular source by a large margin. It was followed by the Internet - cited by a slightly lower proportion (15%) and a family member - cited by a slightly larger proportion (13%).

Similar to the general public, Maori had a variety of sources they would approach that were cited by low proportions; there tended to be slight differences in the proportion of Maori and the general public respondents that cited these minor sources of advice. The more popular of these sources included medical centres (7%), support groups (6%), the hospital and the Alzheimer's society (both 5%). A different foundation or society to do with dementia, a helpline and approaching the affected individual were all mentioned by 4% of Maori.

■ Demographics

Females were more likely to cite the doctor or general public as a source of advice compared to males (81% of GP and Maori females compared to 69% general public males and 58% of Maori males).

There were a few more differences among Maori for the smaller sources of advice. Maori over 44 years of age and females were more likely to cite people that have had experience dealing with people with dementia (7% and 5% respectively) and younger Maori 18-44 were more likely to cite a medical centre (10%) or say they would approach the person themselves (7%).

Younger respondents in the general public were generally less likely to cite any given source of advice. Those 18-29 were least likely to cite the doctor or GP (62%). They were slightly more likely to cite medical centres (6%). Compared to other age groups, respondents 30-44 were most likely to say they would use the internet (27%), those 45-59 were most likely to mention the doctor or GP (83%) and those 60 and over were most likely to mention the Alzheimer's society (10%) and least likely to mention the internet (8%).

■ By experiences and views of dementia

Those that declared knowing 'a lot' or 'fair amount' about dementia were slightly more likely to say they would go to the doctor or GP (79%) than those that did not (71%); although this difference was not significant. They were also more likely to cite the Alzheimer's society as a source of advice (8% compared to 2%).

Those that had already approached an organisation for advice or support about dementia were significantly more likely to say they would approach the Alzheimer's society for advice when asked this question (13% compared to 4% that had not already approached an organisation). This is in line with results that show the predominant organisation approached by those that had already been to one was 'the local Alzheimer's organisation'. Those that were involved in the direct care of a person with dementia were also more likely to have cited the Alzheimer's society (13%).

Sources of advice about dementia

If you suspected someone you knew may have dementia who would you approach or where would you look for help and advice?

	General public %	Maori booster %
<i>Base: n=</i>	750	150
The doctor/GP	75	70
The Internet	19	15
Family member	10	13
A foundation or society to do with dementia	7	4
Alzheimer's society	5	5
The hospital	5	5
Support groups	5	6
Friends	3	2
A specialist in the field	3	2
Medical centre/health professional	3	7
Age concern	2	3
A helpline	2	4
Citizens Advice Bureau	2	2
A rest home	1	1
The phone book	1	-
Social services	1	-
DHB	1	1
Mental health ward	1	1
Would approach the person themselves	1	4
People that have dealt with it, e.g. social workers	1	3
A place for people with dementia (general comment)	1	3
Other	1	2
Don't know/unsure	2	1
Base: All respondents		

6.2 Support or advice sought in the past

Just over one-in-ten respondents (12%) had approached an organisation or group for support or advice about dementia; the proportion was slightly higher for Maori (14%).

■ Demographics

Females were far more likely to have approached an organisation for support or advice compared to males; 17% of general public and 19% of Maori females had approached an organisation compared to 7% of general public and 8% of Maori males¹².

There were also differences by age with 24% of Maori over the age of 44 having already approached an organisation and 17% of the general public that were 60 and over having done so.

Pacific Islanders were less likely to have approached an organisation with only 2% having done so; those living in Auckland were also less likely (8%).

■ By experiences and views of dementia

Those that said they knew 'a lot' or 'fair amount' about dementia (unprompted) were also more likely to report having approached an organisation (20%, compared to 7% that knew 'not that much' and 'hardly anything').

Respondents that claimed to know a person with dementia were also significantly more likely to have approached an organisation than those that did not know someone - 17% compared to just 1% that did not know someone. Results were slightly higher for those that knew a family member with dementia (20%) and were much stronger for those involved in the direct care of the person they knew, with 38% having approached an organisation for support or advice.

Those that were more concerned about being diagnosed with cancer rather than dementia were less likely to have approached an organisation for support or advice concerning dementia (8%).

Approached organisation for support

Have you ever approached an organisation or group for support or advice about dementia? This could either have been a direct approach or visiting their website for information.

	General public %	Maori booster %
Base: n=	750	150
Yes	12	14
No	87	86
Unsure	1	-

Base: All respondents

¹² Results for Maori were not determined to be significant by gender, though this could be due to the low sample size.

6.3 Organisations/ sources approached for support and advice

■ General public

The most cited source of help and advice that respondents said they would approach if they suspected someone they knew had dementia was the local Alzheimer's organisation (31%) followed by the GP or doctor (24%). Other sources were much less popular in comparison, though a website about dementia was a notable response at 10%.

Other sources cited included the DHB or Needs Assessment Service Coordination agency (NASC), residential care provider (4%); Citizen's Advice Bureau (CAB, 3%); home help provider (2%) and church group (1%).

■ Maori booster

The two most popular sources of help and advice were reversed for Maori, with the GP or doctor being the more cited (31%), followed by their local Alzheimer's organisation (24%). Similar to the general public, a website about dementia was the third most popular source of advice.

The DHB, NASC (5%) and CAB (4%) were also cited by Maori, as well as one more source that was not mentioned by the general public - 4% of Maori said they would use Eldernet as a source of advice.

■ Demographics

Those 60 and over were more likely to cite their local Alzheimer's organisation as a source of advice (41%).

Organisations/sources approached for advice

<i>Which organisations or groups did you approach?</i>		
	General public	Maori booster
	%	%
<i>Base: n=</i>	92	21
The local Alzheimer's organisation	31	24
Your general practice/doctor	24	31
A website about dementia	10	11
Your DHB/Needs Assessment Service Coordination agency		
NASC	4	5
A residential care provider	4	-
Citizen's Advice Bureau	3	4
A home help provider	2	-
Church Group (Minister / Pastor)	1	-
Eldernet	-	4
Other	33	36
Unsure	4	6

Base: Respondents that had approached an organisation or group for support or advice about dementia

■ Verbatim responses

Those who selected websites or the 'other' response for places they would go to look for help and advice were prompted for a specific answer.

Organisations/sources approached for advice – verbatim 'other' responses

Which organisations or groups did you approach?

	General public Count	Maori booster Count
<i>Base: n=</i>	36	5
Websites:		
A website about dementia	7	2
Can't remember/ don't know	5	1
Verbatim:		
Alzheimers NZ website	1	
Vascular dementia - I looked up what it meant	1	
Google		1
Other responses:		
Other	29	3
Google it	3	
Alzheimer's society	2	
Age concern	2	
Alzheimers Great Britain	1	
Dementia foundation	1	
Health practitioners	1	
Nurses association	1	
Waikato hospital	1	
Hospice and age concern	1	
Health website which I am not sure about, it was a New Zealand one - looked at it over a year ago	1	
Healthcare NZ	1	
Good partners in Invercargill who organised someone to look after her	1	
Health line	1	
Research books	1	
It was organized by work	1	
Mahana	1	
Auckland district house board	1	
Pamphlets	1	
People who manage dementia units	1	
Geriatric specialists both at Selwyn and the general hospital	1	
The CAT team	1	
Mental health	1	
NZ society of dementia	1	
Ministry of Health	1	
Parkinson society	1	
Specialist		1
Care support		1
Age support, Alzheimer's society		1

Base: Respondents that selected 'a website' or 'other' as a place they go to look for advice about dementia

6.4 Helpfulness of organisations approached for support and advice

The large majority of those that had approached an organisation or group for help and advice generally also found that organisation to be helpful; the two most approached organisations - local Alzheimer's organisations and GP's or doctors - were rated as helpful by around 80% of the general public and by 100% of Maori.

Further evidence that organisations are perceived as helpful can be seen in a crosstab with self-declared knowledge as 87% of those that approached an organisation for advice said they knew 'a lot' or 'fair amount' about dementia (unprompted).

One exception was the DHB or NASC in which just one respondent out of four that had approached them deemed them to be helpful (two gave them a neutral rating and one said they were not helpful). For the Maori booster, Eldernet was the exception with the one person that rated it reporting it as not helpful.

Helpfulness of organisation approached - general public

And on a scale of one to five, where one means - no help at all, and five means - extremely helpful, how helpful were the organisations or groups that you approached.

	Base	1 - No help at all	2	TOTAL 1+2	3	4	5 - Extremely helpful	TOTAL 4+5
	<i>n=</i>	Count	Count	Count	Count	Count	Count	Count
The local Alzheimer's organisation	29	-	1	1	5	6	17	23
Your general practice/doctor	23	-	2	2	3	1	17	18
The website about dementia	9	-	-	-	3	3	3	6
Your DHB/Needs Assessment Service	4	-	1	1	2	1	-	1
Coordination agency NASC								
A residential care provider	3	-	-	-	-	1	2	3
A home help provider	2	-	-	-	-	-	2	2
Citizen's Advice Bureau	2	-	-	-	-	2	-	2
Church Group (Minister / Pastor)	1	-	-	-	-	-	1	1

NB: Table uses counts rather than percentages due to the very low sizes of some subgroups

Base: Respondents that had approached an organisation or group for support or advice about dementia

Helpfulness of organisation approached – Maori booster

And on a scale of one to five, where one means - no help at all, and five means - extremely helpful, how helpful were the organisations or groups that you approached.

	Base	1 - No help at all	2	TOTAL 1+2	3	4	5 - Extremely helpful	TOTAL 4+5
	<i>n=</i>	Count	Count	Count	Count	Count	Count	Count
Your general practice/doctor	7	-	-	-	-	1	6	7
The local Alzheimer's organisation	5	-	-	-	-	1	4	5
The website about dementia	3	-	-	-	1	-	2	2
Your DHB/Needs Assessment Service	1	-	-	-	-	1	-	1
Coordination agency NASC	1	-	-	-	-	-	1	1
Citizen's Advice Bureau	1	-	-	-	-	-	1	1
Eldernet	1	-	1	1	-	-	-	-

NB: Table uses counts rather than percentages due to the very low sizes of some subgroups

Base: Maori respondents that had approached an organisation or group for support or advice about dementia

Section five: Personal experience of dementia

Questions in this section helped to clarify if and how knowing and caring for someone with dementia impacted on respondents' attitudes towards and understanding of it.

7.1 Knowing someone with dementia

Two-thirds (67%) of both general public and Maori respondents said they know, or have known, a person with dementia; this person was a family member for 43% of the general public and 49% of Maori.

■ International studies

The Blendon et al., (2012) study which surveyed the impact a family member with Alzheimer's disease made on views about the disease across five countries found that the incidence of family member's with the disease varied substantially across the countries tested.

The incidence was lowest in Poland at 19% and ranged from 30% to 34% in France, Spain and Germany; it was higher in the United States at 42%. The UMR survey found the self-reported incidence of a family member with Alzheimer's to be 43% - a result almost identical to the United States.

■ Demographics

There was a trend whereby younger respondents were less likely to report knowing or having known a person with dementia compared to older respondents - 45% of those under 30 reported knowing someone, compared to 63% of those 30-44, 72% of those 45-59 and 85% of those 60 years and over.

Those of Pacific and Asian ethnicities were significantly less likely to report knowing someone with dementia; only 29% of Pacific peoples and 36% of those of Asian ethnicity reported knowing someone with the condition.

Aucklanders were also less likely to report knowing someone with dementia (58%), with around 70% in most other regions saying they know someone. Single younger people were the least likely to report knowing someone with dementia (43%) and families with children at home were also less likely (60%). Older couples with no children at home were most likely to know someone with dementia (86%).

■ Impact on knowledge of dementia - summary

Some of the following results have already been discussed previously in their relevant sections but are gathered here for convenience in short summary form.

Those that know or had known someone with dementia were significantly more likely to say they know 'a lot' or 'a fair amount' about it compared to those that did not (71% compared to 29%).

The brief description of dementia given in the survey was more likely to have an impact on those that did not know someone with dementia, with those declaring some knowledge of dementia increasing from 71% to 75% in the case of those that know someone with the disease compared to an increase from 16% to 42% for those that do not know someone.

Respondents were far more likely to have approached an organisation for advice about dementia if they currently knew or had known about someone with dementia - though the proportion is still relatively low at 17%; only 1% of those that did not know someone with dementia had visited an organisation.

Those that know or had known someone with dementia were slightly more likely to be concerned about being diagnosed with dementia (17%) compared to those that did not know someone (13%); however, cancer remained the bigger concern by a margin.

Know a person with dementia

<i>Do you know, or have you known, a person with dementia?</i>		
	General public	Maori booster
	%	%
<i>Base: n=</i>	750	150
Yes	67	67
No	32	31
Unsure	1	2
Base: All respondents		

7.2 Relationship/s to person/ people with dementia

■ General public

Relatives were, by far, the people most respondents knew or had known to have dementia when taken as a collective. Grandparents made up the largest proportion of those that people knew to have dementia with 26% of respondents citing them. Parents were cited by 16% and a range of other relatives were mentioned by smaller proportions. Of these other relatives with dementia, aunts (6%), uncles and mother-in-laws were the most common (5%).

Outside of family, friends were the most common people that respondents cited as having dementia (23%). A range of other relationships were cited by much smaller proportions such as clients and patients (both 5%). All other relationships were cited by 2% or respondents or less.

■ Maori booster

Maori were also more likely to cite relatives as the people they knew or had known to have dementia. Again, grandparents made up the largest proportion that Maori knew to have dementia (37%), followed by parents (12%), aunts (11%) and uncles (7%); a range of other relatives were cited by very low proportions.

Friends were the most common people outside of family that Maori cited as having dementia (19%). Other relationships cited included neighbours (4%) and family members of friends (3%).

■ Demographics

There were some large differences by age in terms of the nature of the relationship people had with who they knew had dementia. Those under 44 were much more likely to cite a grandparent as the person they know or knew had dementia (60% under 30 and 44% of those 30-44 compared to 13% of those 45-59 and 4% of those 60 and over). Those between 45 and 59 years of age were more likely to cite a parent (23%) or uncle (11%) and those 60 years of age and over were also more likely to cite a parent (24%), as well as a friend (36%), a spouse (5%) or a sibling (3%).

■ By experiences and views of dementia

Those that had approached an organisation for advice about dementia were significantly more likely to say that they had a parent with dementia (35%), or a mother-in-law (8%), spouse or partner (both 5%) with dementia. Outside the family, 9% that had approached an organisation for advice said they had a patient with dementia.

Those that were involved in the direct care of the person they knew with dementia tended to be either very close family or have a professional relationship. Those that cared directly for the person with dementia were more likely to say this person was a parent (31%) or their spouse (5%); they were also more likely to cite professional ties with 11% saying they were a patient and 8% saying they were a client.

Nature of relationship

What relationship is/was this person to you?

	General public %	Maori booster %
<i>Base: n=</i>	501	101
Grandparent	26	37
Friend	23	19
Parent	16	12
Aunt	6	11
Uncle	5	7
Client	5	1
Patient	5	-
Mother-in-law	5	1
Partner	2	1
Neighbour	2	4
Person in the community	2	-
Father-in-law	2	3
Other relative-in-law	2	2
Distant relative	2	2
Family member of a friend	2	3
Spouse	1	-
Sibling	1	1
Cousin	1	2
Family member (non-specific)	1	1
Other	1	3

Base: Those that know, or have known a person with dementia

7.3 Involvement in the care and support of a person with dementia

A third of the general public that know, or have known, someone with dementia were also involved in the direct care of them. Maori were slightly less likely to say they directly cared for the person they knew that had dementia (27%).

Those who had a spouse (100%), parent (66%), patient (79%) or client (59%) with dementia were far more likely to be involved in caring for them and those who know a grandparent (23%) or friend (21%) with dementia were less likely.

■ Demographics

Females in the general public were more likely to say they were involved in the direct care of the person they knew that had dementia (39%) compared to males (25%); this difference in gender was not found among Maori with 27% of Maori females and 26% of Maori males saying they were involved in the care of the person.

There also appeared to be a trend by age with 26% of the general public under 45 reporting being involved in the care of the person they knew with dementia compared to 33% of those 45-59 years of age and 42% of those 60 years of age and over.

■ By experiences and views of dementia

Those that declared they know 'a lot' or 'fair amount' about dementia unprompted were more likely to be involved in directly caring for someone with dementia (38%). Most of the respondents that had approached an organisation for support or advice about dementia were also involved in caring for someone with dementia (71%).

Being involved in the direct care of someone with dementia also had an impact on the level of concern they felt about being diagnosed with it; 21% of those that cared for someone with dementia were more concerned about being diagnosed with dementia than cancer compared to 16% that were not involved in the direct care of someone they knew that had dementia and 13% that did not know a person with dementia.

Involvement in direct care of this person

<i>Are / were you involved in the direct care and support of this person/these people?</i>		
	General public	Maori booster
	%	%
<i>Base: n=</i>	501	101
Yes	33	27
No	66	70
Unsure	1	3

Base: Those that know, or have known a person with dementia

Section six: Dementia statistics

(Perceptions)

These questions established to what degree New Zealanders understand the scale of dementia and how this will change over time.

8.1 Number of people who have dementia in New Zealand now

Respondents tended to overestimate the number of people in New Zealand that have dementia; if we take the number of people with dementia in New Zealand to be 50,000 as estimated by Alzheimers NZ, almost one in five (18%) of the general public and 23% of Maori guessed accurately.

A slightly higher proportion underestimated the figure - 21% of the general public and 24% of Maori - and the larger proportion overestimated the figure - 44% of the general public and 43% of Maori.

■ Demographics

Those of Asian ethnicity were more likely to underestimate the number of people with dementia in New Zealand - 13% of them thought there were under 20,000 people with dementia in New Zealand and overall, 32% thought there were under 40,000.

Older respondents living alone were less likely to overestimate the number of people that have dementia in New Zealand with 28% estimating there to be over 60,000 compared to 44% of the general public; however, this is partly explained not by a higher number of correct estimations, but by a higher proportion that said they were unsure of the answer (26%).

■ By experiences and views of dementia

Respondents that reported knowing 'a lot' or 'fair amount' about dementia were less likely to underestimate the number of people with dementia in New Zealand (17%); however, they were no more likely to give a correct estimate.

Those that know or knew a person with dementia were also less likely to underestimate the correct number (17%) and those that did not know someone were more likely to underestimate (33%).

Estimate of number of people with dementia in NZ

Thinking about how many people have dementia in New Zealand, please stop me when I read out the number of people you think have dementia in New Zealand now?

	General public %	Maori booster %
Base: n=	750	150
Under 20,000 people	4	4
Between 20,001 to 40,000 people	17	20
Total underestimated	21	24
Between 40,001 to 60,000 people	18	23
Between 60,001 to 80,000 people	12	16
Between 80,001 to 100,000 people	13	12
Between 100,001 to 200,000 people	10	9
More than 200,001 people	9	6
Total overestimated	44	43
Unsure	17	10

Base: All respondents

8.2 Changes in the number of people who will have dementia over the next 35 years

Three-quarters (74%) of the general public thought that the number of New Zealanders with dementia would increase over the next 35 years, with the larger proportion (44%) thinking this increase would be by a lot; 17% thought it would stay the same and only 5% thought it would decrease.

The majority of Maori also believed the number of New Zealanders with dementia would increase over the next 35 years (62%), though this belief was less widespread than for the general public. Similar to the general public, only 5% believed the number would decrease; they were more likely to believe the number of those with dementia would stay about the same (26%).

■ Demographics

Females were more likely to believe the number of New Zealanders with dementia would increase a lot (49%, compared to 38% of males), though the number that believed it would increase overall was not significantly different to the general public.

Younger respondents under 30 were significantly less likely to believe it would increase a lot (28%) when compared to any other age category; they were more likely to believe it would stay about the same (28%). Those between the ages of 45-59 were most likely to believe the number of New Zealanders with dementia would increase overall (84%).

■ By experiences and views of dementia

Those that said they had 'a lot' or 'fair amount' of knowledge about dementia unprompted were more likely to say that those with dementia will increase a lot in the future (51%), as did those that had approached an organisation for support or advice about dementia (63%).

Those that know a person with dementia were more likely to say it would increase overall (78%, 51% said it would increase a lot) and those that did not know a person with dementia were more likely to say it would stay about the same (24%).

Estimate of future dementia growth

If no cure is found, and looking ahead over the next thirty five years or so, do you expect that the number of New Zealanders with dementia will increase a lot, increase a little, decrease a lot, decrease a little or stay about the same?

	General public %	Maori booster %
<i>Base: n=</i>	750	150
Increase a lot	44	34
Increase a little	30	28
Total increase	74	62
Stay about the same	17	26
Decrease a little	4	3
Decrease a lot	1	2
Total decrease	5	5
Unsure	4	7

Base: All respondents

Section seven: Concerns regarding cancer versus dementia diagnosis

This question tested how fearful New Zealanders are of developing Alzheimer's in the future, compared with cancer and other diseases.

9.1 Standalone survey

Similar to international studies, being diagnosed with cancer was generally a greater concern than being diagnosed with dementia in New Zealand.

Over half of respondents (56%) were more concerned about cancer and only 16% were more concerned about dementia; one in ten were concerned with both equally or concerned about neither and a very low proportion (2%) had already been diagnosed with cancer or dementia.

Maori were also more likely to be concerned about being diagnosed with cancer (62%) than dementia (15%).

■ International studies

An American study conducted for the MetLife Foundation showed that Alzheimer's disease was the second most feared disease among adults behind only cancer. That survey found that 31% of American adults feared Alzheimer's the most and 41% feared cancer the most (Harris Interactive, 2010).

The Alzheimer's Association (2014) study also found Alzheimer's to be the second most feared disease behind cancer.¹³

■ Demographics

Younger respondents were more likely to report being concerned about cancer (65% of those under 30 and 64% of those 30-44) and respondents 60 and over were less likely (45%). Although the difference is not significant, a larger proportion of those 60 and over reported greater concern about dementia (20%); they were also significantly more likely to have already been diagnosed with cancer or dementia (5%).

Older respondents living alone were also less likely to be concerned with cancer (42%) and more likely to already have cancer or dementia (6%). This is in stark contrast to young couples with no children, of whom 65% were concerned with cancer and not one of them had been diagnosed with cancer or dementia.

¹³ The percentages for these studies are not comparable to those found in the UMR survey due to the questions being different, though findings from both surveys confirmed that cancer is more feared than dementia.

■ By experiences and views of dementia

Those that said they know 'a lot' or 'fair amount' about dementia were slightly more likely to be concerned with being diagnosed with dementia (18%) compared to those that did not say this (14%). Those that were involved in the direct care of a person with dementia were also more likely to express concern about being diagnosed with dementia (21%), though none of these differences were significant.

Those that had been proactive and approached an organisation for support or advice about dementia were most likely to have views different to the overall results. Only 38% of the respondents in this group were more concerned about being diagnosed with cancer and 25% were more concerned with dementia, 19% of them were concerned about neither.

Respondents that agreed dementia is one of the things they fear most about aging were significantly more likely to say that they were more concerned about being diagnosed with dementia (30%) compared to the general public.

Bigger concern: dementia or cancer

Would you say you were more concerned about being diagnosed with cancer or dementia in the future?

	General public %	Maori booster %
<i>Base: n=</i>	750	150
Dementia	16	15
Cancer	56	62
Both equally	10	8
Neither	10	10
Not applicable, I have already been diagnosed with cancer or dementia.	2	1
Unsure	6	4

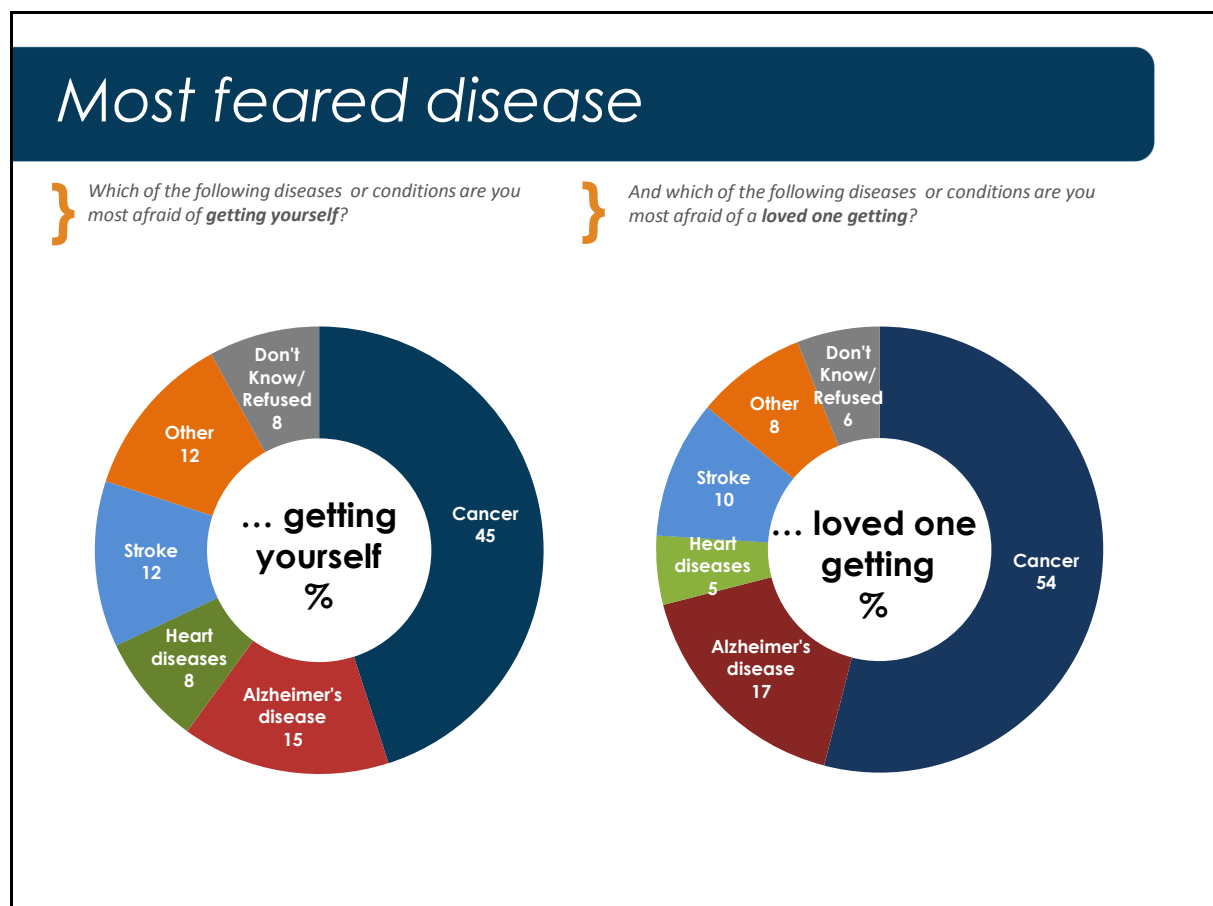
Base: All respondents

9.2 Omnibus survey

■ Fear of Alzheimer's second only to cancer

When asked which disease or condition respondents were most afraid of, from a list of six, 15% selected Alzheimer's disease which placed it second, behind only cancer (45%). Compared to the global average (23%), New Zealanders are less concerned about Alzheimer's.

There was a similar pattern when asked which disease they were most afraid of a loved one getting with 17% stating Alzheimer's disease, again, behind only cancer (54%).



Appendix: Detailed tables

This question tested how fearful New Zealanders are of developing Alzheimer's in the future, compared with cancer and other diseases.

10.1 Question one – unprompted awareness and understanding of dementia (and Alzheimer's disease)

Declared knowledge of illnesses - general public

How much do you feel you know about each of the following conditions? A lot, a fair amount, not that much or hardly anything?

	A lot	A fair amount	Total 'a lot' + 'fair amount'	Not that much	Hardly anything	Total 'not much' + 'hardly anything'	Unsure
	%	%	%	%	%	%	%
Depression	31	45	76	18	6	24	-
Asthma	30	42	72	23	5	28	-
Diabetes	27	45	72	22	6	28	-
Alzheimer's disease	18	36	54	36	10	46	-
Dementia	20	33	53	35	11	46	1
Parkinson's disease	11	24	35	46	18	64	1
Muscular dystrophy	6	15	21	46	32	78	1

Base: General public (n=750)

Declared knowledge of illnesses - Maori booster

How much do you feel you know about each of the following conditions? A lot, a fair amount, not that much or hardly anything?

	A lot	A fair amount	Total 'a lot' + 'fair amount'	Not that much	Hardly anything	Total 'not much' + 'hardly anything'	Unsure
	%	%	%	%	%	%	%
Depression	30	34	64	30	6	36	-
Asthma	30	44	74	22	4	26	-
Diabetes	31	39	70	25	5	30	-
Alzheimer's disease	13	24	37	49	14	63	-
Dementia	12	26	38	44	17	61	1
Parkinson's disease	7	22	29	48	22	70	1
Muscular dystrophy	4	13	17	40	42	82	1

Base: Maori booster (n=150)

10.2 Question four – common symptoms of dementia (prompted)

Prompted symptoms of dementia - general public

<i>Please tell me which of the following you think are common symptoms of dementia?</i>			
	Yes	No	Unsure
	%	%	%
Forgetting things regularly	96	3	1
Getting lost	95	3	2
Forgetting people's names	93	5	2
Misplacing things regularly	93	4	3
Changes in personality	87	9	4
Difficulty performing everyday tasks	85	11	4
Forgetting what things are used for e.g. car keys	85	9	6
Loss of initiative	70	18	12
Language problems	63	27	10
Violence or aggression	60	31	9
Shaking	34	54	12

Base: General public (n=750)

Prompted symptoms of dementia - Maori booster

<i>Please tell me which of the following you think are common symptoms of dementia?</i>			
	Yes	No	Unsure
	%	%	%
Forgetting things regularly	95	4	1
Getting lost	92	4	4
Forgetting people's names	93	6	1
Misplacing things regularly	88	7	5
Changes in personality	88	8	4
Difficulty performing everyday tasks	87	9	4
Forgetting what things are used for e.g. car keys	90	5	5
Loss of initiative	72	15	13
Language problems	67	24	9
Violence or aggression	53	31	16
Shaking	41	43	16

Base: Maori booster (n=150)

10.3 Question five and eleven – statement testing

Statement testing - general public

For each of the following statements about dementia, please tell me whether you think they are definitely true, probably true, probably false, definitely false or if you are not sure.

	Def. true	Prob. true	TOTAL TRUE	Prob. false	Def. false	TOTAL FALSE	Depen ds	Unsur e
	%	%	%	%	%	%	%	%
For someone with dementia, their condition gets worse over time.	59	35	94	2	1	3	-	3
There are things you can do to reduce your risk of developing dementia.	26	46	72	10	4	14	1	13
People with dementia can continue with their regular life activities after being diagnosed.	24	42	66	18	5	23	7	4
People with dementia don't understand what's going on around them.	16	40	56	20	11	31	8	5
People with dementia need to be cared for in a rest home.	13	23	36	31	20	51	10	3
Dementia is a fatal condition.	11	16	27	30	31	61	2	10
It is a normal part of the aging process.	6	19	25	32	38	70	1	4
Only old people get dementia.	3	15	18	30	46	76	1	5
Memory loss is the only symptom of dementia.	5	7	12	25	60	85	-	3
There is nowhere to go for advice and support.	3	4	7	19	69	88	1	4

Base: General public (n=750)

Statement testing - Maori booster

For each of the following statements about dementia, please tell me whether you think they are definitely true, probably true, probably false, definitely false or if you are not sure.

	Def. true	Prob. true	TOTAL TRUE	Prob. false	Def. false	TOTAL FALSE	Depen ds	Unsur e
	%	%	%	%	%	%	%	%
For someone with dementia, their condition gets worse over time.	50	42	92	3	2	5	-	3
There are things you can do to reduce your risk of developing dementia.	15	48	63	8	6	14	1	22
People with dementia can continue with their regular life activities after being diagnosed.	20	42	62	21	8	29	5	4
People with dementia don't understand what's going on around them.	20	42	62	24	7	31	3	4
People with dementia need to be cared for in a rest home.	16	18	34	33	23	56	5	5
Dementia is a fatal condition.	10	20	30	29	22	51	4	15
It is a normal part of the aging process.	7	18	25	26	40	66	1	8
Only old people get dementia.	4	14	18	29	46	75	-	7
Memory loss is the only symptom of dementia.	7	5	12	19	64	83	-	5
There is nowhere to go for advice and support.	1	4	5	22	70	92	-	3

Base: Maori booster (n=150)

Statement testing - general public

Using a 0 to 10 scale where 0 means strongly disagree and 10 means strongly agree, how strongly do you agree or disagree with the following statements?

	0	1	2	3	TOTAL DISAGR EE (0-3)	4	5	6	TOTAL NEUTR AL (4-6)	7	8	9	10	TOTAL AGREE (7-10)	Unsu re
Base: n=	%	%	%	%	%	%	%	%	%	%	%	%	%	%	%
If someone I knew was diagnosed with dementia I would continue to include them in our regular social activities.	2	-	-	1	3	1	6	4	11	9	18	7	52	86	-
If I saw someone in public who I thought had dementia and needed help, I would help them.	1	1	-	1	3	1	8	4	13	8	18	8	49	83	1
If someone close to me was exhibiting confusion and memory loss, I would ask them if I could accompany them to their Doctor to determine if the cause was dementia.	1	-	2	2	5	1	10	6	17	10	17	8	42	77	1
If it was possible to take a simple test to find out if I was likely to get dementia in the future, I would almost certainly take it.	7	3	3	3	16	2	9	3	14	5	12	6	46	69	1
If someone with Dementia needed help I would feel able to assist them.	2	2	2	4	10	4	16	7	27	11	16	5	30	62	1
Dementia is one of the things I fear most about getting older	15	6	8	10	39	6	17	4	27	7	9	4	14	34	-
If I was out in public with someone who had dementia, I would be worried about how they would act.	15	4	8	9	36	7	17	7	31	11	12	2	7	32	1
If a close family member was diagnosed with dementia, I would be reluctant to tell other people about it.	32	15	12	8	67	4	8	2	14	3	5	2	9	19	-
I would rather be diagnosed with dementia than care for someone with dementia.	25	8	8	4	45	4	24	2	30	3	4	2	9	18	7

Base: General public (n=750)

Statement testing - Maori booster

Using a 0 to 10 scale where 0 means strongly disagree and 10 means strongly agree, how strongly do you agree or disagree with the following statements?

	0	1	2	3	TOTAL DISAGR EE (0-3)	4	5	6	TOTAL NEUTR AL (4-6)	7	8	9	10	TOTAL AGREE (7-10)	Unsu re
Base: n=	%	%	%	%	%	%	%	%	%	%	%	%	%	%	%
If someone I knew was diagnosed with dementia I would continue to include them in our regular social activities.	1	2	1	-	4	-	5	5	10	5	12	7	61	85	1
If I saw someone in public who I thought had dementia and needed help, I would help them.	2	-	-	-	2	-	8	3	11	5	12	9	59	85	2
If someone close to me was exhibiting confusion and memory loss, I would ask them if I could accompany them to their Doctor to determine if the cause was dementia.	3	1	2	2	8	1	7	4	12	6	15	5	54	80	-
If it was possible to take a simple test to find out if I was likely to get dementia in the future, I would almost certainly take it.	4	4	2	1	11	4	5	1	10	8	9	6	53	76	3
If someone with Dementia needed help I would feel able to assist them.	2	-	1	2	5	4	18	8	30	7	12	5	39	63	2
Dementia is one of the things I fear most about getting older	22	7	9	8	46	4	22	1	27	4	7	3	11	25	2
If I was out in public with someone who had dementia, I would be worried about how they would act.	19	5	7	10	41	8	20	7	35	8	9	-	7	24	-
If a close family member was diagnosed with dementia, I would be reluctant to tell other people about it.	33	15	11	5	64	5	13	4	22	1	4	-	9	14	-
I would rather be diagnosed with dementia than care for someone with dementia.	25	14	3	4	46	3	24	2	29	-	6	2	9	17	8

Base: Maori booster (n=150)

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Research questionnaires

11.1 Standalone telephone survey

Alzheimers New Zealand Awareness and Understanding Benchmark Survey Final Questionnaire – 20 May 2014

Introduction

Good morning/ afternoon/evening, my name is (NAME) from UMR Research.

We are conducting a nationwide survey about an important healthcare issue. We would really appreciate you taking part.

We can tell you who the survey is for at the end but we prefer not say now as knowing may influence or affect your answers.

Taking part in this survey is voluntary. Your individual answers will remain confidential and any information that could identify you will not be reported to our Client.

We expect the survey will take around 15 minutes.

Is now a good time?

Awareness/ Understanding of dementia (and Alzheimer's disease) - Unprompted

Q.1 How much do you feel you know about each of the following conditions? A lot, a fair amount, not that much or hardly anything?

(Randomised list)

- Depression
- Dementia
- Diabetes
- Asthma
- Parkinson's disease
- Alzheimer's disease
- Muscular dystrophy

Dementia explanatory statement

As you may be aware, the term 'dementia' describes a group of conditions which can affect memory, thinking, behaviour, personality and emotion. It is caused by physical changes in the brain. Because dementia is a progressive condition, symptoms will gradually worsen. There are many different types of dementia, the most common of which is Alzheimer's disease.

Understanding of dementia - Prompted

Q.2 Based on that description, would you say you know a lot, a fair amount, not that much or hardly anything about dementia?

Recognising/ Symptoms of dementia

Q.3 What sort of symptoms or behaviour would make you suspect someone you knew had dementia? Prompt – anything else? (*Open Ended*)

Q.4 Please tell me which of the following you think are common symptoms of dementia? Yes / No / Unsure. (*Randomised list*)

- Forgetting things regularly
- Difficulty performing everyday tasks
- Language problems
- Getting lost
- Forgetting people's names
- Shaking
- Misplacing things regularly
- Forgetting what things are used for e.g. car keys
- Violence or aggression
- Changes in personality
- Loss of initiative

Perceptions of dementia

Q.5 For each of the following statements about dementia, please tell me whether you think they are definitely true, probably true, probably false, definitely false or if you are not sure.

(*Randomised list*)

- For someone with dementia, their condition gets worse over time.
- Only old people get dementia.
- It is a normal part of the aging process.
- People with dementia need to be cared for in a rest home.
- There are things you can do to reduce your risk of developing dementia.
- People with dementia don't understand what's going on around them.
- Memory loss is the only symptom of dementia.
- Dementia is a fatal condition.
- There is nowhere to go for advice and support.
- People with dementia can continue with their regular life activities after being diagnosed.

Interviewer – do not read 'depends' as an option, but code if respondent is unable to choose between the other options i.e. because their answer depends on other factors such as stage of dementia.

Seeking help for someone with dementia

Q.6 If you suspected someone you knew may have dementia who would you approach or where would you look for help and advice?

Prompt: Anywhere else? Anyone else? (*Open Ended*)

Q.7 Have you ever approached an organisation or group for support or advice about dementia? This could either have been a direct approach or visiting their website for information. Yes/ No / Unsure.

If Yes at Q.7, ask Q.7 (a).

Q.7(a) Which organisations or groups did you approach? Prompt – anywhere else?

(Interviewer – code answer, do not read list)

- Your general practice/doctor
- The local Alzheimer's organisation
- Your DHB/Needs Assessment Service Coordination agency NASC
- A residential care provider
- A home help provider
- A website about dementia (please specify)
- A book about dementia (please specify)
- Citizen's Advice Bureau
- Church Group (Minister / Pastor)
- Cultural or ethnic group
- Eldernet
- Other - fill in
- Unsure

If answer yes at Q.7 (Approached an organisation or group for support or advice) ask Q.7 (b)

Q.7(b) And on a scale of one to five, where one means 'no help at all' and five means 'extremely helpful', how helpful were the organisations or groups that you approached.

Repeat for all organisations or groups mentioned at Q.7(a).

Personal experience of dementia

Q.8 Do you know, or have you known, a person with dementia? Yes / No / Unsure

If Q.8 'Yes' Ask Q.8 (a) and (b)

Q.8(a) What relationship is/was this person to you?

(Interviewer – do not read list but prompt for the specific relationship e.g. Spouse / partner / parent / child / sibling / uncle / aunt / grandparent. This may not be just a family member e.g. friend / neighbour / person in the community / client / patient.)

Q.8(b) Are / were you involved in the direct care and support of this person/these people? Yes / No?

Number of New Zealanders who have dementia

Q.9 Thinking about how many people have dementia in New Zealand; please stop me when I read out the number of people you think have dementia in New Zealand now?

- Under 20,000 people
- Between 20,001 – 40,000 people
- Between 40,001 – 60,000 people
- Between 60,001 – 80,000 people
- Between 80,001 – 100,000 people
- Between 100,001 – 200,000 people
- More than 200,001 people

Q.10 If no cure is found, and looking ahead over the next thirty five years or so, do you expect that the number of New Zealanders with dementia will increase a lot, increase a little, decrease a lot, decrease a little or stay about the same?

Attitude / Belief statements

Q.11 Using a 0 to 10 scale where 0 means strongly disagree and 10 means strongly agree, how strongly do you agree or disagree with the following statements?

(Randomise statements).

- If someone with Dementia needed help I would feel able to assist them.
- Dementia is one of the things I fear most about getting older
- If I was out in public with someone who had dementia, I would be worried about how they would act.
- If someone close to me was exhibiting confusion and memory loss, I would ask them if I could accompany them to their Doctor to determine if the cause was dementia.
- If I saw someone in public who I thought had dementia and needed help, I would help them.
- If someone I knew was diagnosed with dementia I would continue to include them in our regular social activities.
- If a close family member was diagnosed with dementia, I would be reluctant to tell other people about it.
- If it was possible to take a simple test to find out if I was likely to get dementia in the future, I would almost certainly take it.
- I would rather be diagnosed with dementia than care for someone with dementia.

Q.12 Would you say you were more concerned about being diagnosed with cancer or dementia in the future?

- Dementia
- Cancer
- Both equally
- Neither
- Not applicable, I have already been diagnosed with cancer or dementia.

Demographics

D.1 Gender

(Interviewer fill in)

Male (1)

Female (2)

D.2 Age

Which of these age groups do you fall into?

- 17 years and under (1)
- 18-19 (2)
- 20-24 (3)
- 25-29 (4)
- 30-34 (5)
- 35-39 (6)
- 40-44 (7)
- 45-49 (8)
- 50-54 (9)
- 55-59 (10)
- 60-64 (11)
- 65-69 (12)
- 70-74 (13)
- 75 and over (14)
- Prefer not to say (15)

D.3 Occupation

What is your occupation? (*Interviewer fill in*)

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D.4 Qualifications

What is your highest educational qualification?

[READ LIST]

- No qualification.....1
- Secondary school qualification.....2
- Polytech degree.....3
- Other Polytech qualification.....4
- University qualification.....5
- Trade qualification.....6
- [DO NOT READ] Refused.....7

- Trade or technical certificate, that is, builder, mechanic.....2
- Professional qualification, that is, ACA, teachers, nurses.....3
- Undergraduate diploma.....4
- Bachelor's degree, that is, BA, BSc.....5
- Postgraduate degree, that is, Honours, Masters or PhD.....6
- Postgraduate diploma.....7
- [DO NOT READ] Don't know.....8
- [DO NOT READ] Refused.....9
- Other (specify).....0
-(11-30)
- Specified Other

D.5 Ethnicity

Which of the following ethnic groups do you belong to? One or several groups may apply to you.

Please select as many as apply.

- NZ Maori (1)
- NZ European (2)
- British (3)
- Other European (4)
- Pacific Island (5)
- Chinese (6)
- Indian (7)
- Other Asian (8)

- Prefer not to say (9) [*Exclusive*]
- Other (please specify): (10)_____ [*Other*]

D.6 Rural Location

Do you live in a rural area or district that has a population of less than 2,000 people?

- Yes (1)
- No (2)
- Unsure (3)

D.7 Relationship Status

[*Randomized answer list*]

Which of the following best describes your current personal situation?

- Single (1)
- In a long term /de facto relationship (2)
- Married (3)
- Divorced/separated (4)
- Widowed (5)
- Prefer not to say (6)
- Unsure (7)

D.8 Household

Which of the following best describes your household situation?

- Young couple with no children (1)
- Family with children at home (2)
- Older couple with no children at home (3)
- Single older person (4)
- Single younger person (5)
- Flatting with others (6)
- Prefer not to say (7)
- Unsure

If this survey has raised any issues or concerns about yourself or someone you know, our advice is to see a GP for a full assessment.

Support and advice is also available at www.alzheimers.org.nz or by calling 0800 004 001.

If respondent wants to know who the survey is for, it is for Alzheimers NZ; a not for profit organisation focused on supporting all people affected by dementia.

Thank respondent and close interview.

11.2 Omnibus survey

Alzheimer's Omnibus Module July 24th 2014

These following questions are about healthcare issues.

- 1 How much do you feel you know about Alzheimer's Disease? A lot, a fair amount, not that much or hardly anything?

As you may be aware, Alzheimer's is a type of dementia that causes problems with memory, thinking and behaviour. Some of the following questions may or may not be closely connected to your own experience.

2. Which of the following diseases or conditions are you most afraid of getting yourself? [**Single response**] [RANDOMISE]
 - i. Cancer
 - ii. Alzheimer's Disease
 - iii. Heart disease
 - iv. Stroke
 - v. Diabetes
 - vi. HIV/ AIDs
 - vii. Something else
 - viii. DO NOT READ Don't know
 - ix. DO NOT READ Refused
3. How much do you agree or disagree with the following statements? Strongly agree, Agree, Disagree, Strongly Disagree, DO NOT READ don't know, DO NOT READ refused [RANDOMISE]
 - a) Alzheimer's is a typical part of aging
 - b) Alzheimer's is a fatal disease
 - c) Alzheimer's is one of the things I fear most about getting older
 - d) If a close family member was diagnosed with Alzheimer's, I would be reluctant to tell other people about it
 - e) I would rather be diagnosed with Alzheimer's than care for someone with Alzheimer's
4. Do you know, or have known, a person with Alzheimer's? Yes, No, Unsure