

Draft New Zealand Dementia Action Plan

Consultation summary

February 2020

New Zealand Dementia Cooperative

Alzheimers New Zealand

Dementia New Zealand

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New Zealand Dementia Cooperative, Alzheimers New Zealand, Dementia New Zealand
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1 Consultation Process

This document summarises the outcomes of the consultative process to gather feedback on the draft NZ Dementia Action Plan.

1.1 **The development of the draft national Dementia Action Plan was led by Alzheimers NZ, Dementia NZ, and the NZ Dementia Cooperative.**

1.2 **The focus for the consultation process was an online survey.**

1.3 **Over 350 individuals and organisations participated in the consultation.**

Background

Dementia presents a major challenge in New Zealand and globally. In response to the WHO's calls for action, many countries around the world are implementing dementia action plans.

The dementia sector has now taken up the challenge by joining together to work on New Zealand's first national Dementia Action Plan under the leadership of Alzheimers NZ, Dementia NZ, and the NZ Dementia Cooperative. The aim was to identify objectives and priorities for action, building on the NZ Framework for Dementia Care (2013).

Consultation

The draft Plan was circulated to as many people and organisations as possible across the dementia sector from September 2019. The focus for consultation was an online survey to gauge support for and to gather feedback on each of the components of the draft plan. The survey was open from 11 November 2019 until the end of January 2020.

The Minister of Health, Hon Dr David Clark, the Associate Minister of Health, Hon Jenny Salesa and the Ministry of Health were briefed on the development. The Ministry supported the process by facilitating the engagement process with DHBs, and providing advice on the strategic fit of the Plan.

Response

The consultation incorporated a broad range of stakeholders through recruitment networks including people living with dementia and their care partners, health, allied health and other professionals with an interest in dementia, Public Service and Crown entities including District Health Boards, national professional organisations and networks, and local and national community networks and groups. There were 358 responses to the online consultation. An additional 14 individuals or organisations provided feedback outside this channel, and a further 25 individuals provided feedback specifically on their experience with Cognitive Stimulation Therapy.

2 Overview
of summary

The length of this document testifies to the engagement of the stakeholders, and it is appropriate that their time, experience, expertise, and commitment are acknowledged.

2.1 There was general support for the draft plan and its components.

2.2 The dominant themes centered on the keys necessary for success.

2.3 There were specific suggestions made across the sections.

Support

The survey asked respondents to rate their support for the different components of the survey. Quantitatively, all the components were supported by a strong majority of respondents.

Keys

Over the survey as the whole, the dominant themes of the feedback focused on factors underpinning the feasibility of achieving the desired changes: funding / resources, workforce / training, outcomes and detailed planning, support for family care-partners, ensuring robust Māori process, a clear focus on equity, and recognising the relevance of a broad range of stakeholders. Areas that were identified to be added included residential options for people living with younger onset dementia, Cognitive Stimulation Therapy, and advanced planning.

Specifics

There were some areas where views diverged on the relative priority to be placed on an action, particularly reducing the incidence of dementia. Across the individual components of the plan there were specific suggestions about the presentation, content, and emphases.

The report is divided into three sections:

Part 1 summarises the ratings of support for the sections of the draft action plan and the overall comments of support for the plan.

Part 2 highlights major themes in the feedback.

Part 3 summarises the more specific suggestions for individual sections.

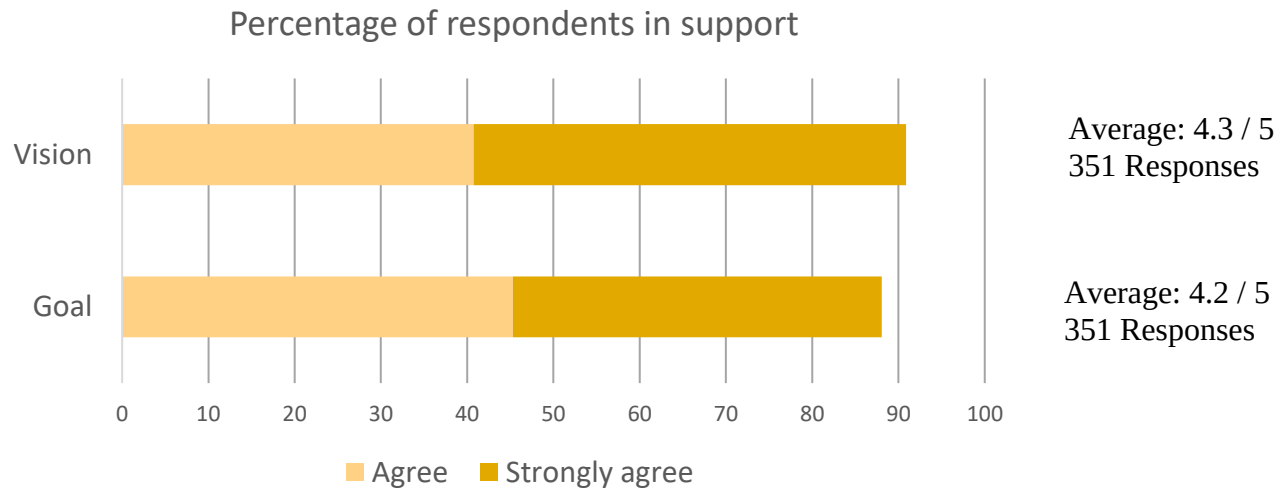
Part 1
General support

3 Vision and goal

Vision - A New Zealand in which people living with dementia, their whānau / families and care partners live well and receive the support they need to fulfil their potential with dignity, respect, autonomy and equality and dementia is prevented as much as possible

The goal of this National Dementia Plan is to improve the lives of people living with dementia while decreasing the impact of dementia on them and their whānau / families as well as on New Zealand communities, the health system and the economy and to promote dementia risk reduction lifestyles.

3.1 Over 80% of respondents supported the vision and goal



Note: Respondents were asked to rate their support as strongly disagree, disagree, neutral, agree, or strongly disagree, which were coded from 1 to 5 to calculate the average (mean) response.

4 Principles

The Plan is underpinned by eight cross-cutting principles that drive the way the plan will be implemented:

Person-directed – people living with dementia, their whānau / families and care partners are placed at the forefront of decisions about their care and support, and empowered to contribute to decision-making

Reflecting Te Ao Māori throughout and guided by the principles of Te Tiriti o Waitangi – Māori kaupapa is critical for in the development of the national plan and in the design, development and delivery of solutions and programmes

Comprehensive – services cover the whole life-course of dementia from identifying that something might be wrong to end of life

Integrated - all parts of the dementia sector work together in the implementation of the plan

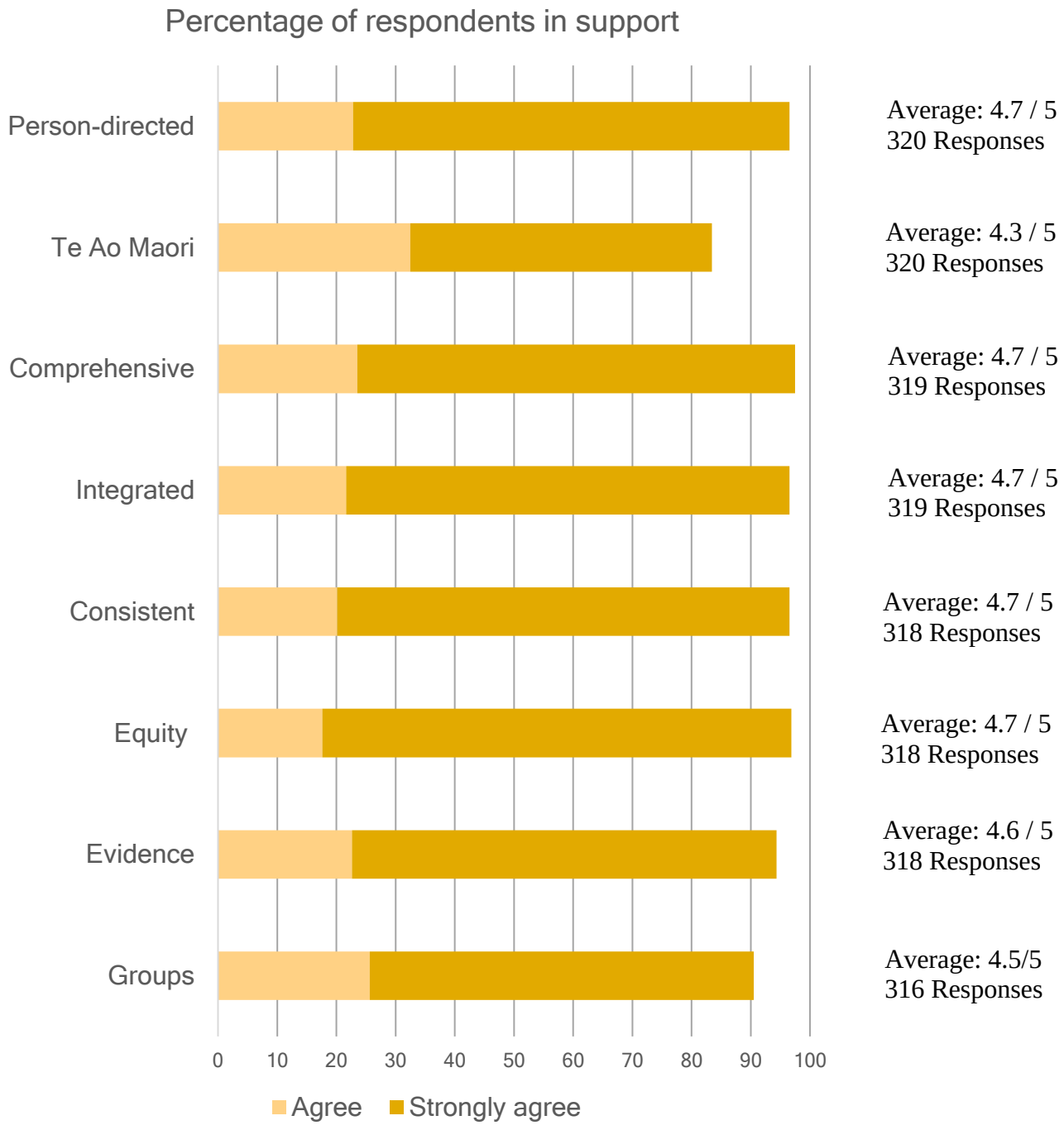
Consistent – nationally consistent quality-assured services are available to people no matter where they live

Equity – people living with dementia have access to appropriate services that deliver the same high-quality health and wellness outcomes whoever they are, whatever their circumstances, wherever they live in New Zealand, and whoever delivers the services

Evidence-based and best-practice – services are grounded in evidence and best practice, balancing medical care with person-centred care, to deliver solutions that are effective, sustainable and affordable

Specific populations – services recognise and respond appropriately to the unique needs of the special groups within New Zealand's population, especially: Pacific people, Asian people, the deaf community and people who have become hearing impaired, refugees, people living alone, LGBTIQA people, people with intellectual disability, people with young-onset dementia, people living with chronic and severe neurological and/or psychiatric conditions and those with addictions.

4.1 Over 80% of respondents supported each of the principles

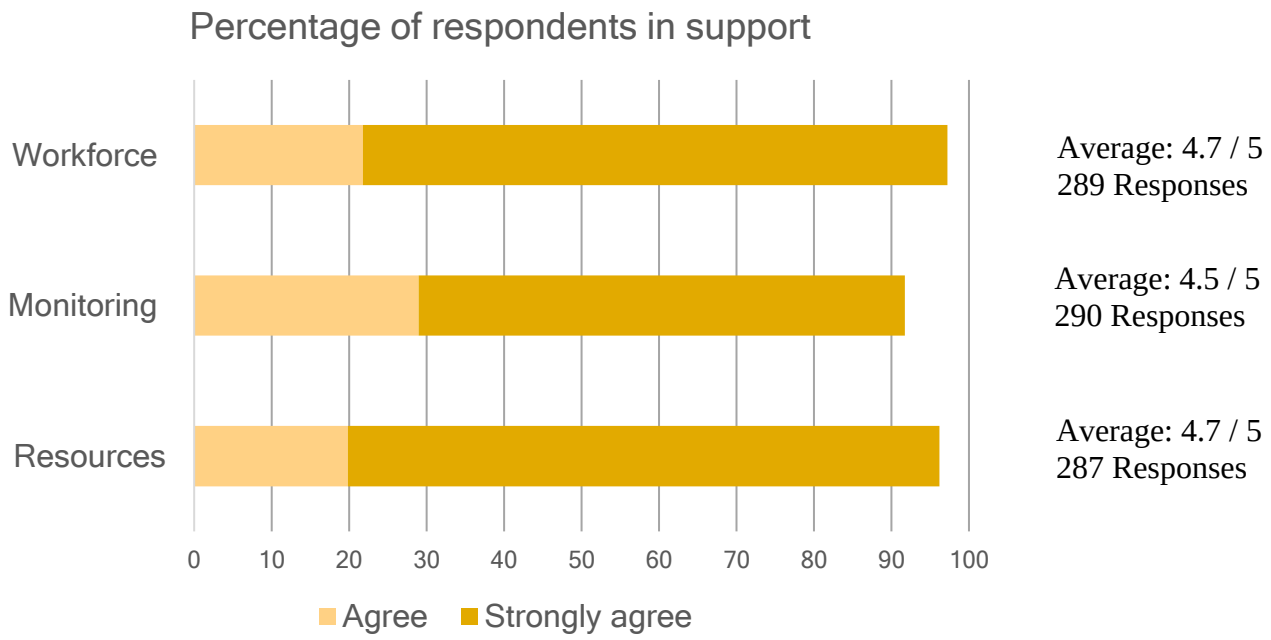


5 Enabling factors

Successful implementation of this plan relies on:

- a knowledgeable, skilled and supported workforce across the sector and health system as a whole – significant investment across the whole workforce is needed to achieve this as is a strategy to recruit and retain staff for the sector;
- systematic, routine population-level monitoring of a core set of dementia indicators to guide evidence-based actions to improve services and to measure progress towards implementing the actions in this plan; and
- sufficient sustainable financial resources that meet the identified service needs and are allocated equitably across the continuum of care alongside the required human and other resources.

5.1 Over 90% of respondents supported each of the enabling factors

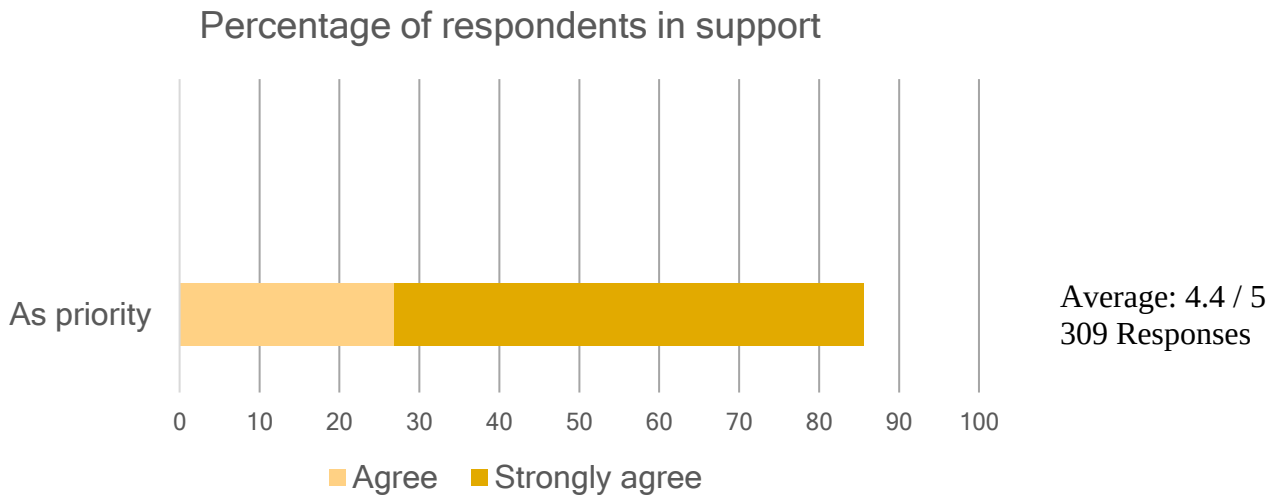


6 Reducing Incidence

Reduce the incidence of dementia. The diseases that cause dementia share many risk factors with other non-communicable diseases including heart disease, stroke, diabetes and cancer. Research suggests that proactive evidence based interventions focused on modifiable risk factors could reduce the risk of developing dementia and/or slow progression by between 10% and 20%

Action:
Work with colleagues involved with other key non-communicable diseases and population health to design a health promotion programme that includes dementia prevention / brain health protection – for implementation, potentially in conjunction with other healthy ageing goals, in the next plan (beyond 2023) Suggested lead organisation/s: Health Promotion Agency/Sector NGOs

6.1 Over 80% of respondents supported this priority



Average: 4.4 / 5
309 Responses

7 Living Well

Support people living with dementia and their family / whānau care partners to live well. People living with dementia and their support people can enjoy more full, active and meaningful lives when they have access to a timely, accurate diagnosis as well as to the right support and assistance. Doing so will improve quality of life, reduce the impact on the health system and reduce the costs caused by higher levels of care and emergency care. These services must be equitable in terms of access, tailored to individuals' needs, and their quality must be assured.

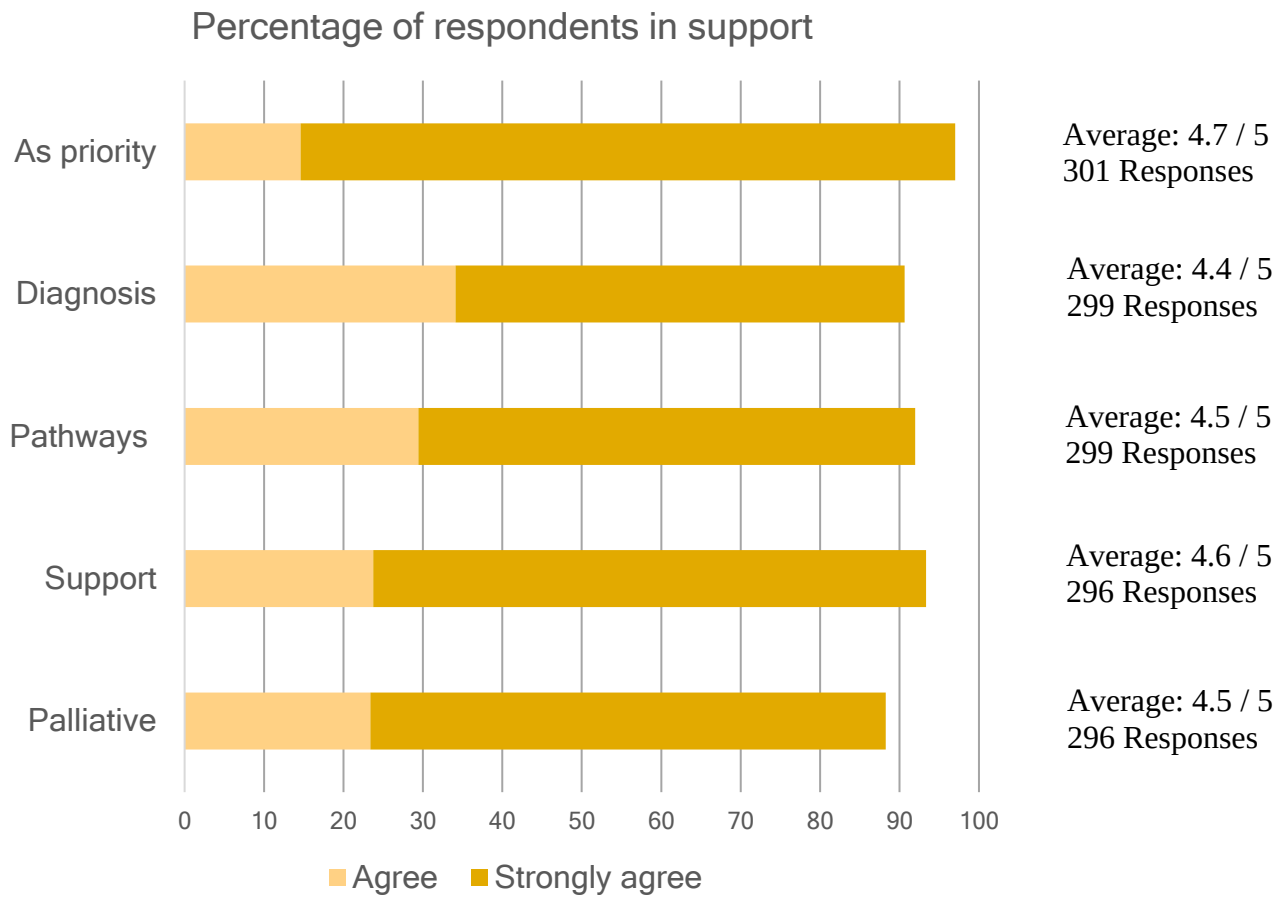
Actions:
Test options to meaningfully support the provision of timely and accurate diagnosis and comprehensive management planning in primary care building on mental health initiatives as appropriate - for implementation in the next plan (beyond 2023). Suggested lead organisations: Lead DHB and PHO(s)

Align / harmonise core features of DHB Cognitive Impairment Pathways to arrive at a national solution including investigating health technology options. Suggested lead organisations: DHBs/Primary Care sector leaders

All DHBs to commission and / or deliver equitable, tailored and quality assured support services: at least 12 months post-diagnosis support to equip people to live well through the local dementia-specific NGO; dementia navigation services for all people affected by dementia in their districts; and flexible, available and accessible respite services so care partners can take a break. Suggested lead organisation: DHBs

Work with palliative care and related partners in accordance with the Palliative Care and Health Ageing Strategy Action Plans to agree the actions required to build capability and capacity in health sector to better assist people dying with dementia - for implementation in the next plan (beyond 2023). Suggested lead organisations: MoH/Palliative care and dementia sector leaders

7.1 Over 80% of respondents supported this priority and each of the actions

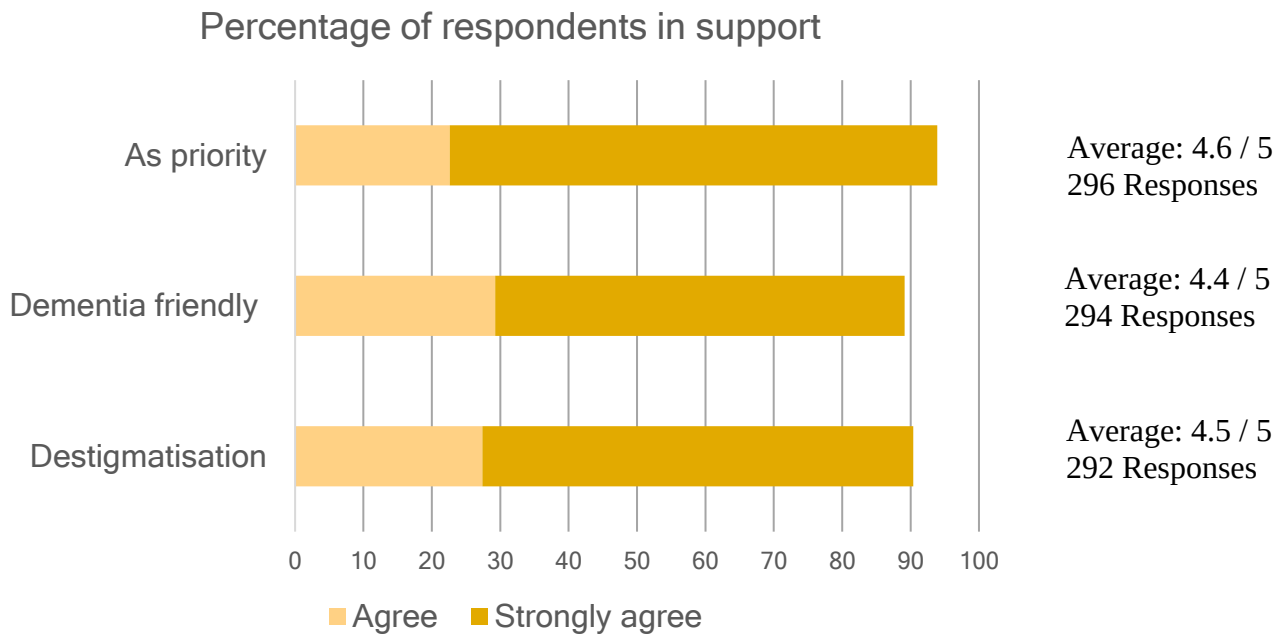


8 Accepting Communities

Build accepting and understanding communities: Stigma and a lack of awareness, poor understanding and barriers to being included are among the most devastating things that people living with dementia and their support people experience – making it harder to get the help and support they need and increasing their isolation

Actions:
Promote Alzheimers NZ's Dementia Friendly Recognition Programme and the World Health Organisation's Age Friendly Cities Programme. Suggested lead organisations: All sector leaders
Design a multi-level multi-channel de-stigmatisation campaign to raise awareness and increase understanding of dementia - for implementation in the next plan (beyond 2023). Suggested lead Organisations: NGOs

8.1 Over 80% of respondents supported this priority and each of the actions



9 Strengthen Capability

Strengthen capability across the sector: The dementia sector is complex and fragmented, services are provided inconsistently across the country and making the changes needed to implement this plan is a major programme of work requiring credible leadership and a strong focus on capability.

Actions

Establish a national cross sector stewardship and leadership group with clear lines of accountability at DHB, regional, and national levels Suggested lead organisation: MoH/DHBs

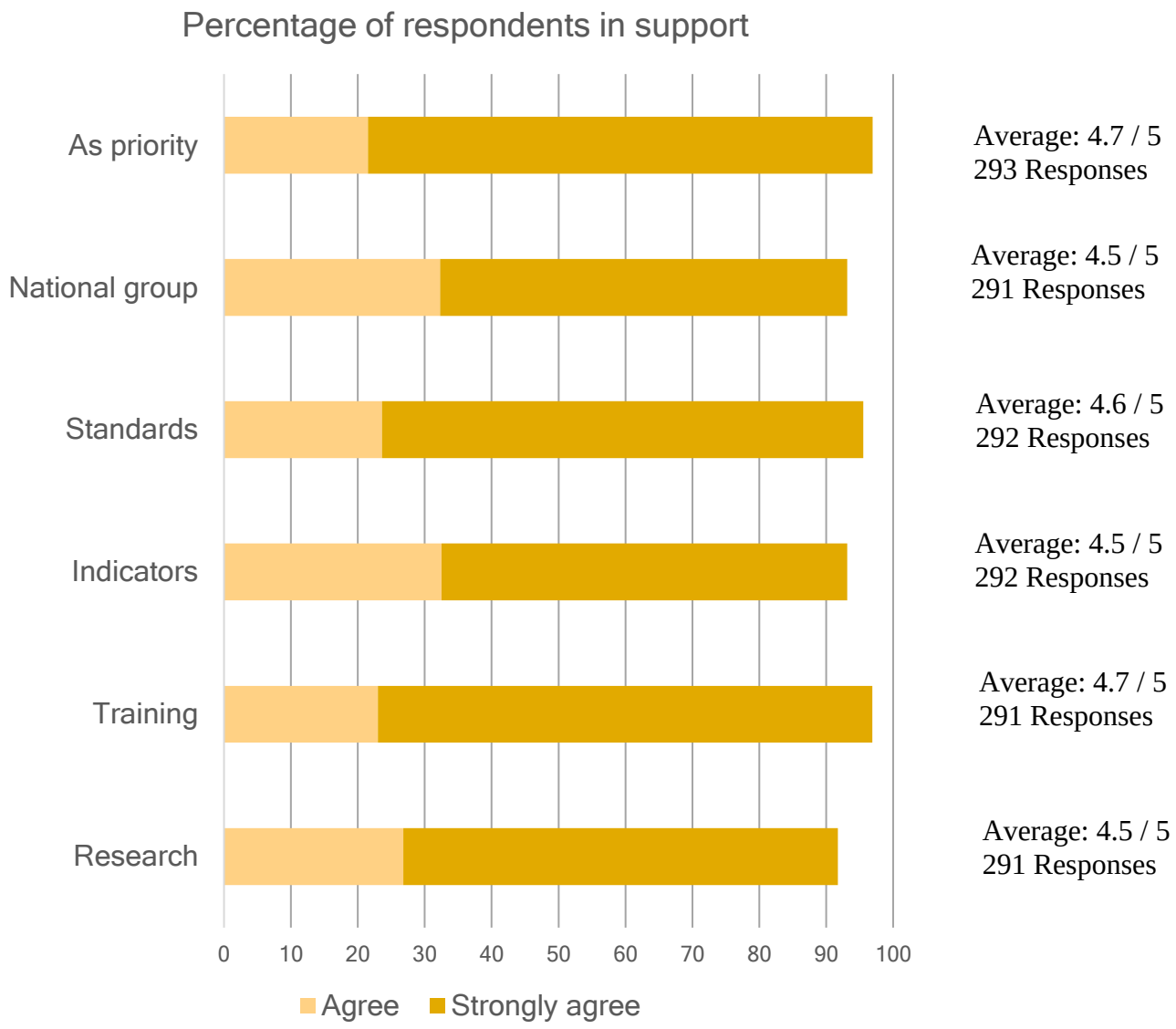
Establish dementia and age friendly standards for delivering high-quality health services for people living with dementia including home, community, and residential/hospital care. Suggested lead organisations: MoH (regulation)

Design agreed national indicators, measures for the dementia sector and roll out this process as part of the outcome measures work within Health and Better Later Life – for implementation in the next plan (beyond 2023) Suggested lead organisation: Sector Leaders

Make training support for best-practice medical care and disability and social support services more available across the sector in all DHB areas Suggested lead organisation: DHBs and provider agencies

Increase investment in research on dementia, in particular on the epidemiology of dementia in New Zealand and on culturally appropriate ways of describing and approaching dementia with New Zealand's non-pakeha cultures Suggested lead organisations: Brain Research NZ/Ageing Well National Science Challenge, universities

8.1 Over 90% of respondents supported this priority and each of the actions



10 Overall Support

10.1 There were supportive comments about the plan as a whole

(Note these were sometimes accompanied by suggestions for improvement that are included in themes later in the report)

Survey question	Comments
Q.20 Overall	Fantastic - 8 digestible pages - well done!
Q.20 Overall	I congratulate those who have put so much time, energy, skill and knowledge into this document.
Q.20 Overall	I would be heartened to see this Action Plan implemented. The designers of this survey are to be congratulated on "making my thoughts able to be heard". Thank you for the consultation.
Q.20 Overall	I would like to see the broad spectrum included in the care of all of our communities. We are a small but large country that needs strong effort working people to make this draft become a reality. I strongly agree with this effort and applause all involved
Q.20 Overall	These steps are vital to improving the outcomes for people with dementia and their carers/whanau
Q.20 Overall	Overall it is a fine start to a much needed process.
Q.20 Overall	The action plan covers all the key points NZ has to focus on! Well done!
Q.20 Overall	Well thought out - and the best of luck
Q.20 Overall	Thanks for the wonderful work, it's so so needed.
Q.20 Overall	This work needs to be set in place urgently!!
Q.20 Overall	I really enjoyed reading the Draft Plan. I think it is very positive and constructive. I think the keyword in the opening paragraph is "practical" and hope that the practical approach continues as this document develops.
Q.20 Overall	It is a well written document that will bring NZ in line with many other countries that have a formal dementia action plan as recommended by the WHO.

Q.20 Overall	no, it is great. moving in the right direction
Q.20 Overall	Overdue so thankyou
Q.20 Overall	Good document, all proposals needed, good luck with this huge amount of work.
Q.20 Overall	We believe this is an excellent document, Well done and thank you for the opportunity to comment.
Q.20 Overall	Agree With The Action
Q.20 Overall	Great vision needing huge changes and cultural shifts at many levels of our society- family/whanau, communities, businesses, DHBs, Primary Health, local and central governments. If able to be implemented as outlined, it will take a generation to notice the real impact.
Q.20 Overall	A great start
Q.20 Overall	The action plan sounds great on paper. Hopefully it leads on to progress. Giving everyone an understanding of dementia and how it effects so many others would be a huge step towards helping those needing care and support get the help they deserve. I for one appreciate the wonderful work you are doing. Thank you
Q.20 Overall	I would like to congratulate those who assisted to put this well thought out and written document together.
Q.20 Overall	Excellent document
Q.20 Overall	Excellent. Well done
Q.20 Overall	Congratulations on coming together and doing this work. I think the big thing is to make sure that the voice of people living with dementia is central to the plan…
Q.20 Overall	A very comprehensive and clear plan
Q.20 Overall	Really great piece of work, much needed
Q.20 Overall	This is wonderful what you are doing. Thank you for letting us get involved in the draft plan and having our say.
Q.20 Overall	I strongly agree with this action plan from the vision, goal, principals, objectives and enablers. There are systems that you have addressed that need to be put in place. There needs to be investment and financial resources need to achieve support in the workforce and therefore making the process supportive, available for people with dementia and families Having experienced difficulties going through this journey I strongly believe government needs to invest in the time to support a growing number of individuals and families affected by dementia.

Q.20 Overall	Thank you to the group who developed this ambitious draft Dementia Plan. People living with dementia and their care partners will be well served if it adopted and implemented with adequate funding.
Q.20 Overall	Fully supportive of the document…
Q.20 Overall	Good document...
Q.20 Overall	Overall this is excellent –
Q.20 Overall	I support this document...
Q.20 Overall	This is a great piece of work, long overdue and if every person who is involved in this Action Plan adheres to the Treaty of Waitangi and the Code of Health and Disability Services Consumer Rights - then the pathway is set for respect and success for everyone involved.
Q.20 Overall	Great job - and GOOD LUCK!
Q.20 Overall	Well done on producing this. Not an easy task.
Separate	On behalf of the South Island Health of Older People Service Level Alliance I want to endorse the Draft New Zealand Dementia Plan 2020 to 2023. We agree with the four overarching objectives. We look forward to a positive response from Hon Dr David Clark and Hon Jenny Salesa that will enable us to progress to providing supports and services for people with dementia and their support partners. Our Alliance has representation from a range of health providers across community, primary and secondary care as well as consumer voice across the five South Island DHBs.
Separate	On behalf of Lakes DHB MHSOP the following comments: Overall, the focus of the action plan focus on key concerns...
Separate	Well done. I think it looks good and includes all the major elements.
Separate	The Draft NZ Dementia Plan 2020 to 2023 is particularly important for women as about 30% more women than men are living with dementia, and women are usually, the main carers for people with dementia. NCWNZ has long advocated for better services and support for elderly people, disabled people and those with chronic conditions including dementia, and for their family/whanau and carers. Our submission in 2005 to Standards New Zealand on DZ8134.6 Guidance for Community Services for People with Dementia and Audit Workbook 1, emphasised many of the objectives and actions set out in the Draft Dementia Plan, including: holistic, integrated approach, access to appropriate, professional assessment, early identification and diagnosis; education and empowerment of the person and family/whanau and carers , active partnerships between family carers, people with dementia, professionals and service providers in the planning and provision of services; good governance and dynamic leadership.

	Therefore, we strongly support these principles, objectives and actions with some suggestions for strengthening and addressing apparent gaps. We particularly welcome the holistic, integrated approach of the Plan, alignment with other Government Strategies and recognition of the importance of a healthy lifestyle and social connection as preventative measures, as with other chronic non-communicative conditions…. NCWNZ supports the key objectives and actions as essential first steps in improving prevention, diagnosis and support to people with dementia and their families; in particular reduction of stigma, development of local, community-based support networks and greater support to carers.
Separate	The RANZCP is strongly supportive of the over-arching themes of the Plan. We tautoko the five major challenges you have outlined in the introduction. These challenges rightly require urgent interventions but we note the He Ara Oranga[i] report did not address the mental health of older people including people living with dementia, and the Health and Disability Systems Review Report[ii] is silent in regards to the possible future configuration of dementia support and services. If major Government policy documents are not focusing on the challenges regarding dementia and not providing people with dementia (or their carers or health professionals) with a voice about future services then we contend the situation is unlikely to improve… We broadly support the intent of the Plan and welcome its development.
Separate	The NZCCP believes that the objective of creating a national strategy for dementia is timely and necessary. Any attempt to co-ordinate, and create greater governance, over dementia services will be of benefit to people living with dementia… We trust that the NZ Dementia Plan will lead to substantial positive change in mental health services in Aotearoa New Zealand, and the improved wellbeing of this population.

Part 2
Key themes

11 Keys to success

Enabling factors

The importance of funding and training for the workforce were among the strongest themes in the responses. There were also calls for the plan as a whole to include more detail and outcomes.

These themes map onto the enabling factors included in the draft plan and parts of the capability section.

11.1 **There was a high level of concern about resourcing.**

11.2 **Workforce training was seen as a priority.**

11.3 **There were calls for more specificity about details and outcomes.**

More funding

There was a perception that it will take more than words on paper to bring the plan to fruition and make a difference. There was a high level of concern about governmental support, for example through national commissioning, to make the plan viable.

More training

The importance of actions that ensure training, valuing and planning for the broad paid-workforce engaging with people living with dementia and their families was emphasised, with care workers (kaiawhina) being a group that was frequently singled out as particularly important.

More detail and outcomes

Some respondents stressed the importance of having more detail and outcomes specified in the Action Plan overall, and particularly for the Living Well section. Some respondents were wary of bureaucratic tick box exercises for monitoring.

There were also suggestions that the plan make more reference to evidence and to existing successful initiatives.

11.1 There was a high level of concern about resourcing

Survey question	Comments
	Needs to make a difference
Q.3 Goals	Actions speak louder than words our experience is people just go through the motions
Q.3 Goals	from feedback from whanau members, there's a lot of words written on a lot of paper, little of which has ever resulted in tangible improvements in this sector
Q.3 Goals	It looks very good on paper, however to implement will have challenges.
Q.3 Goals	I am in support of the draft NZ Dementia Action Plan, however have concerns that there are no timeframes for the proposal goals, and that we will end up in the same position as following the New Zealand Framework for Dementia Care - limited implementation.
Q.3 Goals	I have heard all this stuff before but here on the ground I don't think much is changing. I am constantly meeting people who are "lost" in the system little guidance and little support
Q 5. Principles	It's time to stop surveying and time to take action. This is a cross gender, cultural and health issue stop ignoring the obvious and get on with supporting
Q.8 Incidence	Too many already procrastinating and not doing enough. Action is needed now not a proliferation of wordy documents
Q.17 Capability	Actions speak louder than word. Place the right people in roles to assist a strong go forward
Q.17 Capability	it would be great if this plan actually resulted in some positive action and change!
Q.20 Overall	Standards are often ignored, whereas policies have to be followed. I hope this is simply not another nice looking document which fails to deliver any true change.
Q.20 Overall	We need to see more actual action ie government funding, DHB commitment and greater emphasis in professional health care train programmes. It needs $$$ now, not more reports and action plans. The situation is known and action plans are clear!
Q.20 Overall	Please make sure this goes ahead and is not shelved and ignored as all too many action plans and reports are. This is really important work to be done.
Q.20 Overall	What is the intended status of the strategy? Will it have teeth? How will it be reviewed? By whom? Who will "own" it and be responsible for implementing

	it? Apologies if I have missed something. I have only been able to give this limited time...
Separate	…There have been quite a number of Dementia initiatives over the last 18 years. Reading Chris Perkins Book recently (2004) most of what we are discussion was known about then. There have been initiatives such as the Dementia Pathways and the NZ Framework for Dementia Care which has never been fully implemented. One reason for this is that it was never intended to be a mandatory implementation. According to the Auditor General, it is a guideline and, as such, does not have to be implemented at all. There has been a lot of knowing what to do and very little doing. As a carer, there is still no plan for regular respite in the DHBs. What happened as a result of the research? Carer's support is till the same as it was 25 years ago. I can't point to anything which has improved over the last 5 years. Government inaction seems to get in the way of doing anything so how do we address that?...
	Government funding
Q.19 Enablers	While we agree that these are the critical enablers, we would suggest the Plan cannot take a passive position on these being in place. We would recommend adding the action required to help ensure that these can be relied on to support the long term implementation of the Plan
Separate	We [RANZCP] tautoko the Plan's emphasis on identifying '*sufficient sustainable financial resources'* to meet service needs. Without an ongoing funding model to support dementia services and care it will be challenging to deliver on the Plan's Action Areas, therefore we suggest advocacy activities are directed towards obtaining sufficient funding.
Q.3 Goals	The care system just needs more money. I visit a rest home weekly and always there are staff shortages, showers rationed, meals late or forgotten. Nappies not changed until midmorning. And these are probably just the tip of the iceberg. MPs should have to live helpless in these places prior to voting on budgets in my opinion.
Q.3 Goals	This needs to be funded. The Health Service is competing globally against other jurisdictions eg the NHS. (The current British PM has made dement priority).
Q.3 Goals	I was disappointed that the plan wasn't related to existing resources and didn't indicate what additional resources would be needed.
Q.3 Goals	A broad vision but would need government focus and financial support to achieve
Q.3 Goals	It is fantastic but will require a fair amount of funding.
Q.5 Principles	Clearly the implementation of the plan will involve more Government funding. How much has the present Government dedicated towards implementation of the plan?

Q.5 Principles	Funding is a huge issue for most sectors, if this was improved there may be more opportunity to improve services for all experiences a dementia.
Q 5. Principles	.. and the next major step is to plan for a workforce to care for the growing number of folk with Dementia. Not mentioned at all. Without a stable appropriate workforce nothing will work. Will it? Where will this workforce come from?
Q 5. Principles	again, all laudable aims - however, its tangible services and supports that whanau are calling out for. (I recall lectures about the need to plan for this 'tsunami' of older persons health needs in 1984...)
Q.8 Incidence	I am not sure where the financial resources to sustain dementia -specific NGO agencies is coming from. They are already underfunded, under resourced and stretched to the limit. They were able to provide more appropriate service a few years ago than now. They spend too much of their time fundraising.
Q.8 Incidence	As above, dedicated funding and a committee workforce. Being cared for at home requires a lot more staff if everyone is to receive best care, and family caregivers are also to survive and have a quality of healthy life years
Q.11 Living well	Will the DHBs have the requisite funding????
Q.11 Living well	These suggestions are all positive, but my concern is are they going to be funded? There is currently a lack of financial support for these initiatives, which currently leaves people living with dementia in New Zealand disadvantaged.
Q.11 Living well	…the quality spoken of here all depends on MONEY, who will pay for this wonderful planned level of care?
Q.11 Living well	Again, increased and targeted Government funding is crucial to achieve these aims.
Q.11 Living well	Better funding for non-DHB providers (e.g. Dementia NZ)
Q.11 Living well	Providers of home-based support and residential support are adequately funded to meet the needs of people they serve to live well with Dementia.
Q.11 Living well	These resources for the above actually need to exist! …
Q.11 Living well	Strongly agree significant investment and financial resource across the whole workforce is needed to achieve this strategy
Q.19 Enablers	Funding needs more attention/recognition
Q.19 Enablers	No reference to how the extra resources exceed current resources.
Q.19 Enablers	I agree that sufficient sustainable financial resources are needed to ensure that people receive the services and supports they need by trained professionals
Q.19 Enablers	How much money? Who controls it?

Q.19 Enablers	This will need to be funded to a very high and consistent level to be successfully implemented. Without guaranteed funding, it will not last
Q.19 Enablers	Enough funding will always be an issue.
Q.19 Enablers	Investment and acknowledgement by the government is needed. Aged care is at crisis point as more people come in with severe dementia and the environment and service is not set up for this. Funding and staffing ratios needs to be looked at now not in the future, this is the priority if we are to build a meaningful community for people living with dementia and their families. Support services in the community should be expanded with rapid response teams on hand to deal with crisis as they arise.
Q.19 Enablers	Will require investment in the health sector to ensure workforce is supported.
Q.14 Communities	Funding, Funding and more funding.
Q.14 Communities	An on-going national education plan to cover this and the government to provide the necessary financial assistance to cover costs. The Annual Budget to include this as a separate item and not to be just included under the Health budget. If people really wanted to make provision for the New Zealand Dementia Plan it could be done. I know this would require a lot of lobbying of Parliament to achieve this goal.
Q.14 Communities	To do this there needs to be the services in the community. DHB and government need to acknowledge this.
Q.17 Capability	… If new standards etc are to be implemented, how will the sector, who are already under pressure, support these new standards, where will the funding, workforce etc etc etc come from?
Q.17 Capability	…Already there is a serious lack of staff for these folk and considering the numbers expected in the Dementia area staff for all will become a major issue. Being positive, I hope the money will follow the words.
Q.17 Capability	This is a huge challenge with under-resources DHBs. There has effectively been 10-15 years of 'delayed maintenance' of DHB staffing resources. It is difficult to see how timelines can be stuck to in these circumstances.
Q.17 Capability	Investment crucial.
Q.17 Capability	Increase investment in local agencies to deliver appropriate education and services for all those affected by dementia.
Q.17 Capability	continued need to advise the public at large of your efforts, and aspirations. I know this takes financial support.
Q.17 Capability	Better support for non-DHB services e.g. Dementia NZ
Q.20 Overall	Alzheimers NZ Southland is a v good organisation but grossly underfunded and under staffed. The needs of those with Dementia and their whanau/family are enormous

Q.20 Overall	Would like to see sufficient ongoing funding to enable real change to occur for people
Q.20 Overall	the MoH should be asked to commit funds to achieve measurable outcomes
Separate	**Sufficient, sustainable financial resources**- this is absolutely critical, including realistic financial support to primary carers and sufficient, affordable respite care. – National Council of Women
Q.20 Overall	I just hope that appropriate and sufficient resource will be dedicated to allow its successful implementation. This needs to be given sufficient weight by MoH
	National commissioning
Separate	…Centrally directed and nationally approved standards for dementia care in all health care sector settings that span across raising awareness, early diagnosis support, living well with dementia , and ensures good end of life care, all of which supported by an appropriate direct funding model that are linked to a centralise[d] agency. Provision of a commissioning framework that directs service provision at regional and local level … collated feedback from the national MHSOP leaders
Q.19 Enablers	As the rest home sector funding is multifaceted and differs between DHBs sound evidence based interventions that address the strategic goals should be assessed and awarded funding at a national rather than a regional level. This would reduce bias, encourage innovation, increase research and improve quality of care.
Q.14 Community	Communities need to be supported at a national level.
Q.11 Living well	if services are to be equitable, they must be at the highest, most effective level and not restricted by individual DHB finance issues.
Q.19 Enablers	I believe this plan can only become a reality with sustainable across the country funding.
q.17 Capability	…Again a national, consistent approach with appropriate governmental funding is required to ensure that quality care is provided for all.
Separate	5th Principle: need to employ health professionals to ensure nationwide consistent quality-assured services. Thames Agewise
Q.11 Living well	if services are to be equitable, they must be at the highest, most effective level and not restricted by individual DHB finance issues.
Q.11 Living well	Each individual DHB may be constrained to implement or initiate a program. Needs to be nationally consistent …

	Governmental and policy support
Q.3 Goals	The Government needs to develop policies which will enable this vision and this goal to be realised.
Q.3 Goals	In the election next year, all political parties should be encouraged to state their support for the plan.
Q.5 Principles	Clearly local governments must be on board and must develop policies which enable these aims to be realised.
Q.17 Capability	All political parties need to be on board with the massive spending increase for services that these actions will involve.
Q.20 Overall	There are huge challenges, both financial and human, in the implementation of all these proposals. All people and all political parties need to acknowledge this.
q.17 Capability	These kinds of actions need support from all political parties, because the issues concerned reach well above politics.
Q.8 Incidence	the indifference of government and communities is history in the making we will look at this time and realise the government of today is out of touch and without focus or understanding.

11.2 Workforce training was seen as a priority.

Survey question	Comments
Separate	We [RANZCP] agree that a 'knowledgeable, skilled and supported workforce' is required to implement the Plan. We have demonstrated in our submission that workforce is a critical component in the success of the Plan. We strongly suggest that the Plan is socialised widely across the health and disability workforce but is also provided to other government agencies that will increasingly be working with people living with dementia.
Q.3 Goals	Investment by government is required for an educated workforce to implementation of cares
Q.3 Goals	The challenge is in the practice, integration, education…
Q.3 Goals	The goal of this New Zealand Dementia Action Plan is to ensure the lives of people living with dementia and their whanau/families are valued and supported by recognising the need for government to provide and fund appropriate levels of training for community and residential care underpinned by law changes to the Protection of Personal and Property Rights Act, 1988.
Q.5 Principles	Train the staff. ..
Q.5 Principles	So far there is no mention of funding to ensure the services will have appropriately trained professionals/non-professionals to meet these needs.
Q.5 Principles	National education across all sectors, major knowledge deficit in knowledge around dementia
Q.5 Principles	I think that somewhere in the principles there needs to be an unequivocal statement that services and care must (not should) be delivered by appropriately trained and supervised (in the sense of clinical supervision which can address stress and other concerns of workers) personnel. This may be costly at first but necessary for workers' and clients' safety.
Q. 8 Incidence	Educate clinical and academic colleagues (and the public) about dementia. Most still imagine that all dementia is only seen in people needing 24/7 care in a care home, not understanding that dementia is a progressive disorder (like any other chronic illness) and that 80% of people with dementia have mild dementia and are still living full lives in the community.
Q.19 Enablers	Adequate training and understanding of dementia is urgent
Q.19 Enablers	Tertiary education needs to include core aspects of caring for people with dementia throughout the undergraduate curriculum of all disciplines.

Q.19 Enablers	Re the knowledgeable, skilled and supported workforce - fully agree, and this may require working with undergraduate and postgraduate programmes to ensure some of this knowledge and these skills are included as part of the core programme.
Q.17 Capability	Education and more education. Tasmania University offer free courses on Dementia - one running at the moment is Preventing Dementia. Courses like this should be advertised and spread wide and far to catch as many people directly and indirectly involved with Dementia able to learn for free.
Q.17 Capability	Tertiary training institutions who provide health care training need to devote more time in their courses and trying programmes to issues related to ageing and understanding and caring for those living with dementia whether dementia clients or caregivers and /or whanau. This is a seriously neglected area in the training of health professionals relative to the attention given to other age cohorts.
Q.17 Capability	Training strategies include targeting 'at risk groups' such as mental health and intellectual disability. Review the NZQA qualifications for dementia as they are not fit for purpose. Develop training for leadership in dementia care. Consider role that people with dementia play in developing and delivering new qualification frameworks.
Q.17 Capability	We would welcome training support not just for medical care but training for all people working in the provision of dementia services and solutions.
Q.14 Communities	Appropriate training and media education
Q.17 Capability	This training should be made available at Under-graduate level for all Health Disciplines
Q.17 Capability	Providing better dementia education for undergrad students as well as dementia courses for existing health workforce. This may reduce stigma and increases awareness.
	Care workers
Q.3 Goals	Care workers require further ongoing training …
Q.3 Goals	I think more training for Support Workers both family and via Support Providers. Its fine having paper qualifications ie Level 4 Dementia but it needs to be reinforced regularly to those who are on the cliff face. It is practical every day advice and support that is lacking, someone to provide options and ideas, it would be my suggestion if possible a least quarterly visits to Support Provider companies, by qualified Dementia Nurses/Educators, to educate and give ongoing practical training to Care and Support workers Particularly those in Home care as they work without physical presence from Nurses and don't always have their feedback listened to acknowledged or actioned.
Q.22 Enablers	support workers need more ongoing /regular support and training.

Q.22 Enablers	There should be a strong focus at the "low" end of service provision - such as nurse aids and other care staff in rest homes. This should be promoted as a valued career and pressure maintained to provide appropriate training, professional development, and career advancement options, rather than its current position of being seen as a low-skilled, poorly-remunerated, and non-progressing option. A parallel would be the increased professionalisation that occurred in the childcare sector over previous decades.
Q.19 Enablers	Dementia care services are distorted. Presently the more severe the illness and greater the challenges the less skilled the care staff are. The bulk of the money for dementia care is directed into residential care where the lowest skills levels are
Q.11 Living well	NGO's/carers to have specific ongoing professional development around dementia.
Q.17 Capability	Compulsory dementia education for all aged care workers not just those working in a dementia setting. Improve current NZQA unit standards
Q.17 Capability	I work for a home support provider and we simply do not have the resources available to train all our support workers to be dementia-aware and know how to behave appropriately. They get basic skills but nothing more unless they go on the Walking in Another's Shoes which has so few places every year because it is not resourced adequately either. It would be good to have a training package that is nationally recognised and used nationally so everyone gets the same training. With adaptations for Maori and other ethics groups.
Q.17 Capability	I think carers that are directly involved with the clients, need ongoing support and training tips and advice along with problem solving and stress and burnout management, and somewhere to get together on a regular basis with educators to improve supports for clients and keep up skilling the workforce that are direct support for the clients. this needs to happen immediately.
Q.20 Overall	extensive professional development for carers. Also better wages for carers and in return better care for people living with dementia
Check	Kaiawhina (unregulated health and disability) and Kaiamnaaki (unregulated social and community) workforces, while not medical professionals are regularly the frontline workforces able to support the early intervention and care priorities of the Dementia Action Plan. We recommend that these workforces are specified alongside social workers and the medical, nursing, allied health workforces to ensure that the appropriate allocation of training support is identified and implemented to reflect the different workforce training and/or upskilling needs.
Q.5 Principles	Investment must be put into training and retaining of experts in the field of supporting people with Dementia, e.g. Registered Diversional/ Recreational

	Therapists, especially when clients are living in residential care environments. Also, in Day Care environments where these skilled Therapists work.
Q.22 Enablers	people in this specialised area need to be able to work at the top end of their scope of practice and have career pathways supporting this
Q.22 Enablers	Investing in the work force is critical. At present staff are not well trained or skilled, are poorly paid and working conditions are not suitable for provided the person centred care that people with dementia have a right to.
Q.22 Enablers	Working together we are GP practices and DHB so consistent quality of care with appropriate funding is essential. Pay rates should be looked at for our staff which would attract qualified and appropriate staff.
Q.22 Enablers	Promotion of the skill required to work in the dementia setting is needed alongside pay parity and safe staffing levels to ensure a sustainable ARC workforce. Funding needs to be made available to support nurses, doctors, allied health wanting to specialize in this area
Q.22 Enablers	Complete implementation of the Care and Support Workers Pay and Equity Settlement 2018 (if not already completed)
Q.22 Enablers	Nurse training does not make this area of nursing an appealing option to go into. In DHB's the workforce is aging and there are little moves to recruit into this field. In regards to ARC then staff are often recruited from overseas (with limited training) and expected to work in NZ in a very specialist area of nursing with inadequate training and support.
Q.22 Enablers	I have mentioned this before, that it is critical to invest properly into the human element of this plan, as it is the person contact that has the most impact on the lives of the client. The way they are treated on a day by day basis is far more important to that individual and their self-worth than the loftier aspects of a Dementia Plan. Grass roots and focus on “the coal face” will establish the culture and best practice mentality that is essential to any service involving working with people.
Q.19 Enablers	This workforce will need to be "Valued" caregivers to become a planned future, working within the Polytech environment. Partnerships with schools’ careers advisers for example. Also it would need to have cross party support so that any successive govt will not "pull the plug" on wages and conditions and turn carers away.
Q. 17 Capability	Incentive needs to be in place to attract dedicated people into the sector of dementia support. It is a highly specialized area and needs proper training and selection of candidate for the service to be effective and beneficial to the client. If the position is valued it will attract a person with appropriate attributes to the role. Old adage, “ Pay peanuts, ...”
Q. 17 Capability	Investing in the capability of the registered nursing workforce is also a priority. So too is the availability of nurses to work in aged care areas. Strategies to attract new graduates, experienced nurses and nurse practitioners are needed.

Separate	Strategies to improve recruitment and retention across the various health sector settings and career pathways to enable people to work at the top end of their scope. - collated feedback from the national MHSOP leaders
	Broad and planned
Separate	Centralising training agencies for those working with dementia across the sector - - collated feedback from the national MHSOP leaders
Q.17 Capability	there needs to be a centralised workforce and training agency for dementia and dementia care
Separate	We [RANZCP] support the statement that 'a knowledgeable, skilled and supported workforce across the sector and health system is needed to achieve successful implementation'. Dementia has a complex aetiology and we contend that specialist services play an important function in delivering optimal services and psychiatrists can guide and lead this work.
Q.11 Living well	Develop with Support Providers Care and Support teams within each company in each town, that are specialised and qualified in Dementia care so that new staff are not required to support Dementia patients as this leads to both client and worker stress, and the care and support then becomes specific and specialised. making it easier to train and support staff that work in the Dementia care.
Q.11 Living well	Well trained specialist staff, doctors and community workers
Q.11 Living well	again please keep reminding clinical team workers in DHB, other than their managers, of these priorities as with heavy caseloads it can be easy to lose sight of your actions and planning
Q.11 Living well	The health care work force needs to be urgently addressed and taken into consideration. With Baby - boomers due to retire over the next 10 years, this presents a huge challenge. DHBs are under-resourced and are poor at valuing and supporting Allied Health workers in particular.
Q.11 Living well	The Department of Health to reintroduce workforce planning in DHBs and report to the Ministers of Health on a quarterly basis (dropped by the last Government)
Q.19 Enablers	Sustainable finances alone are insufficient. Workforce development and their sustainability also needs to be addressed alongside this.
Q.19 Enablers	To future proof workforce give some consideration for beginning training at secondary school i.e. introductory education that aims to fulfil workforce needs/gaps.
Separate	We need to liaise with the Education Dept and encourage students to consider working with the elderly including those with dementia. Vocational courses allow students to spend some time working in the field while at school, or even to try it out. Through this the status of these jobs could be raised. I think

	something needs to be done to encourage a stable, well trained work force, including diversional therapists.
Q.19 Enablers	Ensure that the personnel who are part of and delivering these programmes are genuine in their work and that they adhere to and this survey refers to and includes the 10 Code of Health and Disability Services Consumer Rights as this work progresses.
Q.19 Enablers	Sorry probably doesn't fit here but consider asset based approaches - things like 'Living Libraries' this is a different take on education but also tackles stigma and supports the retention of identity a key factor in resilience Develop champion models to support the implementation of new working practices. Consider in workforce training use of technology
Q.17 Capability	As well as accountability perhaps the most urgent need for all the dementia patients I have the pleasure to know is to have a transparent, accessible and relevant advocacy service. This is vital in secondary care acute admission settings where health professionals have limited knowledge of delirium versus normal dementia behaviours, how to reduce risk of falls and anxiety when suddenly being placed in an unfamiliar environment. A generic flow chart for ED nurses and Drs to follow at admission would be helpful for patients and their distressed families at this time.
Separate	Thames Hospital staff attending this meeting acknowledged ward staff need more training re how to provide optimal cares for patients on their wards who are admitted acutely and have a dementia diagnosis. – Thames Agewise
Q.20 Overall	Nursing leadership is key to achieving better outcomes for people with dementia. Quality of care is a nurse-sensitive outcome.
Separate	I think this is great BUT would add "trauma informed care" into the mix Staff need to know about "Adverse Childhood Experiences" research and the consequent trauma informed care in my opinion
Q.5 Principles	Employ more staff
Q.5 Principles	Taking a holistic approach in the patient centred care is very important. Having time and resources which are funded will allow a better outcome for the person with dementia and their whole whanau as carers
Q.17 Capability	D6 level of care needs to be better staffed with RN nurses

Q.17 Capability	We don't need more managers taking funds we need more doctors and nurses and training for them.
Separate	It is not just about training. It is also about ***numbers*** in the workforce. Currently home-based services are stretched and residential care is appallingly short-staffed.
Separate	HR: we need to define minimal proportions of Psychogeriatricians and dementia allied health personnel…..something like: we call for a minimal ratio of XX Psychogeriatricians per 100,000 population….

11.3 There were calls for more specifics about details and outcomes.

Survey question	Comments
	Outcomes as part of plan
Q.5 Principles	The plan would benefit from clear differentiation about how each objective will be achieved and measured
Q.5 Principles	Clear measurable outcomes must be defined as part of the vision
Q.8 Incidence	This is a huge objective - and one that overlaps with other initiatives. It would be good to consider more specific actions and how these may be measured?
Q.8 Incidence	Put in metrics that you can measure progress with. Without this this is not a plan, it is a wish list
Q.8 Incidence	I think the proposed action requires greater detail as to what we are aiming to achieve and clear accountability rather than a suggested responsible agency
Q.8 Incidence	Ideally the actions will have time targets and outcome measures and then it will be possible to determine if a difference is being made.
Q.8 Incidence	Statistics need to be kept on diagnosis from G.P. and specialists to measure against projected estimates. Otherwise we will never know if it is working.
Q.8 Incidence	Be willing to try out new ideas/methods with controlled samples, properly monitored
Q.19 Enablers	So important to be able to monitor a core set of dementia indicators at a population level.
Q.19 Enablers	As stated about population level monitoring is crucial
Q.19 Enablers	Ideally the actions will have time targets and outcome measures and then it will be possible to determine if a difference is being made
Q.14 Communities	While actions exist there are no indicators for the actions which makes accountability ambiguous.
Q.14 Communities	Ideally the actions will have time targets and outcome measures and then it will be possible to determine if a difference is being made.
Q.17 Capability	I am strongly in support of building capability in the sector, but fail to see any specific and measurable goals on what this would involve. As mentioned previously, we have had little progress since the NZ Framework for Dementia

	Care, so how do we think this will be any different? Where is the challenge to ensure this happens?
Q.17 Capability	National indicators should be formulated at the same time as the main Action Plan to avoid fragmented policies / plans being implanted. If this is delayed, there is immense risk that dementia care / support will remain low on DHB priorities The care and support is already fragmented and lacking depending on where you live and which cultural group is needing to access support.
Q.17 Capability	Ideally the actions will have time targets and outcome measures and then it will be possible to determine if a difference is being made.
Q.17 Capability	Standard outcome measures are important to Consistently monitor Outcomes across settings and NZ. This will help greatly with data collection, feedback and review of interventions
Q.17 Capability	How do we ensure that national indicators are implemented - what is the carrot or the stick? In the UK the standards were linked to funding - for example if dementia care standards in hospitals weren't met then the overall funding for the hospital was less, therefore there was a huge financial incentive for managers to support the standards. This would have to include monitoring and inspections by care quality agencies - who would do that in NZ?
Q.17 Capability	accountability is the key.
Separate	Centrally directed and nationally approved standards for dementia care in all health care sector settings that span across raising awareness, early diagnosis support, living well with dementia, and ensures good end of life care, all of which [are] supported by an appropriate direct funding model that are linked to a centralise[d] agency.
Q.20 Overall	In future iterations, actions should be more specific, with corresponding measurable outcomes against which success or failure could be measured. Research for example, could have an associated list of knowledge that needs to be obtained/improved, which could then readily be assessed by what projects addressing them were funded and gave useful outcomes. It wasn't clear to me that the vision (such as a focus on inequity) was necessarily addressed by the selected actions and objectives.
Q.20 Overall	I like the idea of a plan but would also like quantitative measures of success.
Q.20 Overall	I realise you cannot do everything all at once and therefore some actions have been pushed out beyond 2023. However there must be ongoing monitoring of whatever plans you do action from 2020i and the flexibility to bring some of the 2023 actions forward if it is found during the process that this would be beneficial to what you are wanting to achieve in the 2020 more immediate timeframe
Q.20 Overall	I am concerned the plan lacks detail and accountability. I would like the group to consider adding measurable targets and accountable agencies to the plan as well as an expected reporting period.

Q.20 Overall	There is also a need for in depth multidisciplinary clinical engagement to ensure relevance across the health sector. This should include consultation with geriatricians, neurologists and specialists in noncommunicable diseases. The New Zealand Dementia Action Plan outlines a vision which requires expansion and the integration of much greater levels of detail. It must be established who will be spearheading this further development, and where the resources to facilitate it will be sourced from.
Q.20 Overall	Clear guidelines are needed as to what Living Well looks like. Otherwise nothing will change.
Q.20 Overall	We do not have national data or evidence to back up a number of claims made in the Report. How much service is actually delivered, to whom, by whom, where etc. This needs to be established nationally as a priority.
Separate	It is early days and the plan needs more development obviously. Need to see • More detailed time frame • Cost estimates • Monitoring and reporting responsibilities • Workforce development (skills and numbers) plan • Government needs to adopt it as a priority
Separate	…Action Areas; why is it that about half the action areas are put off for another 3 years? What are the equitable, tailored and quality assured support services to be? We need more detail about what people living well will look like What would dementia navigation services look like? I hope huge firms won't be employed to do things such as navigation. People with dementia and their carers need relationships, not faceless firms in which you may be dealing with a number of faceless of people…
Q.5 Principles	Broad ideals are all very well but specifics need to be stated otherwise the DHB's will not change the poor standards of service they offer and the low priority they place on Dementia Care.
Separate	We note that much of the Plan discusses raising concerns about dementia within the community but we argue that greater advocacy has to be done internally, within the Ministry of Health and other government agencies, to ensure dementia services are seen as a key policy concern. We seek clarification regarding the Plan's alignment with the proposed implementation of He Ara Oranga and if the second stage of the Health and Disability Systems Review will describe the future state of services and care for people living with dementia. If the Plan is not interwoven with these larger policy initiatives then there is a risk it will not be seen as a priority and it will not progress in a timely fashion. Te Pou[iii] has published a strategy outlining ten priorities to improve the mental health of older people, and whilst the strategy is not specifically about dementia, many of the actions are aligned with those identified in the Plan. It would be

	useful to draw on the Te Pou Strategy as this would add weight to the Plan and provide greater context to the experiences of older people living in New Zealand We strongly recommend that the next phase of this work includes developing measurable outcomes. This approach will assist in planning interventions, determining 'what works', and supports an evidence-base to advocate for increased resources and funding for older people's health. We call for auditable actions against specified timelines across a number of service areas including assessing, treating and preventing dementia, and providing quality care. The RANZCP notes that the Ministry of Health is currently developing a stocktake of dementia activities and we suggest that this information will provide additional information that may influence the final Plan… The Actions Areas need to be more sharply defined as in some instances we are unsure of the specific components that describe the Action. We suggest greater thought is given to operationalising the Actions including measurement and assessment to ensure the prescribed objectives have been achieved by 2023. …The Plan requires more specific and measurable outcomes to guide future work e.g. understanding what has been achieved by implementing the Plan and recognizing where gaps remain. Measurement tools will also assist in identifying effective interventions that lift the wellbeing of people with dementia. The RANZCP is available to provide further advice regarding developing measurable outcome tools.
Separate	Our research here at the University of Otago DSM shows that ageing in NZ is inferior on most measured outcomes compared to Australia, Italy, Japan or the UK. We cannot have that happen for Dementia Plan as well.
Q. 5 Principles	It is difficult to disagree with any of this, but it is also very unlikely it will all be funded. Needs further prioritisation.
Q.20 Overall	…It may be more successful if there is prioritisation of goals. The problem we have is that everyone looks at this issue and is overwhelmed- so they do nothing useful. Saying this should happen first, then that, etc. is more likely to succeed.
Separate	We believe that this objective is of key importance. There is also an initial need to consider what the current level of skill is across all sectors in the population who provide care for this group, including informal caregivers, acute care settings and residential care settings – i.e a workforce audit is needed. There is a need to consider inequity not just within this population but for this population as a whole when compared to other health populations, e.g. in terms of capability of workforce. Other organisations which should be identified as stakeholders for this objective include academic institutions. -NZCCP
Q.17 Capability	Do a stock take of current workforce first - numbers, skill set and review against current service gaps. Priority needs to be given to commencing the up-skilling and specialist training of both regulated and non-regulated workforce now as you will need them ready to participate in development of these plans and implement role out of plan. Otherwise the implementation of the proposed plan will be compromised and outcomes for clients will be less than satisfactory. Learn from other Govt Plans that have been less successful in the past 5 - 10 years!!

Separate	Overall – good document. Fairly clear. Like short time frame. Bit evidence light…I'd light a wee graphic of the timeline.
Separate	**Strengthen capability across the sector-** these are all important actions but could be made clearer: □ Will the cross-sector group include other Government departments like Education? □ Will dementia standards be mandatory or "guidelines"? □ Will training be mandatory? □ Will education on dementia be given more prominence in basic medical school and other health training? -National Council of Women
	More detail for living well section
Q.11 Living well	actions need to be specific what inputs are needed?
Q.11 Living well	Ideally the actions will have time targets and outcome measures and then it will be possible to determine if a difference is being made. There are several actions within the same action and it is not possible to comment specifically on each one - especially where you might support one component but not the other
Q.11 Living well /separate	1. more detail is needed describing these support services so they can be implemented consistently across populations. Specific measurement outcomes should be generated to ascertain if the services are making a difference and are best suited to the needs of target populations. From written: We support this Action but suggest it be more clearly defined. For example, we note DHBs are to deliver services "at least 12 months post-diagnosis support through the local dementia-specific NGO to equip people to live well." It is not clear to the reader how support services should be configured so they can be "consistent" and "equitable" across all DHBs. We suggest more detail is provided describing these support services so they can be implemented consistently across populations. In addition, specific measurement outcomes should be generated to ascertain if the services are making a difference and are best suited to the needs of target populations. 2.There are sub-groups of people living with dementia who require greater support and increased research to understand their specific needs. See submission for more information. From written: The RANZCP considers that people living with dementia are not one homogenous group. There are various cultural, age, diagnostic, and behavioural sub-groups and some of these are currently poorly served by existing services. There are sub-groups of people living with dementia who require greater support and increased research to understand their specific needs. The RANZCP has identified the following populations where services need to be developed and acknowledged in the Plan. • Māori

	• Pasifika
	• Asian cultures – especially where language is an issue
	• LGBTIQ+
	• People with sensory deficits (deaf and blind especially) living with dementia
	• People with the early onset (age 40 to 65) of dementia
	•
	  • Individuals in the care of the Department of Corrections
	  • Individuals with dementia who have inappropriate sexual behaviour
	  • People with dementia who wander but otherwise are independent.
	
	3. More research and analysis to "unbundle" these specific populations and in particular their requirements to live well. This research should involve key stakeholders (e.g. NGO, carers, primary care, whānau, professional bodies)
	
	… In terms of both specialist services and aged residential care we maintain services and support are not well tailored to meet the needs of the various sub-groups of people living with dementia.

Q.11 Living well	The description of Living Well needs to be clearly described in detail otherwise it leaves the potential for lip service to be paid to this aspect of dementia care. The words Living Well have been used for some years now without any expectations that government money will be used to support this. Living Well is not funding Dementia Day Care only! Living Well is supporting people living with dementia and their families to continue to live a full, meaningful life at home with support.
	How / hesitations
Q.19 Enablers	The monitoring enabler presents as a quantitative outcome rather than both quantitative and qualitative.
Q.19 Enablers	Monitoring should include well-being not just symptoms
Q.19 Enablers	I would also like to see GPs monitoring quality of life at an individual patient level for dementia patients using a validated tool - something like QOMID (Quality Outcome Measure for Individuals with Dementia) which I think has been validated - may need to confirm this. This could be a rich set of information if this data could then be collated as part of research studies to inform better service delivery. Of course, this could be prohibitively expensive
Q.19 Enablers	Simplify any monitoring or measures
Q.19 Enablers	Be careful not to waste money on paperwork rubbish and waste time of people working at grass roots (which happens too much with all of the current computer systems), they look at screens more that the consumer/ person in need- it's pretty disgusting
Q.19 Enablers	Consumers and wider stakeholders need to determine indicators.

Q.19 Enablers	Monitoring can be done at low cost through DHB, Dementia groups, GP's and nurses in the district.
Q.17 Capability	Involvement of those working at the coal face and caring for people with dementia should be paramount when identifying indicators and measures to ensure that they don't become a box ticking exercise and have genuine meaning and effectiveness on future outcomes.
Q.17 Capability	you can't improve real dementia care by having industry standards and measurable outcomes. Dementia outcomes might be measurable but the best outcomes are not.
Q.17 Capability	More practicality, less bureaucracy.
Q.17 Capability	While I strongly agree - in the other spheres of government I've worked e.g. Canterbury Earthquake Recovery, I have found a lot of time has been consumed on standards and KPIs. I think enacting the Dementia Plan is so urgent we must put energy into the doing and gradually put resources to the measuring of success
Q.17 Capability	Cross sector leadership on its own will not work. Cross sector work needs to be driven by community and include clear lines of accountability for DHB's and other sector participants.
Q.17 Capability	You at you want a person centred approach but this section hands full control over to the faceless bureaucrats
Q.17 Capability	making it all a tick box approach never produces a quality outcome. Tick boxes prohibit innovation
Q.17 Capability	Are there already some National measures for dementia sector?
Separate	'High quality dementia care for residential care': discussion… Residential services in NZ already have their own service delivery standards. – Thames Agewise
	Check what is working
Q.11 Living well	Check what's happening in best practice overseas
Q.11 Living well	A lot of the above already exist in excellent initiatives already- so not to take those away with new ones that may or may not work. Staff need to be trained through fully funded courses, recognised and valued through increased pay rates. More Maori, Asian, and Pacific staff that are fully supported is needed. More cultural training for staff including managers, HOD, owners of businesses that provide care.
Q.11 Living well	If there are currently effective Dementia policies / plans being utilised by any DHBs, could these be implanted immediately whilst this proposed Dementia Action Plan is being formulated / finalised? This will ensure immediate strategies are in place whilst recommendations / negotiations with the MOH are

	being considered. Leaving vulnerable people in limbo any longer will contribute the on-going significant strain on the DHBs / community and carers/ whanau.
Q.11 Living well	recognition that where services already exist in the community that DHB's should utilise and fund what already exists. Recognition that not only Dementia specific NGO's provide dementia care. An example would be Parkinson's NZ who deliver care throughout the disease continuum.
Q.14 Communities	grateful thanks for all the hard work that you have done so far, much appreciated
Q.14 Communities	A good start has been made in the greater Wellington Area, thanks to Dementia Wellington. Education is ongoing.
Q.14 Communities	NGO's like Dementia Canterbury are already doing this by groups within communities occurring and education given to clients and care partners/ families/ friends and by taking opportunities as they arise to discuss the topic with other professionals or interested parties of the community and wider public
Q.14 Communities	Prof Anthony David (UK) has presented data at a recent conference to show that proximity campaigns are more effective than educational campaigns to reduce stigma around mental illness. Proximity means getting the person with mental illness out into the community interacting with their fellow citizens thereby reducing stigma from others and self-stigma.
Separate	The Plan's Action Areas and possible outcomes are not referenced with supporting evidence. The RANZCP maintains that evidence should always underpin decision-making, interventions, and policies to ensure the best outcomes are obtained for people living with dementia and their whānau. .. The RANZCP has access to the evidence and best practice guidelines relating to the care of older people living with dementia. We already play a significant role in the multi-disciplinary assessment and treatment of people living with complex dementia and therefore we would appreciate an opportunity to work alongside you in further developing the Plan.
Q.8 Incidence	What can we learn from initiatives in other countries to reduce the incidence of dementia?
Q.8 Incidence	I feel overseas research such as that which is done by Dr Hyman, Dale Bredesen and Tony Dearing amongst many others should be included in the research to reach this goal.
Q.8 Incidence	It will be useful to establish what systems are already in place so that they can be used or adapted to improve education about modifiable risk factors of dementia
Q.8 Incidence	Is this objective one that is seen to be already in place within the dementia workforce and therefore rolled out to other health-care providers in the next plan? I'm not sure that it is necessarily already in pace and I believe there is a need for this to begin sooner than 2023.

Q.20 Overall	…There is a lot of work on health of older people and disability and mental health happening around the country so be sure this does not stand alone but is worked in to these work streams and funding streams
Separate	…Whāia Te Ao Mārama, 2018-2022 The Māori Disability Plan. He Kowowai Oranga Māori Health Strategy

12. Family supporters

Overarching theme

While the initial vision and goal section emphasised family / whanau, there was a strong call for the rest of the plan to follow through on this to recognise and advocate for family supporters.

12.1 **There was a strong call for the plan to advocate for resources for family supporters.**

12.2 **The importance of improving options for respite care was emphasised.**

12.3 **Family supporters were emphasised as another priority target group for education**

Support for supporters

Prioritising support for family carers, particularly financial support, was a very common theme.

Respite care

The importance of improving respite care options was emphasized. The living well section did include the recommendation that CDHBs provide accessible respite services.

Education for supporters

The focus on the paid workforce as a target for training and capability was welcomed. It was emphasized however that training and education should be not just be a priority for paid workers / professionals, but also for family supporters in the community. In some cases the focus of the comments was on education around available options, which could be seen as overlapping with the support for navigators.

12.1 There was a strong call for the plan to advocate for resources for family supporters.

Survey question	Comments
Q.3 Goals	I strongly believe that people living with dementia and their care partners have the right to live well and this needs to be supported and the government needs to commit to funding to enable this to happen as the numbers of people living with dementia is set to treble in the next 30 years
Q.3 Goals	For Govt to rely on partners of whatever aged to be the unpaid care giver is my concern from observation. Older spouses having to provide full time care with little help or respite, so you end up with two needing care. Younger folk with Dementia, the spouse having to give up work to care for the partner, what of other children in the family, mortgages et. There has to be a financial package involved with this vision. It involves more than loving the partner, life has to be paid for and DHB will have to pay or provide a lot more support.
Q.3 Goals	The goals are fine as long as they bring on real help for carers and sufferers alike. Access to daycare, respite care etc, in home assessment of patients' needs and up to date care information.
Q.3 Goals	Dementia is a fatal condition. The lifetime savings of the dementia patient and their family/whanau may be committed to providing institutional care. No credit is given to the family/whanau/partner by way of tax relief for expenditure incurred contributing to institutional care for the patient thus seriously impacting on the welfare of the family/whanau/partner providing the financial support.
Q.3 Goals	Focus on Carers.
Q.3 Goals	We need to increase awareness in the community about dementia, and increase the level of support available to families, especially those with a younger onset dementia
Q.3 Goals	As a care giver for a person with dementia currently there is lots of information in the early stages but little practical support until there is a graded measure of deterioration. This needs to change. The impact on me was quite damaging mentally and emotionally.
Q.5 Principles	We have an issue with resources. Families often play key roles in caring for a relative with Dementia. They perhaps could receive financial support for this. ... Carer Support appears to be too difficult for some families to manage hence don't use.

Q.5 Principles	Resources where are they going to come from. Pay caregiver…
Q.5 Principles	That support will be given to the family/whanau/support person who contributes to the care of the dementia patient financially or otherwise to ensure their lifestyle is not adversely impacted.
Q.5 Principles	…funding must be included to support families/caregivers in the home…
Q.5 Principles	Dementia is a long journey from the start to the end there needs to be support for those with dementia and their families throughout the process. Me mahi tahi tatou mo te oranga o te katoa, we should work together for the wellbeing of everyone. At different stages of this journey we needed the expertise and skills from different services and it was never easy to coordinate as felt a lot of the time was spent us a whanau having to go and find the information rather steps or processes put in place to make it easier or ongoing support person even though Dementia Auckland did support I think there could have be consistency. It's emotionally hard to go through this then on top having to work through the processes it's been a struggle.
Q. 8 Incidence	Also there needs to be more emphasis on early support for families and community organisations who assist in the initial stage so that the continued support of family is not eroded but strengthened.
Q. 8 Incidence	I agree that we need to promote more about dementia and make our communities aware of the illness and break down the barriers between the health sectors so the families get the right support and care needed. This illness can be isolating for families going through it. I didn't see anything about having support groups in the plan.
Q.11 Living Well	So strongly agree carers need support. I struggle along. Used to have a rep ring simply to check in, & we used to receive newsletters. each contact may seem so small, however, to a carer it is a sign someone cares, and has got your back...due to change of staff, we no longer get these services. Such small input, such a big difference it makes
Q.11 Living Well	Important to notify family of diagnosis e.g.: mother diagnosed two years ago of early onset and none of us got this info. If we'd had it we may have been able to take action that would have enabled mother to live independently for longer ie downsized to smaller place to make capital last longer and get earlier support for medication and help to live independent.
Q.11 Living Well	Need to increase funding for carer support.
Q.11 Living Well	carer Support payments are inadequate and not been raised for probably 20 years. There is also a dearth of informal support people to provide the carer support
Q.11 Living Well	Family members who give up work to support 24/7 need a living wage, this would be cost effective, and at the same time recognise the value of in home family care.

Q.11 Living Well	Financial contributions to the care of dementia patients by caregivers, partners, families/whanau should be tax-deductible.
Q.11 Living Well	What can I say this is ridiculous. Families and Carers need support.
Q.19 Enablers	Sustainable funding does not only apply to workforce providing services but also to families who may be providing services at the cost of their own financial and social wellbeing.
Q.19 Enablers	financial systems which impact on spouses/partners needs looking into as they are crippled when care is not subsidised. They have a life as well and are left penalised.
Q.17 Capability	I have waited till last, to include this thought, and it's to do with the residential care subsidy, which in my opinion is not fit for purpose anymore and I will give my own situation that I am facing soon. [I] have been looking after my wife now for 3 years. She is allowed 2 days a week of respite care which I am very grateful for, but soon I can see she is going to need more professional care than I am trained for. The asset test for the care subsidy only gets the honest people, it seems unfair to me that my wife who has worked as a school teacher, and payed her taxes, and it our case, we have a little bit of asset over the threshold, have to pay extra, when somebody who has never worked payed no taxes, gets the state help straight away, and the people who have over the threshold and simply hide the extra in their children's accounts.. maybe you could look into this... I would like to hear your thoughts on this matter please, keep up the good work that you have started.
Q.20 Overall	Additionally, the financial support available for individuals and families in residential care needs to be reviewed because of the anomalies in the system.
Q.20 Overall / separate	The RANZCP notes these elements are omitted: 6. Carers of people living with dementia - especially Maori From written We also acknowledge the carer burden associated with dementia is significant. We note one of the Plan's objectives is '*to support the family, whānau and care partners [of people with dementia] to live well'* but very often whānau/carers are left to find their own support and information about caring for someone with dementia. It is critical that the carers' physical and mental health is not compromised. Evidence suggests carers are at risk of developing depression therefore programmes and interventions should be designed to support the needs of carers alongside those of the person with dementia[iv]. This is a holistic approach to dementia care that will help the consumers remain in their own homes as long as practicable with the assistance of their carer. Economically and socially it is desirable that people with dementia can live in the community rather than in secure settings. The RANZCP acknowledges the Māori perspective that dementia or mate wareware impacts not only on the individual but their whānau and hapu who have 'a collective obligation' to care for the kaumātua.[v] To provide optimal care for their kaumātua, whānau require practical help and support which is often unavailable. Māori prefer to keep their kaumātua within the whānau rather in residential care, where carers may not understand tikanga Māori. Māori face

	challenges in accessing necessary services thus placing an additional burden on whānau[vi]. We would like to see more in the Plan that describes how carers will be supported in the future vision and we suggest that programmes such as START or REACH[vii] are examined for their applicability within the New Zealand context. The RANZCP notes that many centres do not have adequate public transport and therefore relinquishing a licence prematurely is depriving a person of their liberty, yet on the other hand continuing to drive when not safe to drive is a risk to the individual and the community. It is difficult to appropriately assess these individuals as there is little consistency across New Zealand. The gold standard test in order to determine whether a person is safe to drive is an Occupational Therapist (OT) driving assessment. Access to and the availability of OT assessments remains limited and the funding is variable throughout the country. Given the completing priorities of maintaining public safety and maintaining the independence of people with dementia, we believe a nationally consistent approach is necessary. We suggest the plan sets a timeline for the development of a reliable approach with appropriate resourcing.
Separate	Caring for a person with long-term conditions like dementia, can have a huge, detrimental impact for others on health, wellbeing and financial security, and is a major reason that women give up work or work part time and have far less financial security in old age. Benefits, respite care and other support for carers needs to be considerably increased. Local support and "navigation" and respite care are important, but the proposed actions should also specifically include increased financial support. – New Zealand Council for Women
Q.20 Overall	Dementia is a fatal condition which may develop suddenly or over a number of years so has an unpredictable impact on care givers/family/whanau and other people. The impact can affect the quality of life of persons affected and they should receive support and assistance.
	Involvement
Q.11 Living Well	Family ownership will be needed for success
Q.5 Principles	Had you ever considered the spouse and family in your plans. The impact on partners is immense, lifelong and unsupported. I am not aware that the opinion ex carers is sought nor is there knowledge or experience
Q.17 Capability	Don't just talk about action plans actually implement them. Again listen to all families and their needs
Q.17 Capability	More consumer representation to represent all aspects of who this needs to be made applicable for as this will have the biggest influence in delay onset of dementia.
Q.17 Capability	Don't use medical models & make sure all disciplines are included in the process including input from the families & consumers

Q.20 Overall	This plan should be developed from the lived experience of those with dementia and their carers not health professionals and academics who may embellish the plan with their spin on it.
Q.5 Principles	Responsibility for the well-being of society is paramount. Each of us need to take ownership of our wellbeing and the well-being of our loved ones. There needs to be accountability socially and within families.
Q.5 Principles	we all need to know that dementia will affect us individually and with family, friends and community. Like learning to swim or first aid the ownership of the condition is with each and every one of us
Q.5 Principles	A healthy society with strong ownership, pride of family care will provide the best bases for the above action and plan to succeed.

12.2 The importance of improving respite care options was emphasized.

Survey question	Comments
Q.3 Goals	If carers and whanau are well supported, given time by themselves and respite care then they will be less stressed, and able to fulfil their caring role much better and for a longer period.
Q.5 Principles	… Carer relief hours
Q.5 Principles	… The standard respite time is not enough for some families. Options for respite need to be broader…
Q.11 Living Well	One of the biggest problems at the moment is not being able to book and lock in respite times at a facility. I have heard of many carers who have had to cancel their plans at the last moment (overseas trips, flights, family celebrations etc) as there has been no beds available, even though the time has been arranged well in advance. I find this unbelievable that it can't be booked like a motel and confirmed, as it is so very important for carers to have this to look forward to. A well-deserved break from often 24hr 7 day a week caring for a loved one
Q.11 Living Well	Primary Carers are often wives or women - the burden on them can be huge - the only time they can access respite is if it is available to the person they are caring for - Women and Wives need specifically tailored funding, training, beaks and support
Q.11 Living Well	Need more pre diagnosis support at NGO level for programmes which are inclusive of Mild Cognitive Impairment or where MCI is part of chronic plan in client's lives. increase support hours for pp with dementia living alone and in community. needs to be on par and equal with enabling good lives approach to care. Again Keep Stats of diagnosis as this informs funding.
Q.11 Living Well	Respite care available for people with dementia who lives alone
Q.11 Living Well	Early diagnosis may contribute to already overloaded services and further expose the dirt of supports for whanau - e.g. appropriately sited, resourced respite services with well trained staff.

Q.11 Living Well	Flexible respite options are a must. These careers have a long road ahead and to continue to provide care and not burn out regular and safe respite is vital. With flexible options such as day respite through to longer periods to cover a holiday
Q.11 Living Well	NGOs can't possibly keep providing more & more with less & less. There needs to be more people in the DHB's that provide specialist care as so many do not understand the specific needs. Respite care is not working currently as there are never beds available when people need them as providers of care would rather fill the beds with permanent people. Transport provision is an issue restricting people to live well with dementia. The transport that is available for those who can't drive is very costly.
Q.11 Living Well	I also note that access to respite services is quite buried within these actions. This is a considerable gap in support services for people with Dementia and their carers and I believe there should be a specific action area dedicated to establishing adequate respite services that are available and equitable nationally.
Q.11 Living Well	People using respite services in residential care need to receive the same care as those permanent residents. There needs to be meaningful choices for respite care.
Q.11 Living well	At present there is an appalling shortage of respite beds. Partners and family members lack physical, mental and emotional support to develop strength and resilience to withstand the interminable stressors that consume them when caring for their loved ones.
Q.11 Living well	Offer physical help to families. Train people to come into their homes to help at home by giving them a break. People they can trust with their family member
Q.11 Living well	Respite care is very important for carers and people with dementia to keep up cognitive activities. Funding needs to be extended
Q.20 Overall	Whanau comment that the most glaring gap is in terms of respite beds that are close to home in suitably staffed facilities. I have treated a number of worn out and exhausted partners, whose own mental health has suffered significantly due to the strain of 24/7 care for their partner.
Separate	On behalf of Lakes DHB MHSOP the following comments: There should be funding for people living alone to access a short period of respite at ARC facilities. Currently people living alone do not have access to respite at aged residential care facilities unless they have been admitted to hospital (post discharge) whereas those with a carer (usually family in the home) can be eligible for Carer Support funding. A short period in respite can avoid costly admissions and assist older people to remain home for longer. This has been seen on many occasions when mental health crisis funding has been used. The short period of respite provides improved nutrition, assists in re-establishing routines including sleep, socialization and medication oversight. Often other minor ailments are also identified and resolved.
Separate	…Commissioned planned accessible respite care … collated feedback from the national MHSOP leaders

Separate	Discussion re DSL clients with dementia diagnoses who have been funded for Carer Support days are in some areas of the Coromandel unable to go to a respite care facility in their local area and sometimes further afield due to insufficient respite beds. Some care facilities are now reluctant to offer respite bed booking a few weeks/months ahead of time as priority is given to offering bed space to residential clients. Some areas in the Coromandel also have reported lengthy wait list times for people to attend Day Programs. Best option: setting up more WDHB Respite Beds in Residential Care facilities (we understand this was the case in the past when the DHB effectively 'purchased' respite beds). Day Programs: discussion re which other organisations could provide day programs. In parts of the UK-Social Services provide day programs. Sharon (Bupa) discussed how Day Programs are a very costly service to provide. Some clients who attend day programs eventually enter that facility as residential care clients. Sharon discussed how more people with a dementia diagnosis are being cared for at home for longer length of time than previously. The impact of this for Bupa Care facilities is that clients are entering residential care with higher/more complex health needs and their length of stay in residential care facility is shorter than previously. Howard discussed: if given additional funding/resources Dementia Waikato is would be well placed (knowledge & experience) to offer day programs. However current funding of day programmes would not suffice (Residential facilities indicated they are subsidising the true cost when providing day programmes) -Thames Agewise
Q.19 Enablers	More employment in Community care support should be made available and more social day stay hubs should be created.

12.3 Family supporters were emphasised as another priority target group for education

Survey question	Comments
Q.3 Goals	I would recommend at local health board levels a clear, well managed coordination of various 'pathways' of support and education for caregivers. Our journey seemed to be evolving and we finally accessed at least 4 pathways of support, it seemed by accident. I was very grateful, but it was stressful finding out how the systems and the 'professional language' worked.
Q.3 Goals	The goal is great, however I feel that there is not enough education on Dementia for the whanau members and close friends who care for their Mother or Father. A lot of families do not understand the effects, what to look for, the signs of Dementia. Once the family members understand what and how dementia occurs then the family can come to accept dementia is a disease.
Q.3 Goals	To ensure there a community element in both, with both training, education and this being accessible to all communities and cultures in NZ.
Q.5 Principles	Access to free learning and understanding on Dementia for the person suffering this terrible condition as well as family, friends and caregivers.
Q.8 Incidence	There needs to be some educative information available for those who think they or a family member might be experiencing dementia and how to access services in addition to prevention messages.
Q.3 Goals	accurate and well-presented education is needed for all members of the community - it is only through education that people will get a good understanding of this disease, how to work/live with it and support members of the family/community that are facing life with dementia.
Q.11 Incidence	Education, I feel is the key to proving effect[ive] services, or a dedicated group of people insuring that everyone knows what services are provided to ensure the clients are referred to all people who provide services… Often services are available but the person/caregiver is not made aware that the services exist. This can be because the person referring them is not aware of the services, the caregiver does not pick up on the fact the service is available. When the person is first diagnosed shock and grief are major issues for both the person and their family. Often they are given information that they do not take in at the time. If this is not revisited they can miss out on necessary information about available services. People are busy, clients can drop through the cracks. Often in the elderly you have one elderly person as the main caregiver for their dementia impaired partner. This can have a major impact on the health and wellbeing of both.
Q.11 Incidence	Realistic education about late stage dementia

Q.19 Enablers	need to show that the sector is powered by volunteers and while they're part of the workforce - workforce often implies they are paid
Q.19 Enablers	good training/impartation of knowledge is imperative and not just for "professionals" but the untrained/ carers in community and facilities and for whanau/family
Q.19 Enablers	Family members may also elect to take training if possible.
Q.17 Capability	Training and upskilling for the important but less visible family and whanau carers and other volunteers in the wellbeing sector (eg Aged Concern visitors) must also be given priority in this Plan.
Q.20 Overall	I would like to see more education/information sharing for those who support those living with dementia
Q.14 Communities	Alzheimers education should be part of community health literacy programmes. Many people do not know where to start to find information when they suspect a family member may need help. It can be hard to know when to seek a diagnosis.

13. Equity and diversity

Overarching theme

There was concern about the appropriateness of the unspecified process for gaining a kaupapa Māori insight, and a recognition that the Plan needs a clear and compelling approach to ensuring equity.

13.1 **There was concern about appropriate processes and commitment to ensure Maori responsiveness.**

13.2 **Some respondents emphasised equality and consistency.**

13.3 **There was a strong call for equity, flexibility, and responsiveness.**

13.4 **There were suggestions about additional special groups to include.**

Māori Responsiveness

The preamble to the draft plan stated that "A separate process is underway to engage with tangata whenua …to design a dementia action plan for Māori….[[that may stand] alongside or inside the national action plan". Some respondents felt unable to assume the validity of this process, and there was a strong theme emphasizing the importance of an appropriate process to ensure the action plan incorporates a solid kaupapa Māori base.

Equality

Some respondents emphasised equality and equal treatment for all.

Equity

From many others there was a strong call for flexibility and equity to be addressed across the plan including:

a. a perception amongst some respondents that the draft action plan gave mixed messages about equality and consistency versus equity and flexibility
b. the need for cultural partnerships and responsiveness, particularly when attempting to build supportive communities or develop campaigns to promote brain health
c. allowing flexibility across regional needs and recognising that equal/ consistent services may be a problematic goal for rural areas

Inclusion

There were suggestions for additional special groups, including the prison population.

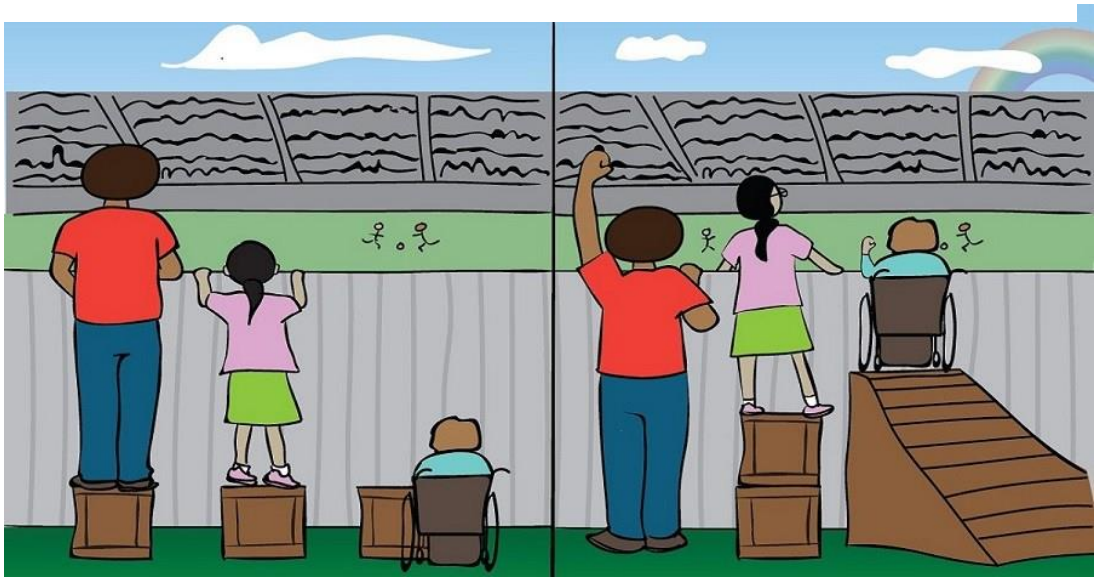
13.1 There was concern about appropriate processes and commitment to ensure Maori responsiveness

Survey question	Comments
Q.3 Goals	The plan would benefit from … the clear consideration of Kaupapa Maori approaches to dementia -> greater discussion regarding changing nature of older population e.g. CALD populations and Pasifika
Q.3 Goals	Please ensure that the plan is developed with the guidance and support of tangata whenua it order for it to be effective for Māori. If you don't go through this process it will be benefit our community in the long term.
Q.3 Goals	Te Ao Maori needs input into the action plan. A representative from a Maori community must be involved
Q.3 Goals	… the specific needs of Māori and Pacific communities should be integrated to a great extent, in reflection of the unique impact of determinants of health which impact on dementia, such as socioeconomic status. This will be increasingly important in the years to come, as the rate of growth of people aged 65 or over for Māori is predicted to be far greater than that of non-Māori. Practically, in the vision statement, this should be implemented by the replacement of the reference to equality, with equity and with specific reference to the social determinants of health.
Q.3 Goals	The plan would benefit from … the clear consideration of Kaupapa Maori approaches to dementia -> greater discussion regarding changing nature of older population e.g. CALD populations and Pasifika
Q.3 Goals	Please ensure that the plan is developed with the guidance and support of tangata whenua it order for it to be effective for Māori. If you don't go through this process it will be benefit our community in the long term.
Q.3 Goals	The plan needs to be designed centred on the voices of people affected by dementia, be consistent with the UN Convention on the Rights of persons with Disabilities and honour the Crown's special relationship with Māori under Te Tiriti o Waitangi.
Q.5 Principles	Definitely Te Ao Maori input including principles from Te Tiriti o Waitangi. Do we have someone on this board or group from the community?
Q.5 Principles	I'm Maori and though mum isn't I agree Maori kaupapa is critical for the development and design in services and programmes. Dementia affects the Haoura taha tinana, taha hinegaro, taha wairua and taha whanau if all these areas are supported not just for Maori families but other cultures or minority groups then that is everyone working together for everyone.

Q 5. Principles	Although I think Maori health practice is best practice, there is a very small percentage of people that will understand it in Maori, so care needs to be taken with wording- and being a multicultural nation it is important to remember that people with dementia often go back to their native tongue at end stage- regardless of how long they have been in NZ.
Q 5. Principles	I hope that Kaupapa Maori will be included in the New Zealand Dementia Action Plan not as a separate document. The Plan must be inclusive of ALL New Zealanders.
Q 5. Principles	While I absolutely agree that the Treaty Principles and Māori kaupapa must be included in the strategy - that should not detract from the goals of the strategy so that it is a box ticking exercise to appease government sector thinking rather than including kaupapa Māori as a supporting principal to achieve the strategy goals.
Q.20 Overall	I would have liked to see a draft document regarding the dementia action plan for Māori released alongside this draft action plan.

Supplementary information for

12.2 – 12.4 Equality and consistency versus Equity and flexibility



Equality is treating everyone the same. Equality refers to equal opportunity and the same levels of support for all segments of society

Equity is giving everyone what they need to be successful. Equity refers to varying support depending on needs, to achieve greater fairness of outcomes. It recognises that not everyone starts at the same place, and not everyone has the same needs.

Amy Sun, Diffen; Picture: Maryam Abdul-Kareem

13.2 Some respondents emphasised equality and consistency.

Survey question	Comments
	Emphasises equality
Q.5 Principles	Everyone regardless of age, gender or race have the same access to help available.
Q.5 Principles	Doesn't matter what race, creed, care for everyone who needs it.
Q.5 Principles	Dementia journeys span across diverse cultures as their personal and collective familial journeys are often grounded from their beginnings. Dementia shows no bias, everyone is equal in their need to be cared for with respect, patience, empathy knowledge and humour.
Q.5 Principles	…The people listed as unique needs are part of the population of NZ, and everyone's journey in dementia is special and each person with dementia is special to their family and friends.
Q.5 Principles	Specific populations - not sure why this is required - groups to be specified - if we are wanting care to be equal to all why do these specifics need to be included?
Q.5 Principles	Why make things complicated having sub-services specific to culture, impairment or sexual preference etc? The same service for all, keep it tidy.
Q.5 Principles	We need a new way forward not one pandering to individual cross sections of the community. Your ideas are too politically correct and will tie implementation up masonry [sic] progress slow and possibly in the washing [sic] direction. We need a new paradigm not a revision of hackney politically correct statements
Q.17 Capability	Equality amongst all New Zealander's regardless of the race or creed. Be sensitive to all cultural differences is the right thing to do.
Q.17 Capability	Investment in research needs to apply to all ethnic / cultural groups due to the existing multi-cultural diversity / planned immigration being considered in the future. "Describing dementia" is no different in one cultural group, and every individual is unique regardless of which cultural / religious / ethnic group a person belongs to. Dementia is a condition which knows no boundaries, therefore its approach / management should not be limited to particular cultures.
Q 5. Principles	We are ONE NATION ..... Dementia should be approached with a united and unified approach. The Action Plan should be ONE system for delivering dementia services support to the whole country. Due to the significant multicultural nation we are, to consider having a separate

	action plan purely for Maori may contribute to discrimination / segregated / disjointed / two - tiered care delivery depending on which cultural / ethnic group is being supported.
Q 5. Principles	We are a multicultural nation so while the needs of Māori need consideration it should not be at the disadvantage of other cultures
q.17 Capability	We need to support all, not just non pākehā -, many people do not know what dementia is or have to cope or understand it. It should be the same for everyone. Again, services need to be in place to do this that are not there at the moment. The government needs to take more responsibility for this in the community, DHB and aged care setting as it is beyond crisis point now.
Q.20 Overall	This also applies to groups with different needs to the majority Pākehā population - instead of describing people as having "unique needs" (and therefore somehow different to the "norm"), the document needs to be more inclusive and recognise that all individuals (including those within Pākehā populations) have individual needs (some of which are shaped by their culture, others by their personal circumstances).
Q.20 Overall	We are ONE NATION ..... yet we are all individuals with unique gifts and qualities. If we approach dementia with a united front, and offer support with fairness and equality, resources will be more easily available and accessed by people. As a side-line:- The current ACC system is a classic example of inequality functioning at it best. Funding for medical or surgical problems / issues caused by medical problems is limited, as opposed to the readily accessible funding / support available to ACC patients. The whole health system needs review ...perhaps it should start with ACC. In addition to the above statement: - If ACC was not available to visitors to NZ, further funding would be available to support people with dementia.
	Emphasises consistency
Q.5 Principles	We need to be offering consistent services across NZ, providing evidence based care, rather than the ad hoc nature it is at the moment
Q.5 Principles	Our experience is that local support is limited in services provided due to poor local direction
Q.20 Overall	I have experienced differing levels of services between our former place of residence and our current one. At first when we moved there was a delay of more than a month to be able to enrol with a G.P. Then another few weeks before an appointment. Once seen by the G.P. referrals were made to local services, and very good assistance was provided. I am grateful for the care and assistance received in Taranaki, our new home.
Q.20 Overall	It will be great to have consistency. Living in a small rural DHB we often struggle with resources to meet the needs of our dementia clients especially when carer / support person wishes to attend support groups etc. often they are unable to do so as there isn't anyone available to support the carer

13.3 There was a strong call for equity, flexibility and responsiveness

Survey question	Comments
	Clarifying equity vs equality
Separate	There needs to be a greater clarity in the way equity (vs equality) and 'specific groups' are framed and conceptualised The Australian Aged Care Diversity Framework would provide a very good role-model https://www.health.gov.au/resources/publications/aged-care-diversity-framework
Q.3 Principles	The principles identified for inclusion in the New Zealand Dementia Action Plan are thoughtful, forward-thinking and largely in-step with the direction of Aotearoa New Zealand's health system. Despite this, the thinking described within the equity and specific populations principles needs refinement if it is to embed Te Tiriti o Waitangi and the needs of increasingly diverse communities impacted by dementia in Aotearoa New Zealand. Equity in the Aotearoa New Zealand health system for Māori and Pasifika people means access to culturally safe services which are designed and delivered. In Aotearoa New Zealand's health system as it stands, in many situations this will mean access to services provided by Māori and Pasifika health practitioners, for Māori and Pasifika people with dementia and their whānau. The equity principle proposed here does not reflect this reality with its focus overall focus on universality, especially the section that refers to 'whoever delivers the services': rather, the Equity Principle in the draft document uses Equality (everyone has access to and receives the same care) as its conceptual basis, as the draft Principle does not reflect the structural biases and injustices that perpetuate inequity.
Q.5 Principles	There should a clearer link to how these principles correspond to the selected objectives and actions. e.g. equity is identified as an important issue, yet this isn't strongly reflected in the selected objectives and actions.
Q.3 Principles	•The Equity Principle describes 'equality' rather than 'equity' and as such is not an equity principle. For example – delivering the 'same high quality health and wellness outcomes' is contrary to the concept of an equitable approach where disadvantaged or deprived service users are given priority advantage to achieve the same outcomes

Q.19 Enablers	If the resources are allocated equitably - is this according to your current principle which argues for equality rather than equity
Separate	[In goal replace] dignity, respect, and equality with Dignity, respect, autonomy and equity …2 aspects of equity: equity across population / equity for people with dementia and others Deliver high-quality health services designed and delivered to achieve equity of wellness outcomes whatever their ethnicity, circumstances…ethnicity, rural etc) and equity for people living with dementia with others
	Flexibility / cultural responsiveness
Separate	The primacy of importance of the strategy reflecting Te Ao Māori throughout and being guided by the principles of Te Tiriti o Waitangi is acknowledged and wholly supported. It is also important to reflect on epidemiological data from New Zealand which suggests we will also be seeing greater ethnic diversity in the over 65 group in New Zealand for Pasifika and CALD populations. Greater specificity as to how we will meet these populations needs would also be welcomed. - NZCCP
Separate	Specific populations- we particularly support the recognition of specific needs of groups who already are disadvantaged in the access to health care and are at risk of misdiagnosis because of existing conditions. -National Council of Women
Separate	…Need for more equitable access and subsidised funding for speciality services i.e DTA… - collated feedback from the national MHSOP leaders
Q.11 Living well	Specific commissioning needs to be developed in partnership with community providers, local Iwi, and relevant health providers. This will mean a locally designed approach not one size fits all. There is a danger of this being taken as a national model, when local models are needed.
Q.19 Enablers	It will be important to consider models of care that support the specific groups of people that the Plan has identified and that the measure consider the unique regional and cultural contexts of New Zealand.
Q.19 Enablers	Recognise the needs of different populations throughout the country.
Q.19 Enablers	We need to build into this approach a culturally flexible approach. Dementia is experienced differently by different cultures.
Q.14 Communities	Stigma is seen mostly in socially isolated groups for example Asian communities. Older people from Asian communities are by far the fastest growing population and yet many do not use traditional NZ media.

	Use videos of whānau talking about dementia form different ethnic groups. And use other media such as WeChat, Pacific Radio Network etc
Q.14 Communities	The priority needs to be consultation with Maori as Tangata Whenua and with representatives of the various Pasifika communities and migrant communities. Flax roots up!
Q.14 Communities	Yes absolutely agree with a fully strong multipurpose multi culture not only heritage culture but social service culture, multi-language and include prison and gang support as well. Very important for our country
Q.14 Communities	Programmes promoted should be consulted with local Māori and incorporate themes and values of te ao Māori to make it NZ specific.
Q.14 Communities	In the campaigns remember to represent the minority groups.
Q.14 Communities	One size doesn't fit all. Any planning and service provision needs to be flexible: families and communities and affected individuals may all have divergent needs.
Q.14 Communities	The RACP strongly supports the identified actions and objectives for building accepting and understanding communities. However, these could be bolstered by supporting the development of Māori and Pasifika whānau and communities' capacity to care for people suffering from dementia.
Q.14 Communities	Please ensure that medical professional are aware of needs of different interventions - To be aware of need to change their practise to suit person. Like Deaf Community
Q.14 Communities	Stigma is seen mostly in socially isolated groups for example Asian communities. Older people from Asian communities are by far the fastest growing population and yet many do not use traditional NZ media. Use videos of whānau talking about dementia form different ethnic groups. And use other media such as WeChat, Pacific Radio Network etc
Q.14 Communities	Need to be careful to include more diverse community approach to decisions around this
Q.17 Capability	We need to recognise that there are cultural perspectives on dementia that need to be built into any national programme. Our western medical model attitude does not work across all cultures in NZ. It does not work for many Maori and also for some other cultures.
Q.17 Capability	Pleased to see recognition of NZ's variety of cultures in the last point. Good to get learnings across different cultures to improve outcomes for all New Zealanders.
Q.17 Capability	Stewardship and accountability must include local iwi and hapu.
Q.17 Capability	Refugees and migrants must be included all the way.
Q.20 Overall	As previous --' inclusion of refugees and migrants via comprehensive consultation
Q.20 Overall	Pacific Island people [in] their churches.

	Educating their leaders to lead a healthy lifestyle for their people.
Q.20 Overall	Generally, the document represents a coherent vision for the future of dementia services in Aotearoa New Zealand. However, it is lacking in a vision that adequately conceptualises and caters to Māori and Pasifika communities, and further work is required in this area if the New Zealand Dementia Action Plan is to be truly relevant to the context of our health system.
Q.5 Principles	As we are a multicultural country we need to have that written in there.
Separate	I think it's a good idea for Māori to have a dementia organization of their own so that it can be run according to their cultural approach. The specific needs of the other groups could [be] addressed in a similar way.
Q.5 Principles	Specific populations - I fully support this principle, but think it needs to go further. Not just services, but the whole system (health, NGOs, MoH) needs to "recognise and respond appropriately etc...." We may need solutions other than Dementia service providers to meet the unique needs of these special groups with appropriate resources and research to determine and provide the solutions. For example, inequity already exists for special groups and is likely to be compounded in small places with small numbers of people within these special groups which may make it difficult for services to respond and for people within these special groups to feel their needs are met because they are isolated and not connected to others in their special group with dementia (This could be true for carers of these people also). This principle needs to reflect that a system-wide approach is required that allows development of ways to connect people and carers within special groups (e.g. IT solutions - blogs, chat groups, special sections on Dementia NZ/ Alzheimer's NZ website that pertain to their group with resources and links to information and support pertinent to their respective special group. Services could also access information and a toolkit of best practice for providing services to people within special groups). This may be covered partly under an action point further on in the survey with respect to research and special groups which would allow the development of these solutions to better meet their unique needs. It could be argued that these solutions like blogs and online support groups may be classed as services and so would be covered under the principle as it is written. My comments may pertain to the actions required but I do feel it is more than services that need to recognise and respond appropriately.
Q.5 Principles	A lot of work needs to be done for specific populations. This should be beginning now at MOH level as I see a lot of replication of services.
Separate	…Need for more equitable access and subsidised funding for speciality services i.e DTA… - collated feedback from the national MHSOP leaders
Q.5 Principles	Like the inclusion of principles around equity and inclusiveness of specific populations.
	Brain health

Q.8 Incidence	needs to be holistic and culturally appropriate.
Q.8 Incidence	I feel that any work on reducing the incidence of dementia needs to recognise that the NZ population is not one homogenous group, and that the risk factors for developing dementia are therefore likely to be different across various ethnic groups as well as likely socioeconomic status. As such any approach to reducing the incidence needs to cater to the needs to the different populations, and research is needed to identify 1) whether the risk factors vary and 2) how best to implement any approaches to reducing risk.
Q.8 Incidence	There is a need to develop programmes which are tailored to different cultural groups
Q.8 Incidence	The RACP believes that the identified actions have the potential to reduce the incidence of dementia. However, this could be further bolstered by targeting of action to the communities most at risk, and further utilisation of the social determinants of health in determining this.
Separate	We [NZCCP] concur that this should be an overarching objective. However, there needs to be an acknowledgement that the epidemiology of dementia is a growing problem and transverses sectors including but not limited to industry, health, and sport. There is very little epidemiological research that is based in New Zealand specifically which help us to understand the inequities in or the drivers of dementia for the New Zealand population. We feel that the action to invest in epidemiological research, identified later in the strategy, should be a primary action for this objective.
	Regional flexibility
Q.5 Principles	Consistency within services is important however I do support that some regions may have additional services beyond this and this service provision should be supported as long as they operate within guidelines and policy.
Q.5 Principles	Whilst we have a DHB system where communities are supposed to influence priorities and service development some inconsistency is inevitable, and indeed desired
Q.5 Principles	Consistency - we need to allow for variations in what and how services are provided in different locations that have different needs. But need to avoid this becoming an excuse to provide inadequate services in some areas, especially remote and rural.
	Rural may look different
Q.5 Principles	Then principles sound great but maybe not always that easy to act on. e.g. you wouldn't be able to guarantee people living in isolated areas would have qualified people available to help.
Q.5 Principles	How will the principles be measured & monitored? Currently people are expected to fit into the services provided rather than the providers meeting the needs of the people living with dementia. I have seen the impact on this taking away from the ability for these people to have their social needs met as their care needs are not met in a timely manner. How will consistency between rural & urban areas be provided & measured.

Q.5 Principles	Probably the most difficult to implement will be that the highest level of care be available wherever people are living - however, it is probably the most important...
Q.5 Principles	Accessibility is more relevant than equity. I agree with all demographics but rural location is very difficult to achieve equity for living with dementia. I however agree that all DHBs need to have continuity of care.
Q.5 Principles	. if you live in a remote location you cannot expect the same level of service as applies in a main city. Fact. don't fight it - esp. when you consider rural communities have other things like lifestyle as a bonus.
Q.5 Principles	Those in rural areas can feel isolated but now that is starting to be addressed by ensuring enough trained professionals available to work within those areas

13.4 There were suggestions about additional special groups to include.

Survey question	Comments
Q.20 Overall	The RANZCP notes these elements are omitted: People with dementia in the care of the Department of Corrections From written: The New Zealand prison population will change rapidly over the next ten years with far greater numbers of prisoners over 65 years of age. General prisons are not geared to manage physically frail, old-age prisoners nor those with psychiatric disorders including cognitive impairment and dementia. Staff may not be adequately trained to understand the appropriate care and management of an offender living with dementia e.g. acknowledging that an individual's behaviour such as failure to adhere to the prisons rules and regulations may be due to cognitive decline. Dementia within the prison populations seems to be overlooked in the Plan and we suggest some attention is given to developing strategies supporting this vulnerable population. We suggest the strategy addresses screening, diagnosing and caring for prisoners with dementia.
Q.5 Principles	Re: Specific populations - there is an increasing number of people in prison with dementia. They need to be included in this group
Q.5 Principles	Under specific populations add people in prison as they are another high-risk group with special needs. See Christodoulou, M. (2012). Locked up and at risk of dementia. The Lancet Neurology, 11(9), 750–751. doi:10.1016/s1474-4422(12)70195-3
Q.20 Overall	I would like to see People with Parkinson's included as a special interest group
Q.5 Principles	Specific population also includes people with Parkinson's. Recognition that Dementia is a symptom of progressing Parkinson's and that transfer from PD specific care to dementia care is not always appropriate and can be distressing.
Q.5 Principles	While the overall goal is OK there is still need to acknowledge there are disparities - not just for Maori/Non-Maori but also for those living in poverty. I think the goal should reflect this.
Q.5 Principles	Also "Specific populations should include people living in isolated areas and those who have no whanau support or are socially disconnected
Q.5 Principles	People who have other multiple medical co-morbidities / issues along with dementia need to be included in the "specific populations" statement ..... my father is one of these people.

Q.5 Principles	Although Kaupapa Māori is identified as its own principle, Māori should also be identified as a specific population group.
Q.5 Principles	specific ages groups should be recognised and dealt with according to their age also.
Q.5 Principles	Specific conditions should also include vision impairment and brain injury
Q.5 Principles	I think in the design of services there need some specific focus on the different types of dementia - age related, intellectual disability, mental health and addiction related as they have different needs, required different approaches and resources.
Q.11 Living well	Consideration needs to be given to those who are homeless as their access to services becomes even more fragmented than others. e.g. will care be provided to people who might be living in emergency accommodation???
Q.17 Capability	Someone needs to be strongly involved with those on addictions. Gang relationship. Social service realm, we cannot forget this area of community
Q.20 Overall	The RANZCP notes these elements are omitted: Alcohol use and dementia From written: Evidence suggests that many older people tend to regularly drink alcohol, with a small percentage drinking hazardously. There are concerns that in the future the proportion of older adults drinking hazardously may increase as the 'baby boomers' have a more liberal view on alcohol consumption. Studies indicate older people have particular risk factors that increase their propensity to consume alcohol e.g. bereavement of spouse, living with pain. Alcohol dependency or hazardous drinking may aggravate or complicate a person's dementia therefore it is important that health professionals, carers and providers are aware of this potential complexity when working with people with cognitive decline. Alcohol misuse can delay or confound a person's timely diagnosis of dementia resulting in misdiagnosis or their symptoms being overlooked[viii].We suggest that the Plan acknowledges the interrelationship of alcohol and dementia.

14 Stake-holders

Overarching themes

There was an overall theme related to ensuring that no part of the puzzle was left out – with calls to prioritise and include across living settings, disciplines, and sectors.

14.1 **People living in their own homes were emphasized as a priority.**

14.2 **Residential care was also emphasized as a priority.**

14.3 **There were reminders that a broad range of stakeholders are relevant.**

14.4 **GPs were seen as a key group.**

People living in their own homes

Some respondents emphasized the role of home-based support and enabling people to live at home. As noted in section 12 supporting family care-partners was a major theme throughout the feedback.

Aged residential care

Some respondents emphasized the importance of residential care, and the adequate resourcing of this as a priority.

Broad

There were also reminders that key players in achieving the plan include groups outside dementia-specific health services, ranging from business and community sectors to the volunteer sector.

There was advocacy for recognition of the importance of Diversional and Recreational Therapists.

As noted in 11.2 care workers were emphasised as priority area of the workforce.

GPs

Many people emphasised general practitioners (GPs) as a key, particularly for the diagnosis objective of living well.

14.1 Supporting people living in their own homes

Survey question	Comments
Q.3 Goals	The challenge is in the practice, integration, education and to place more emphasis on social, financial and care-giving, well-being and flexibility around supported living. In home support is not comprehensive when it focuses on showering and medication. Health model focus is not working for most people let alone those with dementia The service delivery is questionable
Q.3 Goals	The service the DHB's provide need to be more flexible for these clients. Maybe look at Restorative Model again. Care workers require further ongoing training and the service provided needs continuity. Having a different Care worker each visit at a different time doesn't work.
Q.3 Goals	adding that care to be in their own home environment for as long as possible
Q.5, Principles	cheaper to keep people at home with whanau support surely - invest in the care in the home
Q.11 Living well	It is important to provide support for remaining at home and in one's community
Q.8 Incidence	The Kaiawhina Workforce Action Plan will support the Dementia Action Plan with its workforce priorities in prevention and health promotion of dementia prevention/ brain health protection.
Q.11 Living well	The provision of funded services to people is too rigidly applied by some NASC services and my practice experience is that there is little flexibility to meet needs of people who can manage ADLs but not IADLS.
Q.20 Overall	More flexibility is needed in the allocation of home based services allocated by NASC services.
Q.17 Capability	I support these objectives with the proviso that people where ever possible receive not ‘adequate’ support, but great support, preferably in their own home if this is what they wish. This will most likely be less expensive than providing rest - home and other institutional care. Putting the person first and accommodating their and their loved ones’ wishes should be paramount. I realise that this will be a paradigm shift! Also is dementia just a DHB issue - it is as much a social issue, as is any other mental health issue. A safe accepting community where people are valued beyond their contribution to the economy would provide a good living environment for all citizens.
Q.20 Overall	Timely services are important to prevent a crisis. Once a crisis it is difficult and expensive to resolve.

Q.20 Overall	When my own Father was diagnosed with dementia I then began to realise how we as a family struggled with getting help in times of emergencies whilst we all wanted my Father to be at home. Weekends and nights were the moments we needed help and often this was not available. The availability for being assessed took long and only when we had an absolute crisis my Father was admitted into care. That is why I suggest that a 24/7 community dementia service is a must need to families caring for someone living with dementia. A very understanding and well trained team should look after communities of people living with dementia so they know the dementia journey of the client and the family and client is known to each other. This should be available 24/7 Often when there was a crisis in my family situation we had to call police and then a crisis team would come out who were unknown to my parents which created lots of stress. The support team should 'travel' with the clients dementia journey from beginning to the end.
Separate	Concerns over clinical oversight of the care of people with dementia, appropriate environment and community supports - collated feedback from the national MHSOP leaders
Separate	**Support people living with dementia and family/whanau and carers to live well**-this is possibly the most important yet challenging objective and where there can be tension or a mismatch with other policies. The Government aims to keep people living independently and out of residential care, but this can lead to social isolation, a driver and effect of dementia for those living alone. Local support groups can play a vital role here.

14.2 There were calls to emphasize and support residential care

Survey question	Comments
Q.3 Goals	Secure units staffed adequately with trained staff
Q.3 Goals	Extra staff at care homes. Not just 1 carer per 10 residents. This needs to be in line with residents increasing needs.
Separate	Safe staffing levels in aged residential care to meet the needs of those on Psychogeriatric and dementia care units, stipulated nationally beyond the hospital level standards of care and guidelines - collated feedback from the national MHSOP leaders
Q.20 Overall	I have worked in aged care and had a father with dementia. From the care giving side carers need more specialized training and resources. Caregivers need more time to spend with clients for proper care to be given mentally and physically. In some rest homes 8mins per client is not enough time. As a family member we need to have more access to speak with medical professionals when we have questions. Once a care plan is in place 6 monthly reviews aren't enough if u are worried about changes in a family member. Doctors in particular do not seem to have the time or make the time to discuss options with us. Some families give up trying and don't understand they have rights to information. Families first.
Q.5 Principles	Rest home private hospital staff have more training to understand dementia. Secure units are staffed to ensure mental health needs are met, not just physical health
Q.20 Overall	as a caregiver in secure dementia units for over 8 years I would love to see the residents go back to being treated with respect and dignity not as a profit making number. Have left the industry due to the lack of care we were able to give and the reduction of staff implemented making it unsafe for residents and staff. These residents deserve to have a life where they are just not a profit making number but a person in their own right
Q.20 Overall	Dementia care homes should solely be for people living with dementia and compulsory training and practical experience should be a must before working on the floor with these special people.
Q.5 Principles	Rest home private hospital staff have more training to understand dementia. Secure units are staffed to ensure mental health needs are met, not just physical health
Q.17 Capability	ARC facilities are often poorly designed and resourced to best meet the needs of residents. The current business model does not align with any dementia care principles. Facilities are often staffed with under qualified staff expected to provide specialist care to vulnerable people.

	There is often poor frameworks for training and education and an over reliance on DHB staff to support. This is double dipping as the facility are funded to provide care but are often I'll equipped to do this so the DHB will end up providing support to a private, for profit organisation when they cannot manage. The frameworks for staffing levels are poor and provide an equivalent of just over an hour per day per person of 1:1 care.
Q.3 Goals	There is no mention in the plan for the need of secure dementia facilities nor the funding that goes to the providers of these from the DHBs.
Q.11 Living well	The care facilities require more funding development to give those with dementia the appropriate care and make it client centred
Q.5 Principles	Should include the need to provide secure residential living options when this is called for.
Q.11 Living well	This support needs to also be provided to aged residential care facilities so that can provide the best support for the individual. The NGO support should also be available to residents that are needing residential care and supports for the families of these people
Q.19 Enablers	The continuum must include residential aged care and be adequately resourced.
Q.3 Goals	There could be more about how to support people with dementia and their families/whanau who are living in residential aged care.
Q.11 Living well	A large number of people in residential care have MCI or dementia from mild through to severe - I would like to see an action around working with aged residential care to continue the living well with dementia principle through aged residential care - it seems that there is a gap in the principles in the space between living at home with support and dying with dementia. There is currently a number of people living within this space, and the Dementia Action Plan needs to be inclusive of assisting them to live well as well
Q.11 Living well	For those people with dementia living in residential aged care, they require more than just end of life support. People with dementia don't just die with dementia in aged care facilities, they also live there. There needs to be a specific objective about improving quality of life, integration with activities and services outside of the aged care facility. There needs to be an integration of non-medical social care for those in aged care along with excellent clinical care. Examples include intergenerational integration, increase volunteer support, and increased mental and social care support.
Q.17 Capability	And where does the Aged Care sector fit in?
Separate	Inadequate support and care planning: When a person enters a secure dementia facility medical details are taken and their pills are carefully locked away and carefully administered at appropriate times. Then a large amount of detail is written about them as a person, their likes and dislikes, what they would enjoy, what makes them feel connected to life and others and what doesn't. Well I have never seen that information it again. It is person-centred information, something the medical profession, in our experience, regards as irrelevant. More recently in the not-for-profit rest home I was able to speak with the OT about my husband's personal care plan. I was advised that most family members are not interested in

	this part of the plan. Families need to be made aware of the importance of this aspect of information collected on behalf of their family member. I was never told about it by anybody at any time. I am told that remotes can't be kept safe in a secure dementia rest home because there are too many people wandering around picking things up. Well, the patients don't get into the medicines. Having worked in schools where are remote may be shared amongst 35 teachers and classes in one week, it was used and then locked away for the next person. Like the medication, it was never lost. It's a matter of values and a healthy culture… As part of their training, I think every GP needs to spend a week in a secure dementia facility sitting a doing nothing much for a week. It would be an interesting experiment to see how their mind coped with the conditions that many secure dementia patients are enforced to cope with for months on end.
Separate	The focus of HDC's response is on the health and disability services provided to people living with dementia in aged care facilities. HDC supports the development of a plan that will improve the lives of people living with dementia into the future, and we see it is an important health and disability service priority for government. HDC is New Zealand's independent watch dog for the rights of people who use healthcare and disability services. HDC's primary vehicle for protecting those rights is by resolving complaints about those services. HDC received 2350 complaints in the last financial year. Approximately 5% related to services provided to consumers residing in aged care facilities. This percentage has been relatively stable over the past decade. Of the 122 complaints HDC received about residential aged care services in 2018/ 2019, 10% related to services provided to consumers receiving care in dementia units. HDC completed a comprehensive analysis of complaints received about residential aged care over the five year period from 2010 to 2014. The report is published on HDC's website at the following link https://www.hdc.org.nzinews-resourcesisearch-resourcesiother-reports/residential-aged-care-complaints-to-the-health-and-disabiIi ty-commissioner-2010-2014/. The findings from this in depth analysis of complaints about residential aged care services, complemented by an analysis of complaint trends over the intervening five years, suggests a particular focus on services for people living with dementia is increasingly warranted. The findings have been consistent over time. In itself, the small number of complaints HDC receives about dementia services may well indicate this population group is particularly vulnerable and less likely to bring their concerns to the attention of others. Similarly people living with dementia may well not have family and friends to consistently advocate on their behalf. As such the system must be sufficiently robust to protect the rights of people receiving these services. Focusing specifically on the complaints to HDC, although modest in number, issues raised included: • The skill and aptitude of staff to support people living with dementia and meet their complex needs. On rare occasions consumers were the subject of abuse and neglect, be it as a result of physical assault by a staff member or other consumers • The management of challenging behaviours. This included the prescribing and administration of anti-psychotic medication and the application of physical restraint without adequate informed consent • Instances of undiagnosed injuries (sustained as a result of falls and the likes),

	with the consumer less able to articulate pain and discomfort. Further to the list of issues raised in complaints to this Office, supported decision making and informed consent are matters of particular interest to HDC. The Commissioner recently published a report entitled "Health and disability research with adult participants who are unable to provide informed consent" which recommended changes to the rules governing the circumstances when health and disability research can occur. The report published on HDC's website at the following link https://www.hdc.org.nz/your-rights/about-the-code/research-with-adults-unable-to-provide-informed-consent/ highlights that consumers who are unable to make informed decisions for themselves are particularly vulnerable to abuses of their rights and interests. To conclude, HDC supports the principles of the dementia action plan, and we commend the NZ Dementia Cooperative for the work it is doing to address an extremely important issue for New Zealanders. We hope that the proposed actions will lead to an improvement in the lives of people living with dementia and their family/ whānau, and we look forward to having further input into this plan as work progresses.
Separate	"I think the plan should include more about the human rights of people living with dementia in aged residential care who are often segregated into special "dementia units" and locked up in "secure units". This practice should be challenged and stopped." Also I suggest the addition of "Measures to reduce the reduce the use of anti-psychotic medication to manage "behaviours of concern" in residential care. I propose funding for education of Aged Care Providers in the use of the "Wellbeing Framework" (Dr G Allan Power, Dementia Beyond Disease, 2016) as an alternative measure to use of medication.
	Standards / Checks
Q.17 Capability	As aged care facilities are owned and operated separately throughout NZ the standard of care is so variable. Monitoring of standards across all facilities is variable.
Q.20 Overall	More checks on care facility. Ensure said facilities employ fully trained and caring staff. A major problem is the staff turnover. Extremely confusing for the dementia patient.
Q.20 Overall	National standard is required for dementia units design and dementia day care programme.

14.3 A broad range of stake-holder are important

Survey question	Comments
	Broad
Q 5. Principles	More than the health sector - a multi-sector and broader approach is needed. A major part of the sector's delivery takes place in residential or day care and most of this is commercially based, albeit partly funded by public funds. In addition, well-being for people with dementia and their families depends on how the wider community sees dementia.
Q. 11 Living well	Currently we tend to silo conditions/diseases; while this can be helpful so aspects of a condition can be researched and understood, it is unhelpful when it comes to providing treatment and support. Having worked in the education and disability sector I am very aware of the results of 'silo-ing' on people/whanau as this process enables providers to refuse to provide services to those who do not 'fall in their domain' rather than following a holistic, whole person model. We need services for real people, not as squares in bureaucratic forms!
Q.20 Overall	Compared to other countries, NZ's dementia care is appalling. There is almost no involvement of allied health, or collaborative working between mental health and the rest of healthcare. It's tremendously siloed and that is so counterproductive. Dementia isn't, and shouldn't be, kept solely in the realm of older adults mental health. It biases the system against early onset and younger adults, and anyone not involved in the mental health services will not get to work with people with dementia. General medicine don't understand dementia and then leave mental health workers to deal with things they are not set up or trained to do. And the training and funding of support workers, healthcare assistants and nursing aids is appalling. There is so much to do. The final thing to say is... Dementia services (and MH as a whole) need more input from SLT. If people with communication changes are assessed and treated without the input from the communication specialists, you are setting up a system to fail them.
Q.20 Overall	A multidisciplinary approach is essential as we all work in different ways, and a united approach will be effective, and reduce duplication
Q 5. Survey as a whole	Community Pharmacies would be ideally placed to offer support services particularly around medication adherence. Working with the families to assist with information and education as well. Include Community Pharmacy in the primary health team as they are an accessible resource for sharing information and supporting caregivers/whanau. Can offer great adherence support with medications for comorbidities. Include Community Pharmacy in the primary health team as they are an accessible resource for sharing information and supporting caregivers/whanau. Can offer great adherence support with medications for comorbidities.

	Involve community pharmacy in providing access to information and education Involve community pharmacy and pharmacists as part of the primary health team. Working in community pharmacy I regularly see customers and families struggling with dementia and access to services. Adherence support is crucial to relieve the stress for all. Community pharmacy staff can offer great support with packaging, deliveries information and education. Sometimes a lot of pressure is put on the GP or nurses when pharmacists and pharmacy staff can often help. My father passed away a year ago after an 8 year battle with dementia so I have seen the impact from all sides.
Q.11 Living well	Our agreement is based on earlier suggestions regarding a holistic and participatory approach to meaningfully support appropriate provision of comprehensive management planning. The importance of social support services in the comprehensive management process is critical.
Q.20 Overall	Both the Kaiawhina Workforce Action Plan and the Kaimanaaki Workforce Development Plan teams of which Careerforce is an implementation partner would take this opportunity to emphasise the significant need for confident and capable workforces to support the Plan. We would welcome the opportunity to work more closely with you and to have the opportunity align both Plans' objectives with the priorities of the Dementia Action Plan.
Q.11 Living well	ARC providers need to really get on board with this
Q.17 Capability	It is essential to get the top people in companies on board with anything that happens- otherwise nothing will change, as they go back to their own jobs and do nothing with what you train them in- these HOD/ leaders need to BE the change and have 100% buy-in.
Q.20 Overall	Volunteers here in the Waikato ready to help....some very skilled. Need to be included and tapped into by dementia services...communication needs to be improved , which will help with all the above
Q 5. Principles	That the role of communities and businesses is added.
Q 5. Principles	not just services - specialist products/activities designed for dementia should be available with things like GST relief as they do in England
Separate	**Integrated**- other sectors such as Police and other first responders like para medics and the Fire Service, also have an important part to play. Schools are critical to education on healthy lifestyles and acceptance of people who are different, including those with dementia. .. **Workforce-** a well-trained and skilled health and dementia sector work force is essential but other sectors such as Police and other first responders like para medics and the Fire Service, also need training in identifying and appropriately responding to people with dementia. – National Council of Women
Q.17 Capability	Ensure secondary care services are specifically identified in areas where dementia and age friendly standards are established. (2nd point above)
Separate	It is noted that the membership of the working party is predominantly focussed in the health, social care and academic sector. It is unclear whether there was

	representation from Public Health, government bodies, local authorities and other sectors who are identified as important stakeholders in progressing the action plan. Engaging stakeholders at an early stage will be crucial for the success of the strategy. We would like to point out that only 3% of mental health funding is allocated to specialist services for older people, who actually make up 15% (and growing) of the population (please see "MH and older people workforce development NZ – 2019" sourced from Te Pou website). [NZCCP]
Q.8 Incidence	need to keep the focus on these action plans for all who are involved, ie carers but also the work force who may need constant reminders of these priorities, they can be "lost" when working with M H issues, other than Dementia,
Q.5 Principles	In order to these principles, fundamental and far-reacting changes will need to be made to the New Zealand culture, including addressing the long-term effects of colonialism on Tangata Whenua; how we parent / childhood trauma; the standard New Zealand diet, how we use alcohol; the siloed nature of our health system; the inequities of access to health care for rural populations; the differing standards of care and accessibility between DHBs.
q.17 Capabilities	Ensure collaboration of DHB's to put aside differences as they may end up with themselves! Take a leaf out of Mike King's work and find a charismatic spokesperson
Q.20 Overall	You are welcome to add my book, Peter and Me A love story becomes a carer's anguish. Fraser Books 2013
Q.19 Enablers	If NZ continues to do what we have done about dementia we have a very gloomy future ahead. There are opportunities for the medical/ nursing/ research fields to come together with complementary therapies to reduce the number of people developing dementia and to provide better services for those already living with the disease until they die.
	Diversional and Recreational Therapy
Q.3 Goals	We urge you to provide funding for Diversional and Recreational Therapy
Q.8 Principals	As before, ensure to include Diversional and Recreational Therapy.
Q.11 Living well	Qualified diversional therapists/activity co-ordinators in all rest homes. Village based care homes (See Hogeweyk, a village located in Weesp, Netherlands) so that people are not bored in resthomes and can live a normal life. Better for caregivers and family members.
Q.11 Living well	The dementia framework 2013 states - 'to identify strengths and weaknesses so that interventions can be put in place to maintain abilities and offset deficits (Good practice examples: Assessment of Motor and Process Skills: AMPS, Allen Cognitive Levels)' These assessments and subsequent interventions need to be completed by an Occupational Therapist (OT) however OT's are still largely under resourced within all sectors (in particular primary health and

	residential facilities). OT's provide holistic functional and robust cognitive assessments and interventions (such as activity programmes tailored to the persons abilities and advice regarding environmental changes for example) that help to maintain or improve function, independence and wellbeing. OT's can do this and do this well but not with the number currently employed.
Q.11 Living well	Once again, I urge you to get Diversional and Recreational Therapists as part of the plan. You have enough Clinical staff all over and is time to provide people with meaning and purpose through therapeutic recreation.
Q.11 Living well	Could also include Diversional Therapy as a support for those living at home
Q.19 Enablers	Properly trained Diversional Therapists should be seen as an essential part of the service team for clients with dementia, both within a care environment and for clients ageing in place.
Q.19 Enablers	Once again, Diversional and Recreational Therapists
Q.14 Community	Once again, ensure you will get Diversional and Recreational Therapists as part of those teams.
Q.19 Capability	I urge you to look outside the Clinical Box. You MUST include non-pharmacological therapies and include Diversional and Recreational Therapists.
Q.20 Overall	. . also I would like to see Diversional Therapists used to support the families of those caring for people living with dementia

14.4 GPs were seen as a key group.

Survey question	Comments
Q 8. Incidence	A G.P., in many cases would be first point of contact. When I took my Dad in with concerns, the G.P. heard my Dads denial over my request for assessment, a 5 minute Q&A with a little sketching. Took two years to have this assessment done finally. Imagine the progression we could have avoided if G.P.'s would only talk more to patients to convince them of a little test.
Q.11 Living well	Again, there needs to be a role for GP as front line health professional.
Q.11 Living well	Better education and involvement of Primary Health Care providers. People with dementia and families turn to these providers first usually and at present they are not confident in providing diagnoses or offering support after diagnosis.
Q.11 Living well	From experience I have found some GPs need more information about Alzheimers and seem to leave it in the too hard basket rather than be proactive with clients.
Q.11 Living well	There needs to be considered approach to getting buy in from general practice
Q.11 Living well	The hardest part for our family was getting a diagnosis in the first place after that the follow up was great. Maybe GP's should spend a bit more time when concerns are raised as the patient can bluff their way through a five minute set of questions leaving the family at a loss wondering what to do next. It's a big step asking for help in the first place.
Q.11 Living well	There needs to be considered approach to getting buy in from general practice
Q.11 Living well	GP's at the central professional. None of the above is specifically helping GP's. We don't want to lose our privacy in consultations but have a lot to offer patients. Fund our dementia visits?
Q.11 Living well	Provision of timely and accurate diagnosis in primary care is essential
Q.11 Living well	The CCDHB and HVDHB dementia pathway if used has proven to be a great resource for primary health. the challenge has been getting GP's etc interested to look at it. Once they do, they use it. Recommend emphasis on supporting them to view it
Q.11 Living well	Maybe I am not understanding the coordination between the DHB and the GPs - but I think there needs to be a more proactive approach and follow up via the GP for people presenting with risk factors so there is earlier support for them and their care givers
Q.17 Capability	GPs

Q.20 Overall	As a social worker I have noticed huge inconsistencies in the response by GPs to dementia clients. Although there already existed a draft dementia pathway its almost totally disregarded and so carers and patients are left floundering trying to find their way through the maze. This disregard makes the clients even more vulnerable and open to abuse.
Q.20 Overall	Whilst a navigator independent from GP would be easiest to implement, the real need is to increase the capacity in GP for complex co-morbidity, frailty, and mental health, including case management of people with dementia
Q.20 Overall	I am very very very suspicious of this whole thing - I am esp. worried that the poor prescribing (over prescribing) by psychiatrists in particular will become sanctioned as they become the so called experts on management - whereas in fact the experts in dementia care are GP's and geriatricians.
Separate	The limited training of GPs can be devastating to the person with dementia and family/whanau e.g. I was advised by our GP in 2008 when my husband was diagnosed that the first two years would be the worst and then he would be so disabled that I would not be able to communicate with him and that "would make life better for me." It is still easier to communicate with my husband after 12 years than with rest home doctors I have met who tend to bristle whenever asked a question about medication, for example – even though these are questions listed in the Health and Disability Advocacy pamphlet about rights as a consumer and EPOA – a person's to know the name of the medication, the amount to be administered, its effects, any interactions with other medication, any harmful effects and why it is to be given as compared to other ways of dealing with a dementia difficulty. It has been a constant battle to keep my husband off antipsychotics as he sat for days doing nothing. The behavioural approach was to isolate him in his room with a big label on his door, "Isolated".
Separate	Discussion re the need for more GP's to refer clients who have new diagnosis of dementia to appropriate services, e.g. Dementia Waikato. GP's to carry out timely and comprehensive dementia assessments and also to refer to Specialists and to MHSOP team in a timely manner. Bupa dementia help line are taking calls from family members very stressed and asking for assistance/direction to appropriate services, following GP diagnosing with dementia or GP delaying cognitive assessments. Importance of need for early diagnosis discussed. Howard informed group-up to a 1/3 of people who are given a diagnosis of Alzheimer's have this diagnosis reviewed within the first 18 months. Discussion re WDHB 'Map of Medicine Dementia Pathway' is no longer available. 'WDHB "Best Practice' on line resource is not available to all health professionals to access (e.g. Dementia Waikato can only see new referrals – not the treatment pathways). The issues raised from this meeting could ? be discussed with the GP Liaison Person for Agewise within the Waikato DHB. – Thames Agewise
Separate	here is an additional feature of a national dementia plan we need to fight for:

	"AAN Adds Annual Cognitive Screening Quality Metric for Adults 65 and Older With a growing emphasis on early detection and intervention, the American Academy of Neurology (AAN) has published a new set of quality measurements that recommend that physicians screen adults 65 and older on an annual basis for thinking and memory problems.[1] The metric, intended to help improve quality care, will track how often physicians screen older adults for cognitive impairment, share information about the condition with patients, and involve and educate partners and caregivers. "Since thinking skills are the most sensitive indicator of brain function and they can be tested cost-effectively, this creates an enormous opportunity to improve neurologic care," said author Norman L. Foster, MD, of the University of Utah, in a statement. "The American Academy of Neurology is recommending the measurement of annual cognitive screenings for everyone age 65 and older because age itself is a significant risk factor for cognitive decline and mild cognitive impairment is increasingly prevalent with older age. The measure complements past American Academy of Neurology quality measures released for Parkinson's disease, multiple sclerosis, and stroke, and allows for a doctor to meet the measure with a recommended periodic three-minute cognitive test." The quality measure contains multiple components, including:[2] • Conducting an annual cognitive health assessment for patients 65 and older • Conducting a cognitive and functional assessment in patients with MCI or memory loss • Disclosure of MCI diagnosis and patient counselling on treatment options • Assessment and treatment of factors contributing to MCI • Avoidance of anticholinergic medications for patients with MCI • Education of care partners The metric also emphasizes the importance of documenting impaired cognitive health on a patient's shared medical record, as this can better inform other providers who care for the patient."
Q.5 Goals	Primary practice is hesitant to diagnose capacity as its not black and white Decisions can often be made, mostly emotionally based, but the person would not be able to action those decisions. This part of capacity is rarely tested by physicians
Separate	Discussion re Capacity Assessments. Currently there is a lack of consistency within the WDHB region amongst GP's for when Capacity Assessments are carried out. ? are some GP's deferring doing these assessments as the results may be 'contestable'. – Thames Agewise

15 Additions

There were some recurring suggestions for additions to the plan.

15.1 Residential options for people living with younger onset dementia

15.2 Cognitive Stimulation Therapy

15.3 Advanced planning

15.4 Other

Residential options for people living with younger onset dementia

A number of respondents highlighted the needs of those living with younger onset dementia and those supporting them, particularly appropriate residential care options. It was noted that the use of 'aged residential care' in the draft plan compounds the assumption that only older people require residential care in the context of dementia.

Cognitive Stimulation Therapy

There was strong advocacy for the inclusion of Cognitive Stimulation Therapy (CST) as a proven intervention, including collated responses from 25 individuals with experience of CST.

Advanced Planning

A number of respondents highlighted the omission of advanced planning.

Other

Other areas that were noted to be omitted by multiple respondents were medication subsidies, safe walking, and elder abuse.

15.1 Residential options for people living with younger onset dementia

Survey question	Comments
Q.3 Goals	people diagnosed with younger onset dementia are not catered for and tend to be "lumped in" with the older population, these people and their whanau need more resources available to them to help them on this journey. Dementia care needs to be able to cater for all levels of dementia patients without putting them altogether and treated all the same.
Q.19 Capability	We need accommodation now for young people with dementia that is fully supervised. It is not fair to put a forty year old in with people in their eighties.
Q.19 Capability	An issue is whether there needs to be work put into the development of dementia units that are specifically for those diagnosed with an early onset dementia. A person with this diagnosis at age 60 or younger has possibly quite different behavioural management requirements. If they are this young then the situation involves dealing with a wife or husband that is still active and possibly still working. This becomes a different scenario regarding the management of their needs.
Q 5. Principles	Please make sure that people with early onset dementia have appropriate accommodation options for respite and end of life care that is no aged residential care. The needs are so different.
Q.20 Overall	Instead of 'aged residential care' use the term 'age appropriate residential care'. This is point 3 of page 1.
Q.20 Overall	Mental health units need to be more adaptable and look out for dementia, even if this is not their main interest. My daughter was told she did not fit their definition for mental health and went undiagnosed for 5 years. She was asked if she was suicidal and when she said no, we were then told they could not help 3 times. I would be happy to tell our story to make people aware that young people get dementia as well. My daughter is 42 years old.
Q 5. Principles	Housing for people with young onset dementia needs to be age appropriate and not mixed in with the elderly.
Q.3 Goals	…Younger folk with Dementia, the spouse having to give up work to care for the partner, what of other children in the family, mortgages et.
Q.3 Goals	…increase the level of support available to families, especially those with a younger onset dementia
Q.5 Principles	people with younger onset need to be included in all areas not just in specific populations
Q.11 Living well	Educate professionals to pick up on early onset dementia as this is happening more often at much earlier ages.

Q.11 Living well	Young onset is different to someone who is older with dementia and should be treated differently, there is stigma, my mum was under 60 and single it was very difficult for us as her children to cope with everything and try to continue working full time, there was no support groups for us to get help, a lot of information relied on us as a whanau going out to find it.
Q.20 Overall	More options for younger onset suffers of dementia.. More support
Q.20 Overall	Priority needs to be placed on the small but very disadvantaged group - people with Young Onset Dementia and their carers/families.

Some of the above comments were noted in earlier sections as well

15.2 Cognitive Stimulation Therapy

Survey question	Comments
Q.3 Goals	We urge you to provide funding for …non-pharmacological interventions such as CST -Cognitive Stimulation Therapy
Q.3 Goals	I feel there should be a goal towards what resources will be funded for example I would like to CST groups fully supported and funded throughout all in all facilities e.g. rest homes private hospital in NZ to improve participation and engage people who maybe otherwise feel lonely disorientated and bored. This is a common message I hear from clients. We so much value in rolling out CST, participants really enjoy the group sessions and has even improved their quality of life.
Q.5 Principals	Cognitive Stimulation Therapy needs to be available to everyone
Q.5 Principals	That non pharmaceutical interventions are explored. Over recent years, throughout the world programmes have been introduced that have proved very beneficial both in improving the welfare of people with dementia and in decreasing the impact of this disease on the person and ultimately their family.
Q.5 Principals	CST needs to be specified as a validated therapy for people with mild to moderate dementia.
Q.8 Incidence	Add CST to the plan
Q.8 Incidence	CST is an effective evidence based programme and should be available to those with mild to moderate dementia as part of this action plan
Q.11 Living well	The New Zealand Cognitive Stimulation Therapy (CST) interest group met in Auckland on the 15th November 2019. We had the opportunity to discuss the draft New Zealand National Dementia Plan. In particular, we very much agree with your objective of supporting people with dementia and their family/whānau care partners to live well. However, we believe this objective lacks specificity; it should include information on evidence based treatment options to guide services to achieve the goals of this objective consistently and equitably across the 20 district health boards (DHBs) in New Zealand. CST is an evidence based non-pharmacological treatment for people with diagnoses of mild to moderate dementia (1,2). It is a structured and manualised group cognitive intervention involving 14 sessions (twice a week over seven weeks) of themed activities. Sessions are aimed to actively stimulate and engage people with dementia, whilst providing both an optimal learning environment and the social benefits of a group of six to eight participants with two CST facilitators. CST has been shown to improve cognition and communication (3, 4) and the World Alzheimer Report (2011) stated that "the evidence overall for the efficacy of cognitive stimulation is consistently positive". (5) The evidence for CST on cognition is also highlighted in the Lancet commissioned report on dementia prevention, intervention, and care. (4) In addition, CST is found to be

	a cost-effective intervention and offers value for money (6). The UK's National Institute for Health and Care Excellence dementia guidance (2018) recommends that people with mild to moderate dementia should be given the opportunity to take part in a CST programme. (3) CST can also improve the quality of life of people with dementia, which is consistent with your objective of living well with dementia. Our interest group is most concerned that the access, provision and funding of CST is fragmented and inconsistent across New Zealand. For example, a small number of DHB clinical services, DHB funded dementia day programmes, and dementia organizations can access public health funding to deliver CST, while others rely on charitable funds and private funding. This is in contrast to the UK where CST is offered to people with dementia by 80% of National Health Service's memory services. You can find further information on CST via the National Health Service website (5). The New Zealand CST interest group strongly recommends the New Zealand National Dementia Plan to include CST as an evidenced based treatment option for people with dementia to live well. References: 1. Comas-Herrera A, Knapp J and Martin R. Modem: A comprehensive approach to modelling outcome and cost impacts of interventions for dementia. Alzheimer's & Dementia: The Journal of the Alzheimer's Association 2016; 7: P815. 2. Woods B, Aguirre E, Spector AE, et al. Cognitive stimulation to improve cognitive functioning in people with dementia. The Cochrane Database of Systematic Reviews 2012; 2: CD005562. 3. National Institute for Health and Clinical Excellence. Dementia: assessment, management and support for people living with dementia and their carers. https://www.nice.org.uk/guidance/ng97 (2018, accessed 11 April 2019). 4. Livingston G, Sommerlad A, Orgeta V, et al. Dementia prevention, intervention, and care. The Lancet 2017; 10113: 2673–2734. 5. Alzheimer's Disease International. World Alzheimer Report 2011. The benefits of early diagnosis and intervention. 6. https://www.england.nhs.uk/wp-content/uploads/2018/01/dg-cognitive-stimulation-therapy.pdf
Q.11 Living well	Specific reference can be made to Cognitive Stimulation Therapy (CST) in this section. It is an evidence-based programme known to be an effective treatment modality which helps maintain and/ or improve cognitive function and quality of life thereby assisting people to age-in-place. It can be implemented immediately post-diagnosis which is often reported to be a time when people feel neglected by health care providers. CST also provides support care partners with respite and information. In addition CST is cost effective to both run and train facilitators and can be easily adapted to meet the needs of specific populations of people (outlined in previous sections of this draft).

Q.11 Living well	Again add CST in line with UK NICE
Q.19 Enablers	Add CST to NZ services
Q.17 Capability	We also believe that day service provision and management can be improved to include effective practices such as CST. Opening hours to enable family/care partners to meet employment obligations as well as engage with providing care and support.
Q.17 Capability	I would like to ensure they acknowledge the huge need for funding DRT in this plan and non-pharmacological interventions such as CST (Cognitive Stimulation Therapy). Many facilities have money but it is not spent on DT and many work on trying to meet the needs of their residents with little or no budget and often on their own with a large number of people in the room. This is just not right when these companies then reveal huge profits each year!! Also, I have seen with my own eyes how facilities pass audits with flying colours but everyday frail/dementia sufferers are wheeled in front of a TV blasting infomercials and left there alone. That to me is torture and it must stop. It has been proven that non-pharmacological interventions reduce distress/confusion, boost physical health/self-esteem and reduce depression amongst other things. The work of the DT improves the quality of life for those living with dementia and gives people a reason to get up in the morning. They should be more valued than what they are and given the resources they really need to do their job. As the first person in NZ to deliver age appropriate resources and activities to frail elderly and those living with dementia I have seen first-hand how the industry cuts corners for a profit and finds it quite acceptable to offer these people, who sacrificed so much for our country and the comfortable lives we live today, second best. I try to keep the prices of my products reasonable but I think it would be very helpful if we could offer GST off so those needing them would find it more affordable. this is achieved in the UK
Q.17 Capability	Yes, you need to ensure you will be including Non-Clinical Staff, people living with dementia will continue to be prescribed with disengagement unless you seriously take health care professionals as Diversional and Recreational Therapists as part of this strategy.
Q.17 Capability /Separate	The RANZCP notes these elements are omitted:… 3. Funding Cognitive Stimulation Therapy From written submission: The RANZCP advocates for the increased use and funding of non-pharmacological interventions for both the cognitive and behavioural aspects of dementia. For example, Cognitive Stimulation Therapy is an evidence based non-pharmacological treatment for people with mild to moderate dementia that improves cognition. We would like the Plan to propose that the range of evidence based non-pharmacological interventions are explored and prioritised for introduction by a stated date.

Separate	The New Zealand Society of Diversional and Recreational Therapists Inc. meets every month. During our last meeting we had the opportunity to discuss the draft New Zealand National Dementia Plan. Although we agree with your goal of supporting people with dementia and their family/whānau care partners to live well, we believe the goal lacks specificity; it should include information on evidence -based treatment options and other professionals such as Diversional and Recreational Therapists to be part of the services to achieve the goals of this objective consistently and equitably across all DHBs. Diversional and Recreational Therapy involves the organisation, design, coordination and implementation of person centred therapeutic recreational programmes. The person regardless of their age, background and cognitive or physical abilities will have a choice of leisure and recreational programs designed for them, to enhance their quality of life through the use Diversional techniques (NZSDRT Inc. 2019). Diversional and Recreational Therapy provides ongoing support through non-pharmacological therapeutic recreation the development of core wellness dimensions –social, intellectual, sexual, emotional, spiritual, cultural and physical. 90% of Diversional and Recreational Therapist work predominately in Aged Care with people living with Dementia. These allied health professionals focus on things that provide meaning, purpose and sense of belonging for the people in their care, yet most of the input for the National Dementia Plan is not event taken these professionals into consideration. A great example of one of the treatment Diversional and Recreational Therapists uses is Cognitive Stimulation Therapy (CST), this is an evidence based non-pharmacological treatment for people with diagnoses of mild to moderate dementia. It is a structured and manualised group cognitive intervention involving 14 sessions (twice a week over seven weeks) of themed activities. Sessions are aimed to actively stimulate and engage people with dementia, whilst providing both an optimal learning environment and the social benefits of a group of six to eight participants with two CST facilitators. CST has been shown to improve cognition and communication and the World Alzheimer Report stated that "*the evidence overall for the efficacy of cognitive stimulation is consistently positive*". The evidence for CST on cognition is also highlighted in the Lancet commissioned report on dementia prevention, intervention, and care. In addition, CST is found to be a cost effective intervention and offers value for money. The UK's National Institute for Health and Care Excellence dementia guidance recommends that people with mild to moderate dementia should be given the opportunity to take part in a CST programme. The New Zealand Society of Diversional and Recreational Therapists strongly recommends the New Zealand National Dementia Plan to includes Diversional and Recreational Therapists to guide good practices as well as Cognitive Stimulation Therapy as an evidenced based treatment option for people with dementia to live well.
	CST: Dementia Auckland survey
Separate	Several of our carers, people living with dementia and staff wanted to give the Draft Dementia Plan some specific feedback on the need to include CST in the Living Well part of the proposal. To make it easy for them to do this we sent out a mini survey and got 25 replies. [All of the participants agreed with the agreed with the statement

	I strongly believe that the draft Improving Dementia Services in New Zealand proposal needs to clearly state that Cognitive Stimulation Therapy is a validated therapy for people living with mild to moderate dementia. The proposal should include an expectation that every person recently diagnosed with mild to moderate dementia in New Zealand will have the option to receive government funded Cognitive Stimulation Therapy. Comments from each of the participants are included below:]
	Farouk was very eager to go to the classics. Keen to learn the song from song sheet. And would look over the homework sheets. Also encouraging them to list where they lived and places they visited was very stimulating. And pictures of current affairs.
	I feel that the careers got a lot out of it as we mixed and got support. I felt involved in the process and that was really important to me.
	I didn't feel that it achieved much at the time, but my caregiver does feel there was some improvement.
	I found that my mother who has mild dementia, when she attended the CST group was profoundly happier and more open to a wider degree of experiences and her interest in things she used to find enjoyable returned. For me personally I fell that the person I grew up with has some-what more present. I also have noticed a level of independence return. All and all it seems to be the only thing that has made much of a difference to the quality of her life is since she attended the CST group.
	I am an Occupational Therapist working in mental health with the over 65. I am relatively new to CST recently completed the facilitator training with Katy Parry. I have been a co facilitator in two CST groups, most recent was supporting Dementia Auckland with a pilot chair yoga and CST group in Auckland. I am motivated to start up in our service next year.
	Over the past 13 months while attending the CST program my personal confidence has significantly improved as has my memory and verbal communication skills with others. Each week I look forward to attending the session and have greatly enjoyed and appreciated the relationships I've built up with other group members. This has become an essential part of my week.
	This is a very successful and excellent program that has helped my husband enormously during the past year. So many people have told us of the big improvement in him since he started doing CST. I can't recommend this program enough.
	It does stimulate those with mild-moderate dementia cognitively and allows them to use parts of the brain that may not be used as much in daily living. It also provides a social context where those with similar situations can come together and talk and just have a good time socializing with one and another and this is an aspect of CST that is also really beneficial for those with mild-moderate dementia. Its provides them with an opportunity to step out of the house and socialize. Those who are really engaged with the activities do enjoy them and has said that it does help them cognitively. With the orientation

	portion of the sessions, the participants had said it really helped them stay on track of time and dates and because we do it weekly, they seem to be able to track the dates quite well in daily life too. Participants of the CST group that I volunteer for has all really enjoyed the sessions and are happy to come every week.
	CST gave my wife a real buzz and something to look forward to each week. She was much more in tune with what was going on around her.
	I have been in receipt of weekly feedback from my wife that strongly confirms the positive outcomes of her weekly CST sessions, her increased well-being, and the work that she completes for her homework. It also helps me as a carer cope better with our journey. She also gains lots of confidence from the sessions and so looks forward to each Wednesday.
	I really look forward to our weekly CST group session - it is the high-lite of my week. We Start off by reading and discussing a current affair article in the Herald which is always interesting. Then we go outside and throw a ball to each other and as each person catches it they have to answer a question that has been put to us by our facilitator - for example "What type of animal is Bambi What planet does superman come from? Name Shakespeare's drama featuring a character called Ophelia. What colours does one mix together to make green. If you have 2 dice how many dots do you have. We are given a list of famous faces and we have to name them and say how many of them are Kiwis. I hope and pray that we can carry on next year with our CST group as I know that it really helps my memory and my confidence.
	I run CST and mCST groups in the community.
	Very good. Involving all clients in lots of different activities and conversations.
	it was great to have something appropriate and stimulating to send my husband to. the "homework" ie find things photos from your childhood gave us something to look for and talk about at home my husband I was told was involved in the sessions and responded well to the questions music general knowledge and activities it is hard to stimulate him at home but in a group run by people that know what they are doing he responds and it showed on the afternoons evening of the sessions that he was more alert and involved with what was happening around him
	This programme has been fantastic. Motivating, inspirational, and something that he really looks forward to and always thoroughly enjoys. Also the others that attend have become friends that he treasures spending time with as they have dementia In common. Because it is every week it makes a huge difference to his week. The facilitator and her helpers are absolutely awesome. I have seen wonderful improvements to his daily life since he started. I would thoroughly recommend it to everyone with cognitive problems/concerns

	My husband's brain was more alert and organized after each session. He seemed to be able to plan' problem solve better and aware of upcoming events. There was less confusion. Conversations were easier. He would benefit from long term CST rather than just the 7 sessions he received. My life was easier for a while but he needs the consistent regular CST therapy for long term benefits for both of us.
	Gives the client a purpose, stimulates and generally a good feeling. The interactive activities and the social aspect is beneficial, especially to someone like my husband who is somewhat of a self-sufficient nature
	My Husband has Lewy Body Dementia and last year he attended the classes. He was not only enthusiastic about going to the class, he was also showing excellent results having been through the course. However due to not enough teachers being available to keep the class going he slowly declined as a result of no weekly cognitive stimulation. I highly recommend these classes to be available for all and having completed the initial course to keep workshops running for those advanced students. It helps the carers to understand different ways they can also do at home to keep the person busy.
	My husband and I attended 14 sessions. Although we had to travel quite a distance twice a week we found the overall experience really worth the effort. We are continuing on with some of the activities learned in the course and have made new friends. My only wish is that this course had been available to my husband when he was first diagnosed with Dementia. The cost is another factor. Because of our present circumstances I could only afford to donate a small amount to the Society which I feel embarrassed about.
	Co facilitating a CST and mCST group. I have seen significant improvements in participant wellbeing. Several examples are below Confidence - i.e. rather than sitting back and observing, people are participating and voicing an opinion. It is ok just to try, without judgement Social skills and relationship building - i.e. keen to engage in conversation with other group members, inquiring about events/people that have been discussed recently Current affairs - i.e. an improvement in awareness out of their immediate home environment to what may be happening within their community/world
	I have done the one day training course and run one CST and one Maintenance CST programme.
	My mother had too many bad side effects to continue taking donepezil in 2018, so CST has been a really good alternative for her. Mum enjoyed the initial course (which started Feb 2019) and looks forward to her weekly maintenance classes, which I hope will continue into 2020. The content and course structure, that Kelly and Dementia Auckland have provided, has allowed my mother to actively participate in an environment where she feels comfortable, has met new

	people and can revisit and share some of the old memories that she still has. CST has noticeably improved the quality of her life.
	Facilitating CST groups and MSCT groups.
	Over the last 3 years I have seen many people living with dementia respond well to CST. It gives hope to carers, families and people living with dementia who see that there is something that they can do to improve the confident, mood, quality of life and sometimes the cognition. I have seen people blossom during CST, resume participating in life in a way they never thought possible. I have seen people with aphasia gain confidence to talk more, people recovering from depression secondary to their dementia return to previous bright self. In turn carers feel better and cope longer as their PLWD is focused and happier. CST truly makes a difference. In New Zealand the government health services funds multiple rehabilitation therapy programmes to support people with heart conditions, strokes, arthritis etc. It is time that New Zealand funds the only validated therapy for people with dementia. Every person with a diagnosis of mild to moderate dementia should be able to receive government funded CST, where ever they live.

15.3 Advanced planning

Survey question	Comments
Q.3 Goals	My only thought in looking through the plan document was that there was no mention of legal preparation, such as EPOAs, which are currently expensive to set up.
Q.5 Principles	More education on and reduce cost of the legal aspect of dementia such as EPOA
Q.22 General	Moreover, there is no mention of the National Advance Care Planning programme aligning with the plan. Aotearoa/NZ already has a national ACP programme, administered by the Health Quality Safety Commission (HQSC). This includes ACP training and Serious Illness Conversation Guide (SICG) training for clinicians, and training for volunteers (due to be launched in 2020). The objectives of the Dementia action plan should align with this program and address the specific ACP needs of people with dementia. Providing the opportunity for people to express their values, beliefs, goals, preferences, and – if they wish – specific decisions about future health events, before they lose the ability to do so, is important if person-centred care is to be provided for people with dementia.
Q.14 Communities	There is a need for health promoting palliative care in the context of dementia including greater public awareness of advance care planning and of the law concerning the PPPR act and Enduring Power of Attorney. This is important in care provision. In nursing homes, ACP can increase alignment between end of life wishes and care provided (Kelly et al 2019). For example, patients whose proxy decision makers understood the clinical course of their family member's advanced dementia were less likely to undergo unnecessary and/or aggressive interventions towards the end of their lives (Mitchell et al 2009). Johnston K, Preston R, Strivens E, Qaloewai S, Larkins S. Understandings of dementia in low and middle income countries and amongst indigenous peoples: a systematic review and qualitative meta-synthesis. Aging Ment Health. 2019 May 10:1-13. doi: 10.1080/13607863.2019.1606891. [Epub ahead of print] Kelly AJ, Luckett T, Clayton JM, Gabb L, Kochovska S, Agar M. Advance care planning in different settings for people with dementia: A systematic review and narrative synthesis. Palliat Support Care. 2019 Jun 10:1-13. doi: 10.1017/S1478951519000257. [Epub ahead of print] Mitchell, Susan L., Teno, Joan M., Kiely, Dan K., Shaffer, Michele L., Jones, Richard N., Prigerson, Holly G., Volicer, Ladislav, Givens, Jane L., Hamel, Mary Beth, "The Clinical Course of Advanced Dementia."N Engl J Med 2009, Volume 361, Number 16, pp 1529-1538
Q.20 Overall	Inclusion of ACP would be relevant including a national focus/education campaign re importance of EPOA, push for national register etc.

Q.20 Overall	In 2013, I was employed as Educator for Alzheimer's Auckland and it seems very little has changed since then in the areas of prevention and the important issues of advance care planning and palliative care for people with dementia. Now I have 2 roles- one in the community teaching residential staff and GP's about palliative care and also working in a self-employed capacity as a qualified Integrative Nutrition Health Coach. I would be very happy to discuss my ideas on prevention and palliative care further.
Q.20 Overall	Legal Initiatives around preparation need more considering. Making EPOAs cheaper and having better options for appointment of Welfare Guardians and Property Managers is essential for people who might be socially isolated. (Sorry I could only respond in brief)
Q.20 Overall	An unaddressed area is the accountability of EPoA and Welfare Guardianship. When decisions are made by the persons holding these positions that are in contrast to best practice, in contrast to the goals outlined, that reduce dignity, respect and autonomy, that deny involvement in decision making; what advocacy is available for those diagnosed, that is appropriate for level of capacity? Also what avenues are available to health professionals forced to concede to those decisions against better judgement?? Legal protection and perspective to be addressed. Welfare Guardianship given unchallenged power over an individual.
Q.20 Overall	There is an absence of reference to the importance of having a current EPOA / ACP in place for all NZrs
Q.20 Overall	I am a diversional therapist and also extensive trained dementia HCA.Having worked in carehome and private home setting. Every person should make an advanced personal careplan. This so everyone can understand the way we want to live when we can’t express the way we want to live.
Separate	Recommend: add ‘Promote all adult NZ’s to complete EPOA’s and ACP’. … Discussion re the need to promote/encourage all adults to complete Enduring Power of Attorney’s and Advanced Care Plans, at a young age.– Thames Agewise

15.4 Other suggested additions

Survey question	Comments
	Medication subsidy
Q.20 Overall	The RANZCP notes these elements are omitted: 4. Improved access to pharmacological support From written: The RANZCP does not seek to medicalise dementia. Alongside developing non-pharmacological approaches we also suggest there are some pharmacological interventions that are useful in alleviating symptoms and we would like to see the range of drugs that are fully funded extended. We suggest some mention is made of this in the Plan so these options can be considered at a later date. The RANZCP does not seek to medicalise dementia. Alongside developing non-pharmacological approaches we also suggest there are some pharmacological interventions that are useful in alleviating symptoms and we would like to see the range of drugs that are fully funded extended. We suggest some mention is made of this in the Plan so these options can be considered at a later date.
Separate	…Drugs: we need the MoH (through Pharmac) to immediately allow free access to existing drugs (Rivastigmine, Melatonin and Memantine) and novel drugs (Pimavanserin, others…)…
Q.11 Living well	Ensuring that all evidence-based treatments e.g. memantine/Ebixa are equitably available for all NZ citizens. Currently this treatment is not subsidised by Pharmac.
	Safer Walking
Q.11 Living well	Include the following objective/action: Actively promote and support access to, and use of, strategies and technologies that promote the ability of people with dementia to stay safe when walking, and to reduce the risk of going missing / increase the ability to locate a missing person who has a high risk of going missing.
Q.11 Living well	People with dementia are at risk of getting lost/not returning home when walking. Such occurrences account for about 20% of land searches. Unfortunately, some people are not found alive. There are strategies and technologies available to support 'safer walking' and reduce the risk associated with people getting lost. We support an additional Action:

	Actively promote and support access to, and use of, strategies and technologies that promote the ability of people with dementia to stay safe when walking, and to reduce the risk of going missing / increase the ability to locate a missing person for those individuals who are at risk of dementia related wandering. Lead - MoH / NZSAR
Q.19 Capability	It needs to have safety included. Dementia patients can wander off without carers or family knowing and sometimes takes a while to find them out in the community. We often hear about it on television.
Q.14 Communities	I have come across one woman a few times, needing help to get home. I knew where she lived as she is local. 3 other stories from family members assisting people home, here in [area]. Perhaps a bracelet with a patient number and an 0800 number for public to call to help get lost people home?
Q.20 Overall	Acknowledge Safer Walking as it applies to people with dementia and strategies to support people to remain living in their communities although they may have a risk of going missing (referred to as 'wandering' in the Search and Rescue sector). Although the risk of a person with dementia going missing maybe be a phase that person passes through it can be the reason that they are admitted into secure care. Consideration of initiatives and strategies to address the risk is therefore important and should be included in the NZ Dementia Action Plan.
Q.20 Overall	NZSAR supports our 'Safer Walking' strategy to enhance connectivity and awareness of the safer walking sector in order to achieve greater alignment and coordination in the support and provision of services for people with cognitive impairment who potentially and actually get lost or go missing. To support this, we have a Partnership Framework supported by a range of agencies.
	Abuse
Q.11 Living well	People with dementia are vulnerable to different forms of abuse so EAN needs to be more robust as do respite options, day programmes etc.
Q.11 Living well	Financial abuse by children of Dementia sufferers, of any elderly actually, needs to be addressed and policed if possible. Perhaps a service could be offered to supervise online banking or check patient statements to avoid abuse.
Q.14 Communities	Consideration needs to be given to safety services associated to those with dementia as a vulnerable population. What about Aged Concern, statutory care and protection services for elders/other vulnerable persons who are being abused etc.

Support and suggestions by section

16. Vison and goal

The vision and goal section received the greatest amount of feedback about improving the writing.

Support and suggestions

16.1 **There were supportive comments about the goals and vision.**

16.2 **There were suggestions for the way the goals and vision were written**

16.3 **There was a desire for a shift in tone to emphasize wellbeing, engagement, and rights.**

Support

Several respondents commented positively about their approval of the goals and vision.

Writing

Some respondents commented that they found this section wordy and unclear.

Some respondents felt reducing the incidence of dementia read as being ‘tacked on’ or an afterthought.

There weas also a range of suggestions for other specific wording changes.

Tone

Some respondents were concerned about the tone of the section (and hence the plan overall), in particular wanting to move from positioning people living with dementia as just recipients of services to emphasising empowering the wellbeing and engagement of the person living with dementia. There were some hesitations about the reference to reducing the impact on the economy.

Reducing incidence

There were differing views of the inclusion of reducing the incidence of dementia as an aspect of the vision and goals and as a priority action area. This is covered in section 18 of this document.

16.1 There supportive comments about the goals and vision

Supportive Comments
I strongly agree having gone through the process with my mother whom had young-onset Alzheimers it has been a huge struggle for us as a whanau for the past 6 years from the symptoms to initial diagnosis to now having to put mum in resident care at the end of last year and currently going through her finances to support her care which is essential. I look back and realise the processes for mum being initially diagnosed at how she would of felt and I believe there should have been quality support and information to make it easier for her. Also as a whanau we found all process difficult, EPOA, finances, mental health, quality care. I just feel the Vision and Goal statement reflect that yes we need to prevent dementia but there needs to be a great shift so other families don't need to go through the struggle and difficulty we did as a family.
Both well thought out and covering all aspects.
a good capture of many issues, we are living with
On the right pathway
No changes required - fully support the vision and goal. Hope there will be appropriate and sufficient resources dedicated to allow this vision and goal to be successfully fulfilled
This is great vision and goal.
I totally 110% support how this document is written
Covers everything
I support the vision and goals

16.2 There were suggestions for the way the vision and goal were written

Survey question	Comments
	Length / clarity
Q.3 Goals	Both the vision statement and goal statements are too lengthy.
Q.3 Goals	The vision may be too long to remember.
Q.3 Goals	The "goal" is actually a list of several goals. Either it should be expressed as such, or be more focused.
Q.3 Goals	The goal is very wordy for a single sentence. Add more punctuation or split into two statements.
Q.3 Goals	The goal seems garbled and difficult to understand. Too many ideas in one sentence
Q.3 Goals	The vision statement and goal fail to clearly articulate what are admirable objectives. Perhaps these statements could be reorganised and prioritised according to the aspects which are considered most important to be addressed in the New Zealand Dementia Action Plan. Furthermore, the language used in the vision statement is not reflected and carried through into the principles. This should be addressed in an updated vision statement.
Q.3 Goals	Keep in simple. Keep it clear
Q.3 Goals	The vision and goal reads poorly. Could be reworded.
	Positioning of risk reduction / prevention
Q.3 Goals	Perhaps the end sentence under vision statement that includes the sentence "dementia is prevented as much as possible" should be a separate vision / goal. In the goal, perhaps "to promote dementia risk reduction lifestyles" could be incorporated into a separate vision / goal with the above statement
Q.3 Goals	Vision- "dementia is prevented as much as possible- comes across is an afterthought". Needs to be included in vision but different wording/emphasis/placement

Q.3 Goals	Preventing dementia and risk reduction feel like an "add on" to the vision and goal, like they are tacked on to the end of the statement and I am concerned the importance of prevention could be lost. Could you consider two goals, one for prevention and one for management. This would allow for focused action and planning for prevention strategies.
Q.3 Goals	"Promote dementia risk reduction lifestyles" is lost in the long sentence and to me has a medical focus. It should be more prominent and possibly in a more positive frame - "Promotion of healthy lifestyles including those known to delay the onset of dementia and encourage risk reducing behaviours."
Q.3 Goals	I very much agree with the intentions of the vision statement and goal but think that within each, there are two distinct ideas in terms of 1) addressing people living with dementia and 2) preventing dementia. I think it's a little confusing having both ideas in the same sentence. I appreciate trying to keep the vision and goal to one sentence but I think it would be clearer if the two ideas can be worded in such a way that they are more distinct. Maybe separate with numbers?...1) and 2) within the sentences.
Q.3 Goals	The vision statement is good in principle - but the punctuation needs to be improved, particularly as last line appears confused as it appears to suggest that NOT having people with dementia is the primary goal, rather than a vision where those with dementia are at the centre of any and all principles expressed in the core vision.
Q.3 Goals	.."and dementia is prevented as much as possible." is clumsy at the end of the vision - suggest it goes at beginning
Q.3 Goals	Prevention of dementia is perhaps part of the goal rather than the vision
Q.3 Goals	Both end with a statement about prevention. It looks like it was tacked on after the original statement had been agreed. Can the wording be changed so the prevention is at the beginning of the statements?
Q.3 Goals	prevention of dementia appears an afterthought in the vision, and is not explicit in the goal statement. I understand the tension between progressing 2 streams of work but think it is necessary to be explicit about both.
Separate	Seems like 2 goals
	Other
Q.3 Goals	The Goal - needs a heading which says "goal'
Q.3 Goals	the words "without compromising" the well-being of the person with dementia should be added into the goal

Q.3 Goals	I am uncomfortable with the word care giver/partner I feel it has negative connotations for people with dementia....my husband has dementia and I am his support person ... I would be interested to hear if anyone else has this issue
Q.3 Goals	Plus don't like the word care partner - prefer supporter. May people with dementia don't perceive themselves as needing care - support is more appropriate particularly in the early stage
Q.3 Goals	'Prevented as much as possible' is okay; I prefer the term 'risk reduction' to 'prevention', which is an absolute and there are no guarantees any of us will not get it.
Q.3 Goals	The principles are described as 'cross-cutting" - this is quite brutal and nobody on our team connected with this.
Q.3 Goals	Delete the following from the goal "The goal of this New Zealand Dementia Action Plan is"
Separate	Under Goal: last phrase: …"to promote dementia reduction lifestyles." This would be better written "To promote dementia reduction" (or similar) since it is not just life style that increases risk, unless you regard medication and education as "lifestyle". The term "lifestyle" also suggests that it is under our control whether or not we get dementia- a neoliberal, *you-are-responsible-for-your-own-health* approach. Being poor or intellectually disabled or Pasifika or female or deaf or traumatised or recurrently depressed might all contribute.
Separate	***Vision Statement***: add…dementia and related disabilities. ***Goal:*** attendees considered this to be a very large goal, ? too broad. Universal messages of health promotion. Recommend change wording from 'to improve' to 'empower' – Thames Agewise
	General comments about writing
Q.20 Overall	This is a document with that sounds good but is difficult to understand because of is couches in techno babble, not plain English. To get my support you need to retire it on lagoon English. Also this is not a plan. It is a desire of a vision. I totally support reducing the impact of dementia on individuals and the community but I think you have lost your way with this document.
Q.20 Overall	Some of the clauses in the document are very wordy and could be simplified to make them more easily understandable for everyone - not just policy makers and strategy boffins!
Q.19 Enablers	This is getting a bit PC
Separate	Please excuse my "non" NZ manners – a few disappointments when actually reading the document. Being "polite" "politically correct" and "nice" is NOT the way to serve our patients and their families.

16.3 There was a desire for a shift in tone to emphasize empowering wellbeing, engagement, and rights

Survey question	Comments
Q.3 Goals	Perhaps rather than focusing on reducing the impact (Burden) of the person with dementia on the community (negative). Focus on empowering the person with dementia to be an engaged and supported member of the community. Compassionate communities model.
Q.3 Goals	That it includes people with dementia actively contributing to society
Q.3 Goals	Both statements reflect a 'doing to others' attitude which conveys a sense of disempowerment - ie that we know best and have the answers. I would prefer us to see the Plan as a 'walking beside' attitude - appropriate resources and tailored support are available to everyone, easily accessed, of high quality, and delivered in ways that help make a difference to people's lives. So we turn the Plan back on ourselves and aim to improve the resources and services we have available and how we deliver these.
Q.3 Goals	Needs to have something about well-being and safety
Q.3 Goals	I believe we need to focus on improving the well-being of people living with dementia
Q.3 Goals	Improving the lives of people with dementia is an excellent goal, as are most aspects of the proposed goal - however, there is a cost to that and while "decreasing the impact on the economy" aligns with the promotion of risk reduction lifestyles, for those with dementia, there is an increased cost for improved services and therefore that conflicts with the goal to reduce the economic impact
Q.3 Goals	I am not sure about the reference to the impact on the 'economy'
Q.3 Goals	Improving the lives of dementia sufferers, and ‘reducing their impact’ on health systems needs to be carefully thought out
Q.3 Goals	I can't see how we can decrease the impact on communities and the health system. The community and the health system have to step up and take more responsibility for people who get dementia, both medically and housing.
Q.3 Goals	Improving the lives of people with dementia is an excellent goal, as are most aspects of the proposed goal - however, there is a cost to that and while "decreasing the impact on the economy" aligns with the promotion of risk reduction lifestyles, for those with dementia, there is an increased cost for

	improved services and therefore that conflicts with the goal to reduce the economic impact
Q.19 Enablers	Once again, it's not only about service, but also purposeful engagement--people need to continue to contribute to their communities in a purposeful way and not just be dependent on services, which can lead to excess disability. Alz Western Australia has had a 10-year grant to connect newly-diagnosed people with volunteer opportunities in their communities. Great stigma-buster!
Q.20 Overall	focus on the fact PWLD live in the immediate now.
Q.19 Enablers	Identifying that Independence is key focus
Q.17 Capability	More work must be included into the non-pharmaceutical interventions, particularly on the impact of social isolation for the people and caregivers of people with dementia.
Q.17 Capability	Within the training to support best-practice include the research based evidence of the intervention of music therapy to increase awareness of success and growth of this intervention with successful goals and outcomes for people living with or caring for people with dementia. See Dr Felicity Baker's University of Melbourne current world-wide research "project/programme … uses music to reduce the despair of dementia.
	Rights
Q.20 Overall	More emphasis on helping people with dementia to maintain autonomy and continue to live independent lives in their own homes for as long as possible (this will require greater investment in community care services as this is usually the factor that decides whether someone moves in to residential care) More emphasis on autonomy and human rights for people who have cognitive impairment. Helping people to understand that even when people start to lose capacity to make decisions about their property and finances, or health and welfare, that it is a spectrum, not black or white. Families, the public, health and social care staff need to be encouraged to continue to treat the person as a fully functioning human being with preferences and wishes, who should still be INVOLVED as much as possible in decision-making and their human rights should be respected throughout their dementia journey. This would be part of a public education campaign, training, hospital and care home standards etc. Family best interest meetings should become a STANDARD part of elderly care, not a luxury…This is about social inclusion on all levels - one of which is cognitive impairment and dementia.
Q.20 Overall / Separate	The RANZCP notes these elements are omitted: 5. Addressing the Rights of People with Dementia From written: We argue that 'detaining' people in secure dementia units without sufficient legal documentation to support this decision-making is a breach of international and national human rights legislation, including the New Zealand

	Bill of Rights Act 1990 and the United Nations Convention on the Rights of Persons with Disabilities[ix] [x] The Protection of Personal and Property Rights Act 1988 is a critical piece of legislation for people with an impaired capacity to make decisions, which includes many people with more advanced dementia. Given that there are known abuses and difficulties we propose a review of this Act to ensure people living with dementia are treated equitably and having their specific needs met. We note many older people struggle to organise and fund the process of getting an Enduring Power of Attorney in place. The objective of the Plan is to ensure people live well with dementia therefore, it is a central tenet that their legal rights are not eroded.
Q.3 Goals	I would like to see more language related to human rights (as in the UN-CRPD and WHO language). I would also like to see PLWD not just as recipients of care and services, but actively engaged in the community, through volunteerism, workplace support, etc.
Q.3 Goals	The plan needs to be designed centred on the voices of people affected by dementia, be consistent with the UN Convention on the Rights of persons with Disabilities and honour the Crown's special relationship with Māori under Te Tiriti o Waitangi.
Q.5 Principles	People affected by dementia need to have access to their human rights - that needs to be somewhere in this document.
Separate	“I think the plan should include more about the human rights of people living with dementia in aged residential care who are often segregated into special "dementia units" and locked up in "secure units”. This practice should be challenged and stopped.”

17. Principles

Support and suggestions

17.1 **There were supportive comments about the principles.**

17.2 **There were suggestions for the way the principles were written.**

17.3 **Some people felt having separate principles for equity and specific populations was redundant.**

17.4 **There were comments about the way the concepts of person-directed, person-centred and evidence based were incorporated.**

Support

Several respondents commented positively about their approval of the principles, and for the importance of integration.

Writing

There were editing suggestions.

Equity / specific populations

As noted in section 12 there was a great deal of discussion of equity. Several respondents felt having separate sections for equity and specific populations was redundant.

Best practice

In the draft plan the principles section opened with reference to services being person-directed, rather than person-centred. There were some hesitations about this emphasis, and about the perceived contrast between person-centred and medical care in the best practice principle.

There was also a perception of a potential tension between evidence based and best practice emphases.

17.1 There supportive comments about the principles

Survey question	Comments
	General
Q.5 Principles	All Principles have been clearly identified.
Q.5 Principles	I support the principles
Q.5 Principles	pretty much covered...
Q.5 Principles	I think the principles have been thought out
Q.5 Principles	Excellent principles
Q.5 Principles	I think these are good principles
Q.5 Principles	keep up the excellent work you are doing
Q.5 Principles	Sounds Great, This Is Long Overdue...
Q.5 Principles	Really can't fault any of the above principals…
Q.5 Principles	The eight cross-cutting principles that drive the way the plan will be implemented are highly appropriate...
Q.5 Principles	All of these principles are excellent.
Q.5 Principles	Strongly agree with basic principles …
Q.5 Principles	I've gone through the process with my mum and whanau and it has been so difficult that I strongly agree with these principals.
	Integration
Q.5 Principles	Working together as a 'team around the client' is crucial. It has been sooooo stressful for me a S an adult child of my elderly mother trying to locate, learn about and get services for her dementia. One professional doesn't seem to know what other is doing. '
Q.5 Principles	There are many allied health/ complementary practitioners available to be involved with addressing dementia prevention through personalised care addressing lifestyle and nutrition issues in the community.

Q.5 Principles	As a health professional (psychologist) and daughter of dementia sufferer I wish to strongly support a single case manager or key worker model so that services can be provided without interruption and gaps. Multiple services stitched together do not work for someone with dementia who cannot inform carers of their needs.
Q.5 Principles	It doesn't mention what services should work together (the 'specific populations' principle lists specific populations, but the 'integrated' principle doesn't mention who the services would be e.g. mental health, gerontology, physiotherapy, occupational therapy, speech language therapy, dietetics, social work, primary care, NGOs etc.
Q.5 Principles	I don't see integration in the Health sector, I'm a hands on carer and feel like I don't have any regular support even my peers are not efficiently trained for our Dementia clients and specific supports, so I would like more put into developing a team around each individual which would include family and health professionals.
Q.8 Incidence	I suggest more teamwork within the professionals that are helping persons with Dementia and their supports.
Q.11 Incidence	Once a person has been diagnosed with Dementia every resource should be involved so there is the you need to contact this person or that person or we need another assessment to see if you qualify.
Q.11 Incidence	And yet people are still being lost in our fragmented health system
Q.5 Principles	Comprehensive and integrated services are essential the service providers need to sign up to this to ensure it is a less complicated service provision the same in all DHB's
Q.5 Principles	Integrated - needs to go beyond the dementia sector with collaboration among all stakeholders to improve prevention, risk reduction, diagnosis, treatment, and care. Requires engagement of health including mental health and aged care, social services, education, employment, justice and transport
Separate	4th Principle: Integrated. Attendees discussed the importance of 'working together, sharing information' -Thames Agewise
	There needs to be a strong alliance between all stakeholders - there are too many trying to dip into the same pot
	Enabling factors
Q.19 Enablers	Actions supported
Q.19 Enablers	Agreed with all the above
Q.19 Enablers	without these things, any plan is unlikely to succeed.

Q.19 Enablers	these enablers MUST be an integral part of the plan without the knowledge skills and support there is no part of this plan that will be successful

17.2 There were suggestions for the way the principles were written

Survey question	Comments
Q.5 Principles	Principles: Specific populations – if referring to the Deaf community, a capital 'D' is expected, an alternative phrasing could be "individuals with a hearing loss (whether congenital, progressive and/or acquired)"
Q.5 Principles	With regards to specific populations above: reference to "intellectual disability" is now considered disrespectful and out of date … the term now used is "diverse needs"
Q.5 Principles	I don't like the expression "something might be wrong" - there is nothing "wrong". We need to change the lexicon around dementia, in order to de-stigmatise it. Better to say from assessment or some other phrase. "Specific populations" - I don't like how this is phrased, it feels like all the "other' groups have been lumped together. May be better to say: Specific populations – services recognise and respond appropriately to the unique needs of the special groups within New Zealand's population. These will include Pacific people, Asian people, the deaf community and people who have become hearing impaired, refugees, people living alone, LGBTIQA people, people with intellectual disability, people with young-onset dementia, people living with chronic and severe neurological and/or psychiatric conditions and those with addictions.
Q.5 Principles	Evidence-based and best-practice – services are grounded in evidence and best practice, balancing medical care with person-centred care, to deliver solutions that are effective, sustainable and affordable - change "medical care" to "health care" which will encompass all the disciplines involved in the care of a person
Q.5 Principles	Suggest numbering the principles.
Q.5 Principles	the wording of some of the specific principles need further clarification e.g. 'specific populations who experience dementia' - ... with 'Comprehensive' instead of 'something wrong' (using wrong is negative and victimising/shaming) suggest using wording such as symptoms or signs.
Separate	3rd Principle: whole of life. Primary health message. -Thames Agewise
Q.5 Principles	I wonder if there is another way of identifying the specific populations groups without using stigmatising or negatively connoted language (such as "Asian people") - this could be done instead by identifying "specific cultural populations, such as Pacifica, Asian (etc) who currently don't receive specific needs through mainstream services"
Q.5 Principles	The last point can be simplified to something like 'all groups in society regardless of age, gender, culture, sexual orientation, and co-existing physical or mental illness. it's a bit lengthy and tries too hard in its current form

Separate	Principles: person-directed: last phrase "empowered to contribute to decision-making" suggests that someone else is making decisions with the family's input. Should be "supported to make own decisions" (or similar).
Q.5 Principles	Why is national consistency given priority emphasis over quality? …Also, to whom does the 'affordable' comment apply? This seems to run counter to the UN commitment about the highest standard of Heath care attainable.
Q.5 Principles	Where is the lack of ability to navigate services addressed at this level?
Separate	…principles that have driven the way the plan is developed and implemented Take out word in – critical for in the development [Te Ao Māori] Enablers – what sector? To achieve equity not equitably [This respondent also included some suggestion about the preamble:] Increasing numbers of New Zealanders Plan sets out a three year horizon of action Dementia predicted [vs going to be] [poor health literacy] – we often talk about poor health literacy when also poor health literacy in the system and among health professionals to clearly communicate and engage and empower patients Gaps should be about current system not solutions Include readmissions and impacts on health of carers [under hidden player] Community expectations are expected to [vs will] increase if / when First Nation Plan iwi/ tangata whenua Te Tiriti O Waitangi / Treaty of Waitangi Whether or not the Maori action plan will stand alongside or inside the NZ Dementia Plan… Doesn't like the word explicit

17.3 There were comments about the way the person-directed and person-centred concepts were introduced, and the tension around evidence based.

Survey question	Comments
	Person-directed / person-centred
Q.5 Principles	We believe a person-directed orientation would be better replaced with the concept of a participatory approach. By this we mean having a model whereby clinicians aren't necessarily the main drivers of the situation. Allowing an equal involvement from those who are part of the person's 'dementia care provision team.' In terms of evidence based and best practice we would prefer to see the concept of 'holistic based' integrated into the policy and practice. This puts equal weight and importance on clinical care and social and spiritual care to deliver solutions that are effective, sustainable and affordable. it goes without saying that these would be grounded in evidence and best practice.
Q.5 Principles	I think care is needed that professionals do not have too much say, but that families etc also need to recognise reality.
Q.5 Principles	I think that rather than person-directed the plan should also consider being relationship-focussed. This recognises partnerships in care - and the circumstances in which a person is no longer able to advocate for themselves
Q.5 Principles	whilst it is vital that the consumer and family are at the forefront of decision making their needs to still be some direction from the specialist dementia teams as sometimes family are unrealistic about the outcomes of dementia care
Q.5 Principles	Person directed but person and family don’t always know best through lack of information or education. Needs something about supported with expert guidance.
Q.5 Principles	Principle 1. Person-centred care foremost promotes working around the person living with dementia.
Q.5 Principles	ideally the person with dementia is empowered with decision making however, as the disease progresses, they are often unable to exercise sound judgement. The whole area of mental incapacity needs to be examined

Q.5 Principles	Person-directed - I think we have got beyond this principle now, People affected by dementia what to be able to have control over their lives as much as possible and support to make decisions.
Q.5 Principles	Regarding the first principle, I strongly agree with the person directed approach but there is a challenge from a practical point of view where the person diagnosed with dementia may not be happy/willing to accept their diagnosis and be empowered to contribute to the decision making. However the intention here is the right one.
Q.5 Principles	**Person-directed-** this should include a clear statement that people with dementia should be accepted and treated with respect.
Q.5 Principles	Emphasise person-centred
Q.5 Principles	The person-centered approach is strongly supported
Q.5 Principles	in evidence based swap medical care and person-centred care as this is a better fit with the vision
Q.5 Principles	Evidence based practice and best practice - services grounded in... I suggest you swap it around to make person-centred care come before balancing medical care Arguably it's semantics but person-centred care MUST be first every time.
Q.5 Principles	Concerned that person centred care would in some way be balanced against a medical model. Not sure what this means. Why would there be a difference to balance.
Q.5 Principles	..It is unclear why the evidence-based and best-practice principle separates medical care from person-centred care – best practice assumes one and the same!...
Separate	**Evidence based and best practice-** the statement "balancing medical care with person- centred care" is somewhat confusing in relation to the "person-directed" principle - that all medical care should be "person centred". Is the intention here to say that medical interventions/medication should be balanced with lifestyle management?
Q.5 Principles	Respect must be given at all times
Separate	Person / whanau directed Not us placing them: …are engaged in decisions about…
	Evidence-based
Q.5 Principles	Note that there can be tensions between evidence based and best practice due to the origins of evidence and whether that has been tested in a New Zealand context.

Q.5 Principles	There has been a preoccupation with evidence-based practice and research over the past 30 years which has not resulted in better services for people and populations. Rather, it has been courageous individuals and groups who have had to lay bare their own circumstances and experiences who have driven the social change which may have positively changed the deficit practices and processes for those most marginalised and oppressed. Similarly outcomes based funding processes which do not really measure
Q.5 Principles	Principle 7. Evidence based practice must take into consideration the personal evidence provided by people living with dementia/family/loved ones and all levels of healthcare professionals. Too much evidence based practice is medically dominated and structured around quantitative measures, which is generally performed by doctors. It is not acceptable to discard other forms of evidence.
Q.5 Principles	Restricting to 'evidence-based' can lead to over-medicalisation of research, as there are many important aspects that may not be grounded in research to date, but should be considered. Qualitative and mixed methods research should not be given the short end of the stick either.
Q.5 Principles	Evidence based is fine, but ignores the many safe things that may help individuals -even if not 'proven' at a population level. This plan needs a more innovative approach in this regard.
	So-called best practice keeps being touted, but it becomes an excise for medical fads to become dogma dictated by a few specialist and interest groups. For example vitamin D for osteoporosis in rest homes has become compulsory and doesn't allow for the fact that there is a body of opinion suggesting harm. I think the industry needs to concentrate on funding and leave the quality of care to the training bodies ie medical and nursing council etc. funding is woeful
Q.5 Goals	At all stages of implementation there should be a clear pathway for evidence-based direction to be readily incorporated
Q.5 Principles	As already stated- ability to incorporate new evidence based practice without delay
Q.19 Enablers	typically medical workforce either pays for our own quality care OR is subjected to DHB directed free so called training which is not training at all - it is usually just a list of things we are allowed or not allowed to do. I suggest great care to preserve the freedom of doctors to use treatments or methods which they find effective.

18 Reducing incidence

There was considerable divergence in the comments about the relative priority to be placed on reducing incidence in the vision and goals and as an action area.

Views and suggestions

18.1 **Some respondents placed brain health promotion as a high priority.**

18.2 **Some respondents were hesitant about the goal of reducing incidence.**

18.3 **Several factors that may help success were raised**

18.4 **Hearing loss is a major risk factor for dementia.**

Support

Some respondents were very supportive of this focus, and some would like to see the emphasis taken further.

Hesitations

Some respondents were hesitant, seeing brain health initiatives as being unproven or covered by other health awareness campaigns or unproven, or as less important than supporting people living with dementia.

Success factors

A number of factors were raised as helping success including having a brain health focus that ties in with other programmes, recognising broader actions, and communication. As noted in earlier sections recognising diverse communities and learning from past success were also highlighted

Hearing loss

The role of hearing loss in cognitive decline was raised by some respondents.

18.1 Some respondents placed brain health promotion as a high priority.

Survey question	Comments
Q.8 Incidence	Making this the foremost effort to be involved in the lives of all people
Q.8 Incidence	Strongly agree on a preventive measure. Research and awareness is important
Q.8 Incidence	I support the actions
Q.8 Incidence	Yes maybe could be included along with other screening and prevention initiatives
Q.8 Incidence	On the correct path
Q.8 Incidence	A no -brainer - makes perfect sense
Q.8 Incidence	This is a big piece of work which is complementary to providing a good service to people affected by dementia
Q.8 Incidence	100% agree that prevention as much as possible is key here, and starting people recognising early what they can do to help their brain is the way to go.
Q.8 Incidence	Sounds Good To Me..
Q.8 Incidence	This is an excellent objective (from one who is in the early stages of this health issue
Q.8 Incidence	Information to be provided on current on reputable research rather than snake oil merchants until a cure
Separate	Reduce the incidence of dementia- we strongly endorse the recognition of the importance of a healthy lifestyle and social connection as preventative measures, as with other chronic, non-communicable conditions. – New Zealand Council of Women
Q.3 Goals	The inclusion of prevention in the vision is important
Q.3 Goals	The goal is limited Thu people already loving with dementia. It is the ambulance at the bottom of the cliff, not the fence at the top. *[]*
Q.11 Living well	This is wonderful in terms of "ambulance at the bottom of the cliff" support, but I believe we can be proactive in the prevention of this disease as well.

Q.3 Goals	Whilst acknowledging people with dementia need all the care mentioned in the vision & goal, my belief is that the focus must be about prevention.
Q.3 Goals	Education for prevention is needed.
Q.3 Goals	the major risk factors are alcohol in any quantity, cigarettes, other forms of nicotine and vascular disease from all causes. So the prevention of dementia is the same as for heart disease obesity and diabetes - a nutritional approach with exercise etc. *[Note – unclear interpretation for theme]*
Q.3 Goals	I like the statement about brain health in general rather than focus on dementia as there is society fear in my view, around dementia, so I think brain health should be first.
Q.3 Goals	Strengthen wording about prevention and the importance of life style choices in preventing Dementia
Q.3 Goals	The inclusion of prevention in the vision is important
Q.3 Goals	The goal is limited Thu people already loving with dementia. It is the ambulance at the bottom of the cliff, not the fence at the top. *]*
Q.3 Goals	Whilst acknowledging people with dementia need all the care mentioned in the vision & goal, my belief is that the focus must be about prevention.
Q.5 Prevention	Say much more about lifestyle programmes and prevention
Q.14 Communities	Raising public awareness about increasing brain health is key to prevention of all chronic disease including dementia. Education programmes to coach people to take responsibility for their health could see a decline in chronic disease (at least 80% caused by lifestyle/ poor nutrition) and reduced burden on the medical system.
Q.14 Communities	Include reference to modifiable risk factors - e.g. "Design a multi-level multi-channel de-stigmatisation campaign to raise awareness and increase understanding of dementia and modifiable risk factors (ie. management of hearing loss1) – for implementation in the next plan (beyond 2023)"
Q.17 Capability	Including a coalition or partnership with organisations that represent the highest modifiable risk factors would benefit this action plan to work through raising awareness on preventative measures etc
Q.20 Overall	I do believe a stronger emphasis on preventative measures is needed throughout the action plan as the focus is on supporting those who are diagnosed and living with dementia which is incredibly important however there are many actionable initiatives that can be implemented and included in the public health programme that can help to reduce the increase in dementia in New Zealand. This needs to be a much bigger focus for the government
Separate	***1st Objective***: 'Reduce the incidence of dementia'. Attendees discussed how this links to primary health/lifestyle and current MOH health/well-being policies. Discussion re chronic inflammatory conditions as a dementia risk factor, preventative life style factors which may impact on dementia type conditions.

	Need for more public education/awareness re life style preventative factors. Dementia Waikato will endeavor to include this topic in more of public awareness talks to community groups. Howard encouraged attendees to consider the on-line University of Tasmania short course on Alzheimer's/Dementia which includes preventative factors. – Thames Agewise
Q.20 Overall	Prevention Services designed to help prevent onset like free Gyms, good nutrient filled prepared meal selection, as well as inclusion in disability allowance. Social recreation, Free IT education and monitoring in the home to encourage healthy minds and bodies
Separate	Requirement for appropriate health promotion strategies that are aimed at dementia reduction but do not to infer that people's lifestyle choices are the only reasons behind an increased risk of dementia. A need to mindful of negative connotations that may occur that an individual is to blame for diagnosis of dementia due to entirely to their own lifestyle. - collated feedback from the national MHSOP leaders
Q.8 Incidence	My comment on this is around stigmatisation-we see it all the time that when someone develops a condition that is seen as preventable assumptions are made that they are somehow to blame for not preventing getting it. I realise this has to be balanced with prevention. Can we be really honest with the population about the degree to which this disease is truly preventable?
Separate	…Create a PREVENTION task force and make sure resources are allocated to dementia prevention independently of the DHB's budget…

18.2 Some respondents were hesitant about the goal of reducing incidence

Survey question	Comments
	Hesitations
Q.3 Goals	Dementia is the brain aging/dying that cannot be prevent forever.
Q.3 Goals	Dementia cannot be prevented. There are a number of factors e.g. lifestyle that can decrease people's chances of getting it but nothing as far as I know can prevent it.
Q.3 Goals	At this time it is very difficult, almost impossible to prevent dementia unless there is significant public education and the will of people to change their lifestyles.
Q.3 Goals	Preventing dementia sounds very negative - you can live well with dementia.
Q.3 Goals	concerned that prevention will be the focus and we have people suffering NOW that need help, support and resources. also, needs to be focus on the people offering services as they need more to do their jobs and meet the needs of the people they are serving.
Q.8 Incidence	I have doubts that dementia can be prevented. My husband was a fit, intelligent, slim man with no other health problems. Nor was he on any meds. I would like to see more studies done on cell phone use.
Q.8 Incidence	I gave a fatalistic attitude. Dementia is a degenerative.... spending massive amounts of funding on reducing the incidence is a waste as it is well-nigh impossible...
Q.8 Incidence	Very idealistic but will be hard to implement.
Q.8 Incidence	We need to accept that in populations with multiple health (and social) needs, this might not register as the top of their list.
Q.8 Incidence	The evidence for specific interventions reducing the development of dementia is fairly weak and should not be a major focus of the programme. Improved cardiovascular and metabolic health is probably what is driving the observed reduction in dementia prevalence and there are multiple programmes supporting this already.
Q.8 Incidence	I haven't heard of any effective dementia prevention practices, the disease is so random, it seems unwise to let people think it can be avoided. We are all living longer is the only constant. Certainly deafness makes it more difficult and some forms of diseases like Parkinson's.
Q20 Overall	…suggest … that Alzheimers NZ ensures it prioritises its core group rather than expend limited resource on risk factor based prevention - that other agencies

	will be doing anyway. Suggest contributing to a healthy ageing strategy but not trying to own that space per se.
	People before prevention
Q.8 Incidence	Reducing the incidence of dementia is an important priority – however, this priority should not be privileged above the second objective below i.e. Support people living with dementia and their family and whānau care partners to live well at all stages of the illness.
Q.8 Incidence	There are so many different types of dementia. Don't waste too much time hoping to reduce causes. Help the people suffering first and foremost
Q.8 Incidence	In an ageing society our FIRST priority should be to care for those who already have dementia. Alzheimers NZ does not need to waste its resources replicating work that is already done by government and by other organisations with the same population attributable risk factors
Q.8 Incidence	We know that people will get dementia and while there is research there is no cure. Should our focus be on other things like new services, support, better funding and staffing in Aged care
Q.8 Incidence	many older people living with dementia were very fit and active before they developed dementia. I believe that more money should be put into what dementia is and trying to reduce the stigma of dementia.
Q.8 Incidence	Although reducing the incidence of dementia would be great, my concern is that a reduction of 10-20% in the near future is overly optimistic. The preventative strategies are mostly covered by other health strategies already in place and we should support them. If too much emphasis is put on this objective we could waste time, effort and money in this area which would be better used managing the real problems in managing dementia that are already with us. I don't disagree with the objective, but it should be of lower priority at this time.

18.3 A number of factors were raised as helping success

Survey question	Comments
	Tie in with other programmes vs own programme
Q.8 Incidence	Need to also make the links that what's healthy for the heart is good for the brain - and links to the health promotion programme
Q.8 Incidence	As with diabetes funding there needs to be discussion where the most appropriate allocation of resources/funding sits. Reducing risk factors in chronic diseases such as diabetes, heart disease are interrelated to dementia and as such are already funded in primary care. Emphasis needs to be in highlighting the associations with the former diseases and conversations started with cognitive impairment discussions sitting alongside dietary and exercise interventions in heart disease and diabetes. Primary care providers such as rest home nurses, and practice nurses can be at the forefront of these discussions.
Q.8 Incidence	To highlight the issue- Stroke Central Region recently launched the #DontBeTheOneNZ Stroke Prevention Campaign with the help of Auckland University of Technology and the World Stroke Organisation. Obviously promoting the Healthy Brain Message without mention of vascular dementia.
Q.8 Incidence	A simple statement is needed, e.g. what's good for the heart is good for the brain. A focus on brain health is a good way forward - it's understandable and demystifies the condition.
Q.8 Incidence	Focus on a healthy living plan rather than disease specific
Q.8 Incidence	Brain health focus rather than dementia prevention focus.
Q.8 Incidence	Dementia prevention should be re-packaged as maintaining healthy brain function (just like we try to maintain healthy function of any organ - heart, liver, kidney - or joints etc)
Q.8 Incidence	Brain and Heart Health as so closely linked that they should go hand in hand
Q.8 Incidence	Pooling resources and collaboration with all organisations that work within brain health is the key to not over lapping services or having to many services involved
Q.11 Living well	Likewise, it is important that as well as maintaining a healthy brain that we also OPTIMISE brain health even when it is beginning to fail. The interventions are the same - what is good for the body is good for the brain
Q.8 Incidence	Even in people aged 75+ CVD has 5 times the burden of disease of dementia. In younger people this is even more so. So whilst the actions needed for

	prevention are similar environmental and personal health promotion needs to focus on these needs
Q.8 Incidence	Adapt existing prevention plans instead of spending valuable resources on developing a plan
	More than just public awareness / how it is run
Separate	We [RANZCP] strongly support the preventative focus articulated in the Plan. We contend universally, including the public and health care workers/professionals, there is poor health literacy around interventions to reduce the risk of dementia. The Lancet Commission's comprehensive report outlining dementia prevention strategies, indicates that quitting smoking, increasing exercise, managing hearing loss, maintaining social contacts, avoiding diabetes and obesity all contribute to reducing the risks of dementia. A study has demonstrated that older Māori identified waiata, te reo, whakapapa and kapa haka as protective activities in slowing down or preventing mate wareware (dementia). Early research findings indicate that many New Zealanders are not knowledgeable about the risk and protective factors associated with dementia: study participants were only able to identify 4 out of 14 modifiable risk or protective factors for dementia. The RANZCP suggests that New Zealand prevalence rates for dementia are collected and then monitored to assess if intervention programmes have a positive impact on reducing dementia. We accept this is a long-term objective and that this approach requires robust measurement outcomes and significant resources. The RANZCP advocates that more funding is directed towards preventative interventions, especially amongst at risk populations identified in the Plan. The funding models have to take a long-term approach, not just to keep abreast of the current population's needs, but to consider future increases in numbers of people with dementia and to document and understand their complex presentations. The preventative strategies should be developed at a population-based level and at an individual consumer level. There are specific populations and individuals who may be at greater risk of developing dementia, therefore tailored interventions are required to reach these consumers. For these reasons, the lead organisations are not only NGOs but DHBs, researchers/ academics working in older peoples' care and the Ministry of Health. The Government's emphasis on cross-government approaches to addressing wellbeing, indicates that other agencies (including but not limited to the Department of Corrections, Housing NZ, The Ministry of Social Development, Te Puni Kokiri) must understand and support the Ministry of Health's objectives in promoting preventive strategies to reduce dementia. The rising tide of dementia has the potential to negatively impact the services, support and strategies of all these agencies therefore we suggest instigating a similar 'hubbed-up' approach as that currently in use by the Department of Prime Minister and Cabinet.
Q.8 Incidence	A workforce that is knowledgeable about dementia prevention and brain health protection will be necessary.

Q.8 Incidence	must come out strongly and unequivocally to recommend total removal of nicotine from the country in all its forms as well as marijuana which is a clear contributor to brain disease. Vaping must be banned. Over prescribing nationwide of sedatives antipsychotics and the like should be targeted as some studies (USA) have linked habitual use of medications which cross the blood brain barrier with later onset of neurological disorders including dementia.
Q.8 Incidence	Look at the impact of loneliness and boredom on the welfare particularly of elderly living alone. There has been a lot of work put into basic care of people ageing in place, but very little on the impact of lack of social input. As people age they tend to get more frail, other health issues tend arise, and their world gradually reduces until they can often only see caregivers coming in quickly to do necessary health cares. Even these reduce as money is less available. The ability to take themselves out reduces as they lose the ability to drive and/or walk or catch public transport. Friends tend to be of the same age/socioeconomic group, reducing further the ability to have social interaction. Families tend to be busier, having to provide money for their family, or even living in different parts of the world reducing further social input. The poor rate of pensions also impacts on the ability of the frail elderly/ person living alone with a disability to socialise. Poor eyesight or hearing also impacts on this. Loneliness has a great impact on both mental health issues and dementia in the elderly living alone. The ones that tend to suffer the most are the ones in the lower socioeconomic groups, which tends to include Maori, Pacific Islanders and other smaller ethnic groups.
Q.8 Incidence	I believe there is a strong link with diet and lifestyle and this preventative approach to educating our communities before the onset of dementia is critical to its prevention and/ or management. It has been studied widely that the essence of a Ketogenic diet with support from essential supplementation can aid and in some cases reverse the symptoms of dementia. Investment needs to be placed in education and incentivizing of healthy eating and living.
Q.8 Incidence	Lobby government to place a sugar tax on foods and beverages with high sugar. Lobby government to implement recommended changes to the sale of alcohol. Both of these strategies have been proven overseas to make a real difference to non-communicable diseases.
Q.5 Goals	Physical activity is very strongly protective of cognitive decline. It's not mentioned anywhere - that's a fail
Q.8 Incidence	The action ignored is physical activity as the main driver of protection from cognitive decline, in the same way that its highly protective against heart disease, diabetes and cancer. Don't be vague and talk about lifestyle when clearly you don't understand the evidence of physical activity
Q.8 Incidence	The actions must address improving nutrition and physical activity which are key to prevention and quality of life
Q.8 Incidence	Employers could perhaps support employers more. Provide free health checks for employers. Have a space for exercise or exercise cycles etc. Encourage staff groups to walk at lunch times etc.

Q.8 Incidence	It is not clear what form a "health promotion programme" would take. Does "promotion" simply imply public awareness campaigns, or would it include specific actions such as lobbying government to take actions on reducing the obesogenic environment (such as eliminating the massive spending on sponsorship and advertising of unhealthy foods that lead to obesity, high blood pressure, and then cognitive impairment)?
Q.8 Incidence	Pg. 5 add dental care to list of conditions in “reduce incidence of dementia” objective.
	Communication / Community led
Q.8 Incidence	Comment. Better education is needed throughout the country and it must be communicated in a way that the population really understands how dementia impacts on lives and the communities they live in.
Q.8 Incidence	Effective, clear communication to the consumer will be very important. Currently there are so many different health campaigns - it's difficult for people to know what the latest, trusted source of information is to go to. When my mother was diagnosed with dementia, I found it confusing knowing which websites to go to for information. The Ministry of Health/government website provides a range of links - some look like private companies, e.g. Bupa? Why do they have Bupa and not other providers? Why links to Alzheimers NZ and not Dementia NZ? It's very confusing for people and does not look trustworthy. Families need a clear, trustworthy source of information - a website preferably with a .govt or .org - like the Ministry of Health website - although at present the information there is not very helpful. The Alzheimers NZ pdf brochures were very helpful and practical.
Q.8 Incidence	Communicate often with them
Q.8 Incidence	Community engagement in some form is paramount
Q.8 Incidence	The public of New Zealand need to be on board with these actions.
Q.8 Incidence	Better communication who be a help especially with people who attend a day programme. They need to be involved in all aspects of their care
Q.8 Incidence	Working with colleagues is great but prevention programme should be focused on education of general population. Also GPS should have some role.
Q.8 Incidence	The work of dementia prevention should follow a community development model of practice and not be primarily located within the health and other professions. It should be driven from the flax roots up.
Q.8 Incidence	7. The proposed action is: Work with colleagues involved with other key non-communicable diseases and population health to design a health promotion programme that includes dementia prevention / brain health protection – for implementation, potentially in conjunction with other healthy ageing goals, in the next plan (beyond 2023) Use co-design to include people with dementia, family and others in developing health promotion as they will know what worked / did not work for them

Separate	Not just colleagues – people with lived experience of dementia, their whānau / carer and health sector
	Focus / approach
Q.5 Principles	Rather than reduce impact - delay impact is more realistic for first plan with current knowledge.
Q.8 Incidence	As previously suggested - "delay is more attainable"
Q.8 Incidence	Same comment about the word 'prevention'. As well as reducing the incidence, applying this research to those living with dementia will help maximise brain function, perhaps that can be worked into the wording
	Target
Q.8 Incidence	Emphasise the lifestyle preventative habits to the age 30-40 cohort...they are the future of dementia
Q.8 Incidence	Risk reduction is on 3 levels. Risk reduction strategies should not only be targeted to level 1 and 2
Q.8 Incidence	Education needs to begin decades earlier re healthy living and its relationship to brain health
	Leadership
Q.8 Incidence	DHB needs to support and lead direction as it does with other LTC
Q.8 Incidence	I think it would be important for the groups working on this to have one strong leadership organization to ensure consistency and that information is always up to date.
Q.8 Incidence	Suggest that the Health Promotion Agency has an explicit role in the development / delivery of this action. While research about the cause and cure/treatment is included elsewhere in the actions it could also be included here

18.4 Hearing loss is a major risk factor for dementia

Survey question	Comments
Q.8 Incidence	Suggest include in the objective statement reference to the impact of hearing loss. There is a strong association between hearing loss and dementia (the mechanisms of the association continues to be investigated) and as such hearing loss is the highest rated modifiable risk factor for dementia1" (Lancet Commission 2017 - Dementia Prevention, intervention and care.)
Q.14 Communities	Include reference to modifiable risk factors - e.g. "Design a multi-level multi-channel de-stigmatisation campaign to raise awareness and increase understanding of dementia and modifiable risk factors (ie. management of hearing loss1) – for implementation in the next plan (beyond 2023)"
Q.14 Overall	NZAS wishes to highlight the strong association between hearing loss and dementia. Though the mechanisms of that association are still unclear hearing loss was identified as the highest rated modifiable risk factor for dementia in the 2017 Lancet report - Dementia, Prevention, Intervention and Care (Livingston et al. Lancet, 390, 2673 - 2734) The report identified the complexity of distinguishing between hearing loss (ie. person has not heard and so can't recall) from dementia (ie. heard but can't recall). The presence of any hearing loss is associated with nearly a two-fold increased risk of developing dementia, and a more severe hearing loss is associated with a higher risk (up to four-fold).
Q.8 Incidence	The plan should overtly recognise the importance of sensory systems - and particularly hearing as the highest modifiable predictor of dementia
Q.8 Incidence	Untreated hearing loss should be reflected in the action plan
Q.8 Incidence	Please ensure that hearing loss screening and vision screening occurs before dementia assessments which use these modalities. Please ensure that staff in dementia units appreciate the role of not hearing well in the effects of dementia .. and that they encourage their residents to use hearing aids well and care for the aids. This is a huge lack!
Q.19 Enablers	Audiologists potentially have an important role in the assessment of cognition and mitigation of cognitive decline associated with hearing loss. This requires resourcing of audiology training programs to address the knowledge gap.
Q.14 Communities	I think the stigma is not just associated with dementia it is associated with hearing loss and raising awareness of the impact of untreated hearing loss on cognitive decline.
Q.17 Capabilities	Please look at DCAL @ UCL Deafness Cognition and Language Research Centre.

19 Living Well

18.1 **There were supportive comments about Living Well as a priority.**

18.2 **There were comments to consider the specification of 12 months support and DHBs as lead.**

18.3 **Palliative care.**

Support

There were supportive comments about the priority area and its link with reducing stigma and also comments about the importance of the action areas such diagnosis and assessment and navigators.

Suggestions

Two main suggestions for consideration centred on the specification of 12 months support which might be used to limit services, and possible issues around DHBs as the lead organisations. There were a range of more general comments as well.

Palliative Approach

There was support for the inclusion of palliative care approaches and a detailed response outlined how this point could be improved and how palliative care was relevant in other areas of the plan.

Living well

a.1

Support for

Survey question	Comments
	General support
Q.11 Living well	This should be priority number one
Q.11 Living well	This is the main focus - we need to do what we know we should be doing and are not currently doing consistently.
Q.11 Living well	Agree with all of the above but need to prioritise further.
Q.11 Living well	I strongly support the aim of living well with dementia, however have concerns that the actions do not demand change now, but instead are looking at what can be implemented in the next plan (beyond 2023). We already have limited implementation of the New Zealand Framework for Dementia Care, and aiming for implementation in the next plan feels like the rights and needs of those with dementia and their family/whanau are being dismissed/deprioritized once again.
Q.11 Living well	I hope you are able to implement your objectives to assist those of us who are inflicted with this awful disease!
Q.11 Living well	Sounds Good To Me..Long Overdue...
Q.11 Living well	I support the actions
Q.11 Living well	The RACP strongly supports the focus on flexible and available services which can cater for the great diversity of individuals and whānau who live in Aotearoa New Zealand.
Q.11 Living well	A very urgent and needed draft plan needed for our community. I look forward to hearing results of this survey
	Link with de-stigma
Q.11 Living well	Many of the people I have met with the disease do not want to have the diagnosis because of the stigma attached to it. Until their dementia is quite advanced it can be difficult to get a diagnosis yet the carers are well aware of what it is. Some family members resist the label also as they find it difficult to face the reality of dementia.
Q.11 Living well	That inclusion and control are incorporated to significant factors - living well is much more than post diagnostic support - people also need broader interventions to tackle stigma
Q.11 Living well	I am really uncertain about what constitutes timeliness of diagnosis. Right now, people with an early diagnosis run straight into stigma and discrimination

	problems. Without some serious effective work on stigma and discrimination, people are better off leaving getting a diagnosis for as long as possible. Care services are probably a good place to start dealing with the stigma / discrimination issue. I do not understand the second action - needs clarification.
Q.11 Living well	Comment. Having lived and cared for my husband over a number of years with dementia, family support and understanding of this condition is paramount. The stigma of dementia is prevalent in many families and this is why I am so insistent that better education is necessary. The person with dementia may have several types of dementia or other health problems and the impact on a person can be frightening. All medical/nursing education must be improved so that these people have a real understanding of dementia and not just text book understanding.
Q.11 Living well	Many of the people I have met with the disease do not want to have the diagnosis because of the stigma attached to it. Until their dementia is quite advanced it can be difficult to get a diagnosis yet the carers are well aware of what it is. Some family members resist the label also as they find it difficult to face the reality of dementia.
Q.11 Living well	The Ministry of Health needs to run a public campaign promoting these actions.
	Support for consider options for diagnosis / assessment
Q.11 Living well	DHB's should be funded and required to make a firm commitment to services such as Memory Clinics, rather than the ad hoc situation that currently exists.
Separate	Good idea to test options for making diagnosis: some GPs still won't. If there are mental health nurses in GP practices (per recent MH recommendations) they should be trained in dementia diagnosis.
Separate	Consider alternative means of diagnosis - If there are mental health nurses or advanced nursing roles that can support diagnosis GP practices (per recent MH recommendations) they should be trained in assessments that will add to GPs ability to provide dementia diagnosis. - collated feedback from the national MHSOP leaders
Separate	Discussion re other health professionals being involved with carrying out cognitive assessments, to take this work load off GP's. e.g.: ?Dementia Waikato staff, Clinical Nurse Specialists. – Thames Agewise
	Support for pathway
Q.5 Principles	National consistency of the cognitive pathway would be beneficial. Need to have GP's etc. to follow pathway prior to on referring to other agencies and important for the agencies to have a confirmed diagnosis.
Separate	…Cognitive impairment pathways should be a national strategy

	Direct accountabilities and governance structure…- collated feedback from the national MHSOP leaders
Q.11 Living well	Cognitive impairment pathways need to significantly improve, and outlining what this looks like will improve consistency. if left vague, the poor and inconsistent services will continue unchallenged, and dependent on the preferences of a few managers and psychiatrists alone.
Q.11 Living well	A national Cognitive Impairment Pathway needs to be developed to provide consistency. We need to be wary of significantly increasing medical costs with little benefit (e.g. how and when we use brain imaging, use of cognitive enhancing medications). e.g. may have to make some difficult choices to rarely image brains, but always provide care.
Q.11 Living well	It is vital that timely early diagnosis is made a priority – presently is random and haphazard. The Dementia Pathways need to give very clear directions for specialist services to see people with potential young onset dementia.
	Navigators
Q.11 Living well	Consider having dementia navigators as the FIRST port of call for people with cognitive impairment - this is a cost-effective way to carry out an initial assessment to decide whether a person might have dementia and needs further assessment, or whether the person only needs health advice on how to AVOID dementia at this point (this fits in with prevention policy)
Q.11 Living well	Dementia navigation services - please emphasise this - without assistance to navigate services none of the other actions can be easily accessed by family or client
Q.11 Living well	Everyone needs to work collaboratively for this to happen. information is often given to tick a box but it is not often followed up to see if people want to know everything to start with, others just aren't ready initially. Some people like someone to go through the information months later when ready to digest. If not being visited by a health professional this doesn't happen. Navigators are a definite need.
Q.11 Incidence	Living this right now and the lack of coordination, the lack of help to understand what is available, the disconnected ness of the "system' creates appalling and unnecessary stress on people already overloaded.
Q.20 Overall	Grateful for the help I have received from various professionals in getting care for my mum but was unnecessarily very stressful navigating this- housing, income, support to live independently. ‘working in partnership’ should’ve a priority.
Q.20 Overall	Listen to the families/whanau of those with dementia to make sure each person is supported and not just classed as all requiring the same kind of support or options. Remember those with the dementia are not lost in a complicated health system and are treated with Respect and Dignity.
Separate	On behalf of Lakes DHB MHSOP the following comments:

	There is a need for clarity around dementia navigator services as ease of access (easy navigation) or one point of information (ease of navigation) or one person (navigator) guiding the person living with dementia through-out their journey. The latter would be the gold standard, but most often is not possible.
Separate	Discussion re the importance of people who have a dementia related diagnosis and their families being offered assistance with dementia navigation at ***all stages*** , in order to live well. This needs to be client/family driven. -Thames Agewise
Q.14 Communities	Alzheimers education should be part of community health literacy programmes. Many people do not know where to start to find information when they suspect a family member may need help. It can be hard to know when to seek a diagnosis.

19.2 Suggestions / comments

Survey question	Comments
	Concern at 12 months
Q.11 Living well	...quality assure support services ...- at least 12 months post-diagnosis support - this support needs to over the full term - from diagnosis to death.
Q.11 Living well	Re testing options for supporting timely & accurate diagnosis - this may be helpful but one size may not fill all and different regions may find different models work well for them. I do support testing these options though as evidence of what works may support appropriate resourcing of successful models that may be more costly but more effective and accurate. Dementia can be a long journey and more than 12 months support post-diagnosis may be required to help someone live well with their dementia. Different inputs may be needed at different stages of their dementia journey and the person and their carer may not be ready to engage immediately post-diagnosis
Q.11 Living well	Investigate capacity for services to continue supporting post-12 months/during transition periods (e.g. into respite/care) / ensure individuals are not lost in the system post-12 months
Q.11 Living well	Why 12 months and not as needed? The progression of dementia varies so much that it should be as long as needed. Also, people's situations vary so much that again it should be as long as needed.
Q.11 Living well	Supporting people living with dementia and their care partners to live well is needed at all stages of the illness trajectory. It is unclear what the research evidence is for 12 months post diagnosis support.
Q.11 Living well	People with dementia sometimes live for many years beyond diagnosis and support should not be limited to 12 months but articulated clearly as lifelong support. We would recommend wording change to reflect this. Workforces supporting both people with dementia, and their family and whanau will vital to the success of the Plan. It is recommended that the training and/or upskilling of those supporting workforces should be an individual and specific action within the Plan.
Q.11 Living well	...quality assure support services ...- at least 12 months post-diagnosis support - this support needs to over the full term - from diagnosis to death.
Q.11 Living well	12 months post diagnose. I just feel there could have been more support for mum and anyone going through young onset. When mum was diagnosed she should have been assigned and supported by someone with regular meetings; to support her mental health and coping with the diagnosed, prioritise setting up

	EPOA and given her health and finance support to make decisions when she was able to. Also as a whanau we attended a carer workshop which was great but there wasn't regular support. … I strongly agree there are so many services (DHB, local doctors, Dementia Auckland, Work and Income, Workplaces, Occupational Therapist, Miss Daisy, local church; day programme, My Care, Residential Care Homes, Police, Wandertracka) that we and are affected by Dementia and I feel it's vital to have these services working together and set up to make it easier for families. As mum moved through different stages of Alzheimers there was always difficulties because processes where not consistent, easy or informative therefore as a family everyone felt rushed and exhausting to keep up with living with someone with Dementia.
	Issues around DHBs as lead
Separate	[re: at least 12 months post-diagnosis support through the local dementia-specific NGO] We cannot agree to this directive. As an organisation with statutory accountabilities, The DHB will only contract with agencies that meet our procurement requirements.
Separate	Again we concur with this objective, however we wondered again whether primary health has been represented in the development of the strategy and whether decisions about the delivery of assessment and care can be stated without this discussion being an initial action point. -NZCCP
Q.11 Living well	This second section objectives and actions suggest to rely on DHBs and PHOs for lead. This outcome is in danger of delivering a status quo which would only serve to reuse and republish what has already been authored, which is then overridden by a culture of referral and assertive reduction to the very same procurement of external services being referred to. I would suggest to please consider including MSD as another stakeholder into the discussion about supporting. MSD would be a major provider of support for many as both DHB and MOH (NASC) deny supervision is a care requirement and will actively refer to MSD for supports. This is arguably one of biggest concerns and a very difficult area to navigate for carers of highly mobile dementia sufferers (definitely for under 65s). MSD need to be better trained and equipped as they are by proxy a very important part of the dementia support network.
Q.11 Living well	DHBs are unable/unwilling to do all they can
Q.11 Living well	I am not sure whether it should be driven specifically by DHB's Decision making should include those actually delivering the service NGO"s are probably best suited to deliver these services with social work support and a wrap-around service delivery Also work from a strengths based perspective
Q.11 Living well	Not just primary care - diagnosis at any point requires this i.e., secondary care and liaison with primary health care providers of ARRC

	Test options to meaningfully support the provision of timely and accurate diagnosis and comprehensive management planning in primary care building on mental health initiatives as appropriate. Preparation of recommendations and business cases for local DHB and national solutions - for implementation in the next plan (beyond 2023)
Q.11 Living well	I feel all of this would need leadership as well - who will drive this and ensure it happens?
Q.11 Living well	? NGO perhaps some services should be or are DHB
	Comments about writing
Q.11 Living well	The first point is very wordy and difficult to follow - perhaps could be re-worded so it is more straightforward?
Q.11 Living well	Can you please take this document using plain English principles. WTF does timely accurate diagnosis actually mean when the only definitive diagnosis is checking a brain tissue agree death
	Again, I agree with the principle behind these strategies but I believe the language used to describe the actions should be strengthened. E.g. instead of "test options" it should be something like "identify, trial and implement a national roll out" Also an agency should be identified as responsible to increase accountability
	General suggestions / comments
Q.11 Living well	The cognitive testing options for assessing/diagnosing dementia in Aotearoa are not appropriate. There needs to be new assessment tools co-designed with Maori, Pasifika and migrant communities as a priority before any other work is done.
Q.11 Living well	Aligning DHB cognitive impairment pathways will be very dependent on outcome of national discussions re MOCA issue. Core business of palliative care has been malignancy with its steep downward trajectory - the palliation of dementia/frailty patients is somewhat less predictable and features a slow decrease in function, end of life care is often now occurring in RACFs and should be everybody's business.
Q.11 Living well	To make sure that correct cognitive testing for Deaf is tailored to their cultural & language needs
Q.11 Living well	Make sure that specialist skills are not lost. Cognitive testing is just a screen and many people who test positive do NOT have dementia, but have some other reversible cause for their cognitive impairment. The exclusion of other causes of cognitive impairment must be emphasised in cognitive impairment pathways. And include review after assessment as if measures to improve brain health have been implemented,

	cognitive improvement may have occurred (and it is important for the assessor to get this feedback)
Separate	Discussion re the range of cognitive assessments, the MOCA is not the only cognitive screening tool available.- Thames Agewise
Q.5 Goals	Might be worth including reference to improved access to early identification and support
Q.5 Principles	A category for diagnosis could also be included as from past experience this is often a very slow, nonspecific pathway that is brushed aside /not owned by health professionals.
Q.11 Living well	More funding is needed to ensure that early diagnosis of dementia is a priority and that it is consistent around NZ
Q.11 Living well	Is a clinical environment appropriate when history is obtained? A person may not present as they would in their home environment is this a barrier? Finances can also be a barrier as a person sees the GP initially three times for a diagnosis of dementia ie first visit is 15miutes, second visit is 15 minutes then third visit is 30 minutes this can be a financial strain on someone and their family
Q.11 Living well	Again Keep Stats of diagnosis as this informs funding
Q.11 Living well	The person/whanau must be supported to be able to keep their independence
Q.11 Living well	A programme to support individuals diagnosed with dementia understand and make necessary changes to their lives post diagnoses, seems a critical first step, followed by education, training and support for carers.
Q.11 Living well	Some emphasis on self-responsibilities. Teaching Carers self-help techniques. Look at alternatives for Cognitive Impairment - yoga, Meditation,
Q.11 Living well	e.g. In some instances this might mean allowing those with dementia into a safe kitchen of a Dementia Unit, if all they have ever known is serving in a kitchen (this should not be padlocked)
Q.11 Living well	All services should be available 24 hrs
Q.3 Goals	Painchek

19.3 Palliative Approach

Survey question	Comments
Q.5 Principles	Special requirements for end of life care are at present vague and not consistent.
Q.11 Living well	Great to link with palliative care and dying
Q.11 Living well	Definitely agree more input with palliative care at end stage. How many times can interventions with sub-cut fluids & antibiotics occur, when there is no quality of life.
Q.11 Living well	I would like to see palliative care given higher priority than waiting until the next plan (beyond 2023)
Q.17 Capability	The focus needs to shift to prevention strategies and to provide better palliative and end of life care for people with dementia & their families /whanau, rather than focussing on trying to find a cure.
Q.20 Overall	People suffering dementia are still people, our loved ones. Heart breaking for families to see them "go", but they need to die with dignity and be respected and looked after.
Separate	Most people with dementia in NZ die in Aged Residential Care someone from this sector should be involved in leading planning and implementation.
Separate	Development of appropriate services to support advanced care planning that includes health, legal, social and other agencies to ensure that individuals end of life decisions around care are well coordinated and planned Appropriate access and funding for palliative care for Dementia Sector involvement in the planning and implementation of palliative care in ARC - collated feedback from the national MHSOP leaders
Separate	End of life cares for people with dementia similar cares needed as for all clients who have communication issues. Dementia Waikato staff have provided in-services to Hospice NZ (Waikato) staff. .– Thames Agewise
Q.17 Capability	Also reconsider euthanasia option at early onset stage.
	Comprehensive submission
Q.3 Goals	As the draft plan states- "Dementia is a condition with no treatment or cure on the horizon". In 2015 Dementia accounted for 27.3% of total deaths in New Zealand. We therefore recommend, that the plan fully acknowledge that

	dementia is a life-limiting progressive illness by making this explicit in both the Vision and Goal and throughout the entirety of the document. As such, we suggest the vision statement and goal read as follows: Vision A New Zealand in which people living with dementia, their whānau / families and care partners live well and receive the support they need to fulfil their potential with dignity, respect, autonomy and equality at all stages of illness and until the end of life, and dementia is prevented as much as possible. Goal - The goal of this New Zealand Dementia Action Plan is to improve the lives of people living with dementia at all stages of their illness including end of life, while decreasing the impact of dementia on them and their whānau / families as well as on New Zealand communities, the health system and the economy and to promote dementia risk reduction lifestyles.
Q.5 Principles	The eight cross-cutting principles that drive the way the plan will be implemented are highly appropriate. In addition - the plan: 1. Recognizes dementia as a condition with no treatment or cure 2. Aims to increase support to enable people living with dementia and their family/carers to live well. Thus we recommend that a palliative approach to care of people with dementia is made explicit within these cross-cutting principles and throughout the document as part of its foundation and in keeping with International research evidence (Senderovich and Retnasothie 2019). Senderovich H, Retnasothie S. A systematic review of the integration of palliative care in dementia management. Palliative Support Care. 2019 Nov 18:1-12. doi: 10.1017/S1478951519000968. [Epub ahead of print]
Q.11 Living well	We strongly recommend that the plan make explicit that people with dementia should be supported to live well, at all stages of the illness trajectory including at the end of life. People with dementia can experience distressing symptoms similar to patients dying of more commonly recognized life–limiting illness such as cancer (Sachs, 2009). They require a palliative approach to care as their illness advances, not solely in the terminal phase of illness (Amador et al, 2019). This is particularly important in the context of the prognostic uncertainty associated with dementia. This difficulty prognosticating in advanced dementia underscores the notion that access to palliative care for these patients should not be guided by life expectancy, but rather by patients' needs and preferences and on maximizing and quality of life. Further it is not clear to whom the plan refers where it states ‘work with palliative care’ and this should be clarified e.g. should this read the palliative care sector including Hospice New Zealand, Palliative Care Nurses New Zealand, ANZSPM, Hospital Palliative Care. Amador S, Sampson EL, Goodman C, Robinson L; SEED Research Team. A systematic review and critical appraisal of quality indicators to assess optimal palliative care for older people with dementia. Palliat Med. 2019 Apr;33(4):415-429. doi: 10.1177/0269216319834227. Epub 2019 Mar 11. Sachs, Greg A."Dying from Dementia."N Engl J Med 2009, Volume 361, Number 16, pp 1595-1596.
Q,14 Communities	Promoting understanding of dementia, as well as focusing on stigma, needs to address common misconceptions associated with the disease. For example, dementia is often thought of as a condition of memory. Understandings of dementia often exist within “conceptualizations of aging, mental illness, traditional cultural beliefs and the trauma of colonization” (p1 Johnston et al 2019). There is limited understanding that dementia is a progressive life-limiting illness resulting in deteriorating physical function. Health promotion

	strategies need to focus as much on helping people understand the condition as much as on stigma.
Q.17 Capability	Waiting till 2023 to 'work with palliative care to build capability and capacity' will be too late. Palliative care is integrated across the disease journey. We strongly recommend a move to strengthen capability across the sector as an urgent objective now. All levels (professional and non-professional) of the health and social care workforce should have the capacity to provide person-centred care for people with dementia, regardless of place of care or stage of dementia. This should include palliative care for people with dementia as studies have consistently shown that palliative and end of life care for people with dementia is often poor (Denning et al 2012) Dening KH, Greenish W, Jones L, et al. Barriers to providing end-of-life care for people with dementia: a whole-system qualitative study. BMJ Support Palliative Care 2012; 2: 103–107. Fogg, C. , Griffiths, P., Meredith , P. Bridges, J. Hospital outcomes of older people with cognitive impairment: An integrative review Int J Geriatr Psychiatry. 2018 Sep; 33(9): 1177–1197.
Q.19 Enablers	Tertiary education needs to include core aspects of caring for people with dementia throughout the undergraduate curriculum of all disciplines. These core aspects should include content relating to all stages of the illness trajectory and include a palliative approach to care for people with dementia and their families and whanau. Dementia indicators should include palliative care indictors. See for example Amador S, Sampson EL, Goodman C, Robinson L; SEED Research Team. A systematic review and critical appraisal of quality indicators to assess optimal palliative care for older people with dementia. Palliat Med. 2019 Apr;33(4):415-429. doi: 10.1177/0269216319834227. Epub 2019 Mar 11.
Q20 Overall	A focus on prevention and public health approach along with addressing service gaps support services gaps as priorities for the next 3 years is appropriate. However, this should not be prioritised over what is an urgent and critical need to improve the care of people with dementia and their family and whānau wherever they are cared for in the health system. This should include integration of a palliative approach to care. We see no reason why these objectives should not have parallel initial action points. We strongly agree there is a need for greater synergy between palliative and dementia sectors. Current hospice services and models are not set up to accommodate the needs of people with dementia. Data from the Trajectories of Care at the at the End of Life in New Zealand project highlights that only 13.9% of those with Dementia accessed hospice services. People with dementia often have several other conditions including chronic illness - there is a need for the Dementia plan to interface with other New Zealand health policy and strategy documents. There is no mention of the interface with the palliative care plan under the heading "Links to other strategies and plans". .. Finally we would be delighted to contribute further to the vision, goal and planning to improve the palliative care of people with dementia

20. Accepting Communities

Support and suggestions

20.1 **There were supportive comments about accepting communities as a priority.**

20.2 **Some respondents had hesitations.**

20.3 **Suggestions were made, including about the focus of the campaign and the value of collaboration.**

Support

There were comments supporting this priority, particularly the efforts to reduce stigma, and some were keen to see quicker progress.

Hesitations

Some respondents had hesitations around the relative weighting for this priority compared to others, and about the Dementia Friendly and Age Friendly programmes.

Suggestions

Suggestions for the section included

- that the campaign should be positive, practical, and based on the lived experience of the people living with dementia
- that the importance of collaboration with local government and other stakeholders should be recognized.

There were also some comments around the use of identifications cards, media, and suggestions for editing (including using the term enabling communities rather than accepting communities).

20.1 There were supportive comments about accepting communities as a priority.

Survey question	Comments
Separate	Build accepting and understanding communities-- Dementia attracts stigma whereas other chronic illnesses like stroke, do not do so to the same degree. Much of this arises from lack of knowledge, fear and embarrassment. we support the dual approach which combines, long-term community development approaches like local groups of Dementia Friends with specific campaigns to reduce stigma. It is encouraging to see initiatives like Westpac Bank's dementia friendly actions, that highlight the important role business can play in reducing stigma and providing support. – National Council of Women
Q.14 Communities	very keen to help with the campaign!!!
Q.14 Communities	All actions supported
Q.14 Communities	We do it for cancer, heart disease.... so why wouldn't we
Q.14 Communities	A public campaign is essential to overcome prejudice.
Q.14 Communities	I feel this is the most important objective. So many of us learn about Dementia when a family member is involved - and we know nothing.
Q.14 Communities	Promoting dementia friendly communities is good for all people not just those living with dementia.
Q.14 Communities	Address the issue of the reluctance to diagnose
Q.14 Communities	Great - the more people are aware the better outcomes/support in the long run on different levels.
Q.14 Communities	Sounds Good
Q.14 Communities	As previously mentioned compassionate communities approach is vital.
Q.14 Communities	Lack of awareness and poor understanding sums it up. If we can make everyone aware it would make a huge difference.
Q.14 Communities	De stigmatisation would be great but it's not a quick fix. Many families are stressed out by the work they are doing caring for a loved one.
Q.14 Communities	I strongly support both actions; especially when people with complex needs e.g., sensory and other cognitive/social conditions and their whanau need support and services.
Q.14 Communities	Community engagement at every level is important as understanding the myths and debunking them is important to enable a person to remain in their society

Q.14 Communities	Love it
Q.14 Communities	Strongly agree. There is stigma …Having gone through this journey so far I feel very passionate to want to support people, even though I had family and friends to support it's different emotions that only those going through will feel, mentally draining need a better support system.
Q.14 Communities	Demographic studies, there have already been enough of these done over the years both international and national levels- (trust that the people working with dementia can inform of levels and that assessments take place easily and smoothly) should be limited, as the need in communities is already evident with education and how to 'be' with a person with any related confusion/ dementia issues. The more everyone knows and is trained in, the better everyone will react and become more accepting (Wave Effect). More community friendly initiatives where everyone is invited to community opportunities (with dementia in mind) and making it normal, instead of labeling everything.
Q.14 Communities	RANZCP] Support a public health campaign to reduce stigma From written: all organisations must be involved in developing this campaign as stigma towards those living with dementia occurs across the health and disability sector (both in primary and secondary settings) and within the justice, employment and social service sectors From written: We concur that more must be done to reduce the stigma associated with dementia. A public health campaign to influence and change people's views and responses relating to people with dementia would be beneficial. Evidence indicates that some individuals avoid diagnosis as they feel stigmatised by others or in their own mind.[xi] Older people living with mental health issues, such as dementia, experience both the stigma of mental illness and ageism. We are aware that modifying beliefs is a long-term objective, but the 'Like Minds, Like Mine'[xii] mental health de-stigmatisation programme has successfully improved people's perceptions about mental illness.
Q.14 Communities	Education +++++ to all levels of society
Q.14 Communities	Again, education is the key. A lot of work has happened recently on mental health issues, possibly the same is required for dementia
Q.14 Communities	One of the issues with dementia is, like mental health, it may not be visible o worse stigmatised
Q.14 Communities	Teach about elder care in schools and dementia at secondary level. Have courses for families dealing with dementia giving easy to understand information and advice
Separate	According to this meeting the most pronounced action needed, underpinning all the objectives of the plan, is public education to de-stigmatise dementia.

	Discussion re need++ for education for people of all ages, including school age children re dementia awareness. Discussion re need for health professionals to use clear (easy to understand) written/verbal language when referring to dementia related topics. Avoid over complication! Howard is aware of module re dementia which is incorporated into school curriculums in some parts of Australia (9-12 year olds). Financial resources would be required to set up similar school education programs in NZ. – Thames Agewise
Q.14 Communities	Understanding communication with a person with dementia, and how they're feeling is key to this.
Q.3 Goals	Would like to see a Dementia Friendly NZ reflected in the vision.
Q.3 Goals	With family abuse continuing to rise within the homes a holistic community is a healthy community which would provide a bases which is so desperately need for our families to thrive and be of benefit for a healthy New Zealand society. This bases is needed now so that the suggested vision and goals for dementia can thrive plus the mental health of all New Zealand communities. I fully support the health and well-being of all individuals and families across all ages, which will provide an environment that is needed now to help prevent and reduce dementia and other mental health issues. The above goals are very achievable please make the right decisions so the above vision and goals can be achieved.
Q.19 Enablers	Additionally, an educated, compassionate public would be a great asset.
Q.19 Enablers	The government needs to work across the sectors to ensure everyone has some understanding of the impact dementia will have in all areas. Giving school children some dementia awareness training, making sure WINZ staff understand how to manage their own behaviour around people with dementia, hospital staff, and so on. Everyone is going to need to know because we're coming!
q.8 Incidence	Education outreaches to the community and professionals to locate dementia as a disease/condition of the brain, and to reduce fear and stigma
Q.3 Goals	Would like to see a Dementia Friendly NZ reflected in the vision.
Q.3 Goals	With family abuse continuing to rise within the homes a holistic community is a healthy community which would provide a bases which is so desperately need for our families to thrive and be of benefit for a healthy New Zealand society. This bases is needed now so that the suggested vision and goals for dementia can thrive plus the mental health of all New Zealand communities. I fully support the health and well-being of all individuals and families across all ages, which will provide an environment that is needed now to help prevent and reduce dementia and other mental health issues. The above goals are very achievable please make the right decisions so the above vision and goals can be achieved.
	Sooner

Q.14 Communities	I feel we need to address stigma now, not aim for implementation in the next plan. This once again feels like we are putting off what needs fixing now!
Q.14 Communities	with respect to the second action - 2023 is still 3 years away - get going now!
Q.14 Communities	Why are all these suggestions so late in being actioned. They are basic and should already be in place
Q.14 Communities	A de-stigmatisation programme should be given higher priority. It is required now, urgently and will support progress in some of the other priority areas
Q.14 Communities	Education should commence immediately. The terms Alzheimers, and dementia still cause confusion within the community. The main umbrella term is dementia, this should be the core focus on the education planned, which needs to start immediately, not in 3-4 years' time

20.2 There were some hesitations

Survey question	Comments
	As a priority
Q.14 Communities	Agree awareness is vital but not over and above helping those who have cognitive impairment and promoting research. These need to take priority
Q.14 Communities	The previous (second objective) is in my opinion much bigger than this one. Public awareness is pretty acute. It's happening organically
Q.14 Communities	Just as with diabetes the number of people diagnosed is rising rapidly, this brings its own level of awareness as increasing families are affected. It is my observation working within the sector as a practice nurse, dementia care nurse, and daughter of a dementia patient that communities are supportive and stigma are reducing or absent in my daily routines in any health setting.
Q.14 Communities	I think this is very important but I don't feel it is as high priority in terms of budget as some other areas of the dementia support.
Q.14 Communities	However don't think this is the biggest issue in NZ.
Q.14 Communities	in my opinion, this objective needs to be secondary to the other objectives that have a greater immediate impact on the lives of those already affected by dementia - you do say this is an urgent issue!
Q.14 Communities	Could get bogged down in the multi-channel de-stigmatisation programme. Not sure what the evidence is for these.
Q.14 Communities	IT is a medical model approach. It needs to be biopsychosocialspiritual approach.
Separate	Please don't call it a de-stigmatisation campaign. Those have been tried before- it is an old-fashioned and stigmatising word. Use something more positive. Talk about what can be done, then people might be willing to engage with dementia… if they see it's not all hopeless. IMPROVING CARE IN THE COMMUNITY AND ARC WOULD BE THE BEST WAY TO ENCOURAGE NZ SOCIETY TO ACCEPT DEMENTIA. Currently people see how inadequate, belittling and disregarding of individual needs care is. No wonder no one wants to get dementia or thinks euthanasia is an option if they got this diagnosis. Does the research done by Somerset / Summerset a couple of years ago help?

	Dementia friendly recognition programme
Q.14 Communities	The DFRP needs more emphasis on meaningful training/education of staff of organisations to gain the recognition. Its currently a bit light.
Q.14 Communities	Enhance promotion of the programmes by considering how corporates and public facing organisations can offer awareness and training to staff and whether having this credentialised would be an incentive to uptake and to consistency of training.
Q.14 Communities	There needs to be monitoring of dementia friendly recognition. Some banks were given this and I have found negotiating through the process for the care givers a nightmare as there is inconsistency with individual staff understanding and using the information correctly.
Separate	Discussion re how do you measure the effectiveness of a 'dementia friendly city/town'? Westpac bank market themselves as a Dementia friendly bank: considered environment of bank branches, staff training etc. Incremental steps for change is needed. Need for education++, to raise awareness and increase people's knowledge/understanding. Discussion re Alzheimer's NZ's Dementia Friendly Recognition Programme as 'being a start' in developing awareness but could be improved. – Thames Agewise
Q.14 Communities	Local programmes are needed where local communities get involved. Dementia Friendly is a one size fits all programme which does not recognise different cultural perspectives on dementia.
Q.14 Communities	Should not have only one agreed dementia friendly programme. Not all support organisations affiliate with Alz NZ and locally derived programmes may work better, e.g., an Iwi programme.
Q.14 Communities	It is confusing to the general public, carers, families and people living with dementia that Alzheimer's New Zealand operates in this programme when they do not represent the whole country nor offer on the ground services to 70% of people living with dementia.
Q.14 Communities	As an organisation we have found great value in becoming recognised as Dementia Friendly
	Age Friendly Cities
Q.14 Communities	There isn't a lot of research to support "aged friendly cities" at this point. This type of initiative should be well articulated and include specific outcomes.
Q.14 Communities	I am hesitant about spending a lot of money on dementia friendly cities and cafes. I don't know what the research says. I wouldn't waste too much time energy and money on this course, without knowing more

Suggestions

a.1

Survey question	Comments
	Positive, practical, and based on real experience
Q.14 Communities	Life stories brings realism to situations and struggles. Destigmatisation can begin by people sharing stories, difficulties in life, difficulties in navigation etc
Q.14 Communities	Practical strategies should be released in the campaign to help the public actually realise ways in which they can support a person with dementia. I think having those practical strategies may reduce the fear of dealing with people with dementia.
Q.14 Communities	Negative advertising such as pictures of shoes in the fridge do not work
Q.14 Communities	My husband has dementia....We had the best people educate us from Waikato DHB..6 week course. The support, skills and total acceptance was gratefully received. Given by OT Verity Brown, Social worker Kerri Challis from our memory clinic...We were so lucky to go through his service, and Dr Etu...these people are practising patient centred care, and supporting the carer. we are evidence.. I wrote to hank he then CEO of Waikato....!! nil response to any person. I , as a retired NZRN & ASM Wintec , would be happy to help with education from a carers point of view. My fine articulate husband would be happy to speak as a person with dementia. In fact he has on 2 occasions. No doom and gloom on those days. James does amazing woodturning still. We have much welcomed care in the home(very grateful) Education. education...presentations presentations. I don't know they may be in place...rotary, younger organisations.....Education...education for he carers Some people unwittingly treat him as a child...treat him as dumb for he is deaf.....for whatever reason, the bureaus need to provide beer training, they need to audit their staff, and speak with the clients....This is a huge area...nil genuine evidence based here...simply ticking boxes...Many elderly people do not like to make waves, and do not speak up...with my 40 years' experience ..I know how people should be treated....Education. Some providers do not know what they don't know....I can articulate our needs, I believe very few in our position are able to do that
Q.14 Communities	It is important to include people and families living with dementia in the campaign.
Q.14 Communities	Alzheimer's NZ videos representing different people with dementia and their families are very good at destigmatising the condition. Building a campaign through different media channels using these videos and their message would be of benefit.

Q.14 Communities	Examples of people with dementia living good lives with support (see Des O'Brien poetry book How Art) and also examples of caregivers who have been supported. Caregivers need support to prevent burnout and may also need some training on how to communicate with dementia people to reduce stress and find ways to stay connected.
Separate	Need to increased public awareness and understanding, development of a campaign programme that highlights the positive actions that can be taken to support people living with dementia as opposed to focusing on the negative and sends a strong message that there is hope and all is not lost. - collated feedback from the national MHSOP leaders
	Collaboration
Q.14 Communities	I would add to share work being done in regions which are successfully linking with councils and other groups to provide dementia friendly/ age friendly spaces and services but this may fall under actions taken to promote the two specified programmes
Q.14 Communities	Local government need to be involved. Not sure that the local DHB's can establish dementia and age friendly standards. Needs to be national for consistency.
Q.14 Communities	Not sure whether one organisation is the key to communities understanding needs a collaborative approach with LTA's, NGO's
Separate	Attendees consider central government to be the best organization to lead NZ in meeting Objective 3. Need for consistent/credible leadership. – Thames Agewise
Separate	Again we feel that it is important to consider representation from stakeholders in local authorities in conceptualising action plans. - NZCCP
Q.14 Communities/ Separate	[RANZCP] note that the Plan is considering a *"multi-level multi-channel de-stigmatisation campaign"* relating to dementia. We strongly support this proposal, but we consider all organisations must be involved in developing this campaign as stigma towards those living with dementia occurs across the health and disability sector (both in primary and secondary settings) and within the justice, employment and social service sectors[xiii].
Q.14 Communities	Start with Health Professionals. e.g. Those with Dementia should be just as welcome in an Allied Health Clinic as others
Q.14 Communities	These actions are not just required for communities but for health professionals too. Health professionals who one would expect to understand dementia can be surprisingly ignorant/naive about the practical implications of these conditions.
Q.14 Communities	Ensuring other healthcare professionals outside of DHBs are "dementia friendly"

Q.14 Communities	Look at offering training for employees of local businesses around recognition and behaviour management
Q.14 Communities	All big retail outlets / social / recreational venues should provide staff understanding dementia training.
Q.14 Communities	I feel very strongly that the community could help with this. Include Lions etc, individuals who have a passion who can talk to their local supermarket manager, their post office, their bank and be persistent until these places put in place dementia friendly training for staff and dementia friendly premises, e.g. the Westpac bank's initiative; realising that by doing this they will increase their market share.
Q.14 Communities	As per my comments for Objective 1, I think that clear communication to communities is important. It is confusing at the moment with different Dementia information sources such as Alzheimers NZ, Dementia NZ, Healthline, Min of Health website. People living with dementia and their families need a clear, trusted "go to" source for information which is up to date/updated regularly.
Q.14 Communities	Having so many different charities / groups raising awareness about dementia / Alzheimers is continuing to cause confusion, with funds being split across groups with money being lost to those who actually need that financial support. All the different groups should unite and become ONE.....
	Use the media
Q.14 Communities	Constant information in the media. Maybe a press officer or something.
Q.14 Communities	Constant news on research developments and successful and innovative care.
Q.14 Communities	I think national advertising re television would work well to promote awareness and decrease the stigma around Dementia. A prime opportunity is World Alzheimers month in September where local organisations did the best they could to promote but if it had been on TV the message would have reached far more people just like the promotion of blue prostate we should be promoting purple to link it with Alzheimers awareness and all our event like Cuppa for a Cause and our Memory Walk. I am sure local organisations would be happy to pull resources to make this a national event every year
	Consider cards
Q.14 Communities	Strongly agree. There is stigma, I did have those cards that Dementia Auckland gave me to inform people which were helpful but at the same time I always felt people didn't know how to react. Having gone through this journey so far I feel very passionate to want to support people, even though I had family and friends to support it's different emotions that only those going through will feel, mentally draining need a better support system.

Q.14 Communities	Cards that can be given out discreetly to advise people around you that the person you are with has dementia etc. Wellington Alzheimer's use to have one that I used and it helped
Q.14 Communities	People may not talking about it but friends need to know so that they can support them. Maybe a little card magnet that says someone at this house has some type of dementia please be understanding.
	Writing
Separate	Attendees would like the use of the term 'dementia enabling' to be used in the Dementia Plan in the appropriate sections, being more active than just 'friend'liness. … Recommend: Change wording of Objective wording from: "Build accepting and understanding communities' to 'Build enabling communities. – Thames Agewise
Q.14 Communities	what do you mean destigmatize??? explain. ? A dementia patient is unreliable and needs to be treated differently.
Q.14 Communities	Less jargon in the plan
Q.14 Communities	Look the is just too much business speak in this document. To remove signs you need to want to and talk with people at their level. The writers of this "plan" have already shown their inability to do this
Q.14 Communities	Consider the implications of using term 'accepting' also problems with dementia 'friendly' - coming from a human rights perspective these just don't work

21 Strengthening capabilities

See also key themes in section 11

Support and suggestions

21.1 **There were comments supporting the importance of strengthening capability.**

Support

There were comments supporting the importance of strengthening capabilities. As discussed earlier in Section 11, there was a strong theme supporting the importance of workforce training and frequent comments about the importance of monitoring / outcomes.

21.2 **Views on the role of research varied.**

Research

While some respondents were very positive about the role of research others saw it as a lower priority.

21.3 **There were suggestions on how to improve the section.**

Suggestions

There were a number of suggestions about wording and extensions.

21.1 There were comments supporting the importance of strengthening capability

Survey question	Comments
q.17 Capability	Strongly agree and may of commented in previous pages on the services delivery as vital for people with Dementia and families there are so many services that help families but the processes are not collaborative and feel families have to do a lot of work to take initiative rather than support services being regular and available. Strongly agree this action plan is on the right track and looking forward to seeing what comes from it.
q.17 Capability	I support all actions
q.17 Capability	for me this is the most important objective - are the objectives prioritised? What if we had to choose where to focus first?
q.17 Capability	Totally agree, this is looking really good. Great initiative If ever I can be of help within my capabilities(another story) I would like to
q.17 Capability	All of the above desperately needed.
q.17 Capability	Fully support the objective and actions
q.17 Capability	It would be great to see standards rolled out, particularly in residential care environments where there appear to be dictated by the provider organisation. In a residential care facility, for example, how many trained carers should be available to every resident (as seen in preschool and school structures).
q.17 Capability	better control of dementia units and the rules they operate by
q.17 Capability	From personal experience "fragmented" is a major problem at present. Very difficult to coordinate care at home for a person suffering from early stages of dementia - requires a single person/advocate to be aware of needs and communicate them to services repeatedly, plus regular reassessment to determine current level of need.
q.17 Capability	Fingers crossed it can be done
q.17 Capability	When health professionals are knowledgeable and competent in discussing dementia with their patients and colleagues this will go a long way to reduce the associated stigma as the correct understanding will demystify the condition.
q.17 Capability	Definitely needs a clear pathway and cohesion of services. NGO s just as important as the DHBs
q.17 Capability	More information is needed on the incidence of dementia in New Zealand and more education is needed.

q.17 Capability	These all sound fantastic, as long as the funding follows them through to be able to be implemented by those "at the coal face".
q.17 Capability	I think the whole concept is superb…
q.17 Capability	Collecting national data would be a massive positive step forward.

21.2 Views on the role of research varied.

Survey question	Comments
	Support
Q.8 Incidence	It seems to me that the issue of brain research is being side stepped with comments about non progress.
Q.8 Incidence	Funding for research needed
Q.17 Capability	Research should be considered to find dementia at a much earlier age and before signs show than is being done at present –
Q.17 Capability	Comment. Apart from increased investment in research on dementia, we also need more research relating to New Zealanders on changes in lifestyle, diet, activity etc showing the benefits that may/could help and delay the onset of dementia.
Q.17 Capability	Data on incidence and prevalence of dementia in NZ is virtually non-existent. Need to increase investment in research. There is also a need for more educational resources for people working in the sector. The University of Tasmania model of education in dementia and ageing provides a standard that we should be looking towards.
Q.17 Capability	NZ should work closer to leading research facilities around the world to enable inclusion of New Zealanders in international research. There is ground-breaking research happening but New Zealanders are missing out on the opportunities these bring.
Q.17 Capability	There is a difference between research about dementia and research for a cure
Q.17 Capability	We agree that there should be an increased investment in research on dementia. However, as well as: “epidemiology of dementia in New Zealand and on culturally appropriate ways of describing and approaching dementia with New Zealand's non-Pākehā cultures”, we strongly recommend priority is given to health services research to investigate appropriate service models of care for people with dementia including how specialist dementia services best interface with other specialist and non-specialist services including palliative care services. Further, there is an urgent need to ensure that people with dementia are provided the opportunity to participate in all aspects of research including clinical trials. Current ethics regulation in Aotearoa/NZ has the potential to marginalise and further stigmatise people with dementia by excluding them from research (Douglass and Ballantyn, 2018). Douglass, A. and Ballantyn, A. 2018 From protectionism to inclusion: A New Zealand perspective on health related research involving adults incapable of giving informed consent

	Bioethics. 2018;1–9. Special Issue McLeod, H., & Atkinson, J. (2019). Technical Note on Trajectories of Care at the End of Life Research.
Separate	Howard discussed there is no current statistical information re the numbers of people living with a dementia diagnosis in NZ. InterRai data is only gathering data on clients with dementia who are DSL clients. Last NZ Census asked question re memory issues. Current epidemiological projections are extrapolated from the approximations of other similar populations – we need better data in NZ. – Thames Agewise
	Hesitations
Q.17 Capability	With regards to research in dementia we should not spend money on repeated studies already provided internationally. I believe we initially need to be focusing on improving standards of assessments/interventions/education/dementia friendly communities.
Q.17 Capability	in my opinion, because there is loads of research being done overseas, our limited investment needs to be targeted to the provision of services that help achieve the vision and goal and set up a health system that can cope with the predicted increase of people affected by Dementia in the next 10-20 years.
Q.17 Capability	to be honest I feel that more funds should be put into employing more suitably qualified allied health and other professionals (such as Occupational Therapists) on the front line as opposed to increased funding for further academic studies and decision and policy writers.
Q.5 Principles	Funds going into evidence based medical research should be diverted to care of the carer(s) . ..Dementia " needs" are more social/psychological/emotional support than medical or research...
Q.11 Living well	To avoid repeating research which has already taken place and is a waste of money to do again- money better used at grass root level.
Q.17 Capability	Don't waste vast sums on pointless research. What is a non Pākehā culture? We need cultural awareness, empathy and understanding including language understanding and translators. What will anyone do with research into epidemiology of dementia if ever there is "one" answer?

21.2 Suggestions Capability

Survey question	Comments
Q.17 Capability	Also, please re-consider the use of the word "disability" in the narrative descriptions. This needs to be reviewed.
Q.17 Capability	I am very pleased to see the Disability section included here.
Q.20 Overall	Recognition by NZ Government following WHO guidelines that Dementia is identified a disability
Q.17 Capability	Spell Pākehā correctly. I think we may mean Anglo Saxon Pākehā cultures. For example Irish Catholic culture tends to be somewhat collective and has a more fatalistic approach to life, as do those of more central and southern European heritages.
Separate	"Non-Pākehā" is not deemed to be acceptable terminology – suggest it is removed or replaced with "all cultures"
Q.17 Capability	This section is muddled and muddly. Is it about building workforce capacity? What does capability mean?
Q.17 Capability	Fourth point - we suggest replacing medical care with "holistic clinical care" or maybe "medical/clinical care" AND we suggest adding training for end-of-life care medical may be interpreted as only doctors
Q.17 Capability	I feel making training available is not the same as training being a requirement for anyone working in that area. I'd like it to be a requirement. I didn't fully understand 'Design agreed national indicator, measures for dementia...' so I marked it neutral.
Q.17 Capability	Collecting national data would be a massive positive step forward. Spell Pākehā correctly. I think we may mean Anglo Saxon Pākehā cultures. For example Irish Catholic culture tends to be somewhat collective and has a more fatalistic approach to life, as do those of more central and southern European heritages.
Q.17 Capability	Where it states "Establish dementia and age friendly standards for delivering high-quality health services for people living with dementia including home, community, and residential care", this should include acute care given between 25% to 40% of people admitted to hospital have cognitive impairment and at risk of dying there (Fogg et al 2018) People with dementia are more likely to be hospitalised than those who are not and can have significant hospital complications. Skills and capacity to deliver safe and high quality dementia care needs to be integrated into all health and social care delivery and services.

Q.17 Capability	These plans also need to be rolled out within the DHB's as well. There is a lot of inconsistencies in delivery of care as well as stigma within the DHB.
Q.17 Capability / separate	1. Link to Health & Disability Systems Review to address dementia 2. Develop integrated patient record 3. Undertake a benchmarking project to establish staffing levels 4. involve Consultation - Liaison psychiatrists to improve outcomes for people with dementia & physical conditions 5.widen the Plan to include all health professionals who work with people with dementia 6. Improve quality of care in ARC facilities From written: The RANZCP considers that the current Health and Disability Systems Review (HDSR) should be addressing the challenges of national stewardship and leadership issues within dementia services and care. The Interim Report from HDSR does not provide any detail regarding the leadership and management strategies required to fully address the needs of people with long-term conditions. People living with dementia and cognitive decline are increasingly common within the health service, therefore we advocate for strong sectorial leadership and adequate planning of services to reduce the burden of dementia within the sector. The strengthening of workforce capability will only be truly realised when all providers have access to an integrated patient record that allows each provider to deliver care according to need, role and responsibility. Currently services for people living with dementia are fragmented, with no clear care pathways, resulting in consumers not being diagnosed appropriately and in a timely fashion, or failing to receive the care and treatment they need . We strongly recommend that a benchmarking project is undertaken to establish staffing levels and staffing mix (e.g. clinicians, care-givers) required to provide optimal dementia care across New Zealand. We recognise services can be strengthened when clinicians, such as psychiatrists, geriatricians, neurologist and general practitioners - work together to achieve the best treatment outcomes and care for people living with complex co-morbidities that may include dementia and physical frailty and/or addiction and mental health conditions. Within the field of psychiatry, we consider Consultation-Liaison psychiatrists have an increasingly important role in advocating for those living with dementia. Consultation-Liaison Psychiatry Services for older people in hospitals and the community are critical services that are cost effective and facilitate patient flow and access to care. There is a gap in the availability of Consultation-Liaison Psychiatry (CLP) services for older people in many New Zealand hospitals. Failure to expand CLP services and ensure they have staff with specialist skills in working with older people represents a concerning risk within the health system. Research in the United Kingdom has demonstrated that investment in CLP services yields approximately a fourfold return on investment. Given the progressively ageing population, more people are being seen in the general hospital setting for physical health and mental health conditions. Presentations can include behavioural agitation, delirium, dementia, addictions and mental health disorders comorbid with poor physical health e.g. cognitive impairment/depression/psychosis in the context of neurodegenerative

	conditions or coping with chronic ill-health. Additionally, there can be stressors related to those caring for the elderly with the risk of burnout for example within families and residential aged facilities. Moreover, concerns about someone's decision-making may arise in the general hospital setting for example following a stroke or myocardial infarction, poorly controlled diabetes or cancer diagnosis, to manage independently or look after their physical wellbeing. This often requires close collaboration between the multi-disciplinary clinical team, the individual and their carer and community supports. Overall, Consultation-Liaison psychiatrists are highly-skilled clinicians who bridge the gap between physical and mental wellbeing and permit a considered and holistic approach to an individual and their families. The Plan's purview should be widened to include all health professionals who come into contact with people who may be starting to experience cognitive decline or are living with dementia. Our concern is the proportion of older people in our society with dementia is rising and will likely continue to increase significantly in the next decade, therefore we contend all health professionals will need to be upskilled and educated around working with people living with cognitive decline. For example, in the future a surgeon undertaking a Total Hip Replacement will also have to understand the implications of working with a patient who is challenged by complex information requests such as informed consent and who may have limited capacity to make decisions about their care . In our opinion, developing a targeted awareness campaign within the health sector is critical to ensure that people with dementia are managed and supported to have the best health outcomes no matter where or when they enter the health system. High quality care can only be delivered when staff working in Age Residential Care facilities are trained to deliver the best care possible. This includes understanding the mental health needs of people with dementia including programmes on the behavioural and psychological symptoms of dementia from mild to severe. …The quality and quantity of dementia services requires improvement. Two specific examples are the inconsistent level of Mental Health Services For Older People around the country and the questionable quality of some dementia unit residential facilities. We anticipate that the Plan will start to address these issues and provide a useful framework for further advocacy to support better outcomes for older people.
Q.17 Capability	Where it states "Establish dementia and age friendly standards for delivering high-quality health services for people living with dementia including home, community, and residential care", this should include acute care given between 25% to 40% of people admitted to hospital have cognitive impairment and at risk of dying there (Fogg et al 2018) People with dementia are more likely to be hospitalised than those who are not and can have significant hospital complications. Skills and capacity to deliver safe and high quality dementia care needs to be integrated into all health and social care delivery and services.
Q.17 Capability	Second point - we suggest adding "hospice" to the list

Separate	Need for national leadership around dementia inclusive of representations from all stakeholders and forums to support this.- collated feedback from the national MHSOP leaders
Q.19 Enablers	Dementia should be identified as neurological rather than mental health. The impact of this change will enhance and support destigmatisation
Separate	dementia needs to come under Mental Health.

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