**NEW ZEALAND HEALTH STRATEGY 2015**

**CONSULTATION SUBMISSIONS**

**55 – 84**

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| **55** | Submitter name | Heather Came |
| Submitter organisation | Health Equity Now |

5 November 2015

**Re: Submission on the Update of the New Zealand Health Strategy**

To Whom it May Concern,

Thank you for the opportunity to participate in the redevelopment of the revised *New Zealand Health Strategy* (NZHS). We acknowledge the commitment to Māori health, reducing inequities and Te Tiriti o Waitangi demonstrated in the strategy. We also recognise the complex challenge of refreshing such a strategy for the health sector.

This submission is on behalf of **Health Equity Now**. Formed in 2013 our rōpū is a professional network of public health professionals committed to promoting health equity within the administration of the public health sector. The current membership is Dr. Nicole Coupe, Claire Doole, Ngaire Rae, Trevor Simpson, Associate Professor Tim McCreanor, Dr. Jonathan Fay, Emma Rawson, Grant Berghan, Lisa McNab, Robert Muller, Sue Turner and Dr. Heather Came. Collectively we have nearly 250 years of experience working within the public health sector!

# Core Recommendations

1. **Prioritise investment in public health within the NZHS**.

Investment in public health is cost effective. Such investment saves considerable clinical treatment costs, and maintains the health of the workforce - which is a prerequisite for economic prosperity. Tailored public health measures are critical to population level efforts to advance health equity, and have more reach and impact at a population level than interventions in the secondary and tertiary health sectors.

1. **Specifically how you will meet your Te Tiriti o Waitangi obligations**.

Te Tiriti o Waitangi is the foundational document of New Zealand and is embedded within health legislation. Over and above what is articulated in *He Korowai Oranga* (Ministry of Health, 2014); we would like to see the NZHS specifically address the following questions:

* i) Kāwanatanga - How will hapū/iwi/Māori be involved in decision making at all levels of the health sector?
* ii) Tino rangatiratanga – How are hapū/iwi/Māori aspirations reflected within the NZHS?
* iii) Ōritetanga – What specific actions will be undertaken to ensure equitable outcomes between Māori and other New Zealanders?

Being specific is important as it enables accountability around Māori health and allows Māori as Treaty partners the opportunity to monitor and track progress.

1. **Commit to transforming institutional racism within the administration of the heath sector**.

Institutional racism is a pattern of differential access to material resources and power by race, which advantages and privileges one sector of the population while disadvantaging enacting racism against another (Came, 2012). Addressing institutional racism is central to efforts to address health inequities. We would like transforming institutional racism to become a target and/or priority of the health sector. To credibly champion health equity, we believe health funders and policy makers as leaders in the sector need to get their own houses in order. Our research shows systemic racism within the administration of the New Zealand public health sector and this needs to be urgently addressed (Came, 2014; Came, Doole, Lubis, Garrett, McCreanor, & Coupe, 2015).

1. **Address the negative determinants of health for Māori and Pacific populations**.

The evidence around the impact of the wider determinants of health on health status is considerable (Pickett & Wilkinson, 2011) particularly in relation to indigenous peoples (Mowbray, 2007). We support the ongoing investment into healthier housing. However, we want the NZHS to clearly articulate what the contribution of the health sector will be to addressing other modifiable determinants of health. Without committing to specific actions, the NZHS discourse on determinants of health risks becoming rhetoric.

1. **Continuing to improve access to primary care services for the sections of the population with unmet need.**

There is a pattern of access in primary care; those who need the most get the least (Jatrana & Crampton, 2009). New Zealand has a mixed business and government funded model of primary health care. Visits to the general practitioner and medications from pharmacy are still beyond the reach of the most financially disenfranchised New Zealanders. Improving access for very low access New Zealanders makes sense fiscally and as a measure to improve quality of life.

# Other Feedback

## Health Equity

It is heartening to see the commitment to health equity throughout this strategy. The challenge this opens is how to ensure these words become everyday praxis within all levels of the health sector rather than rhetoric. We welcome the work of Fiona Cram (2014) that articulates specific evidence-based recommendations about how to embed equity within the health system. She focusses on the domains of leadership, knowledge and commitment, and nominates action points for the whole health system, health organisations and practitioners. This body of work needs resources invested into it, to ensure it is well operationalised, monitored and evaluated.

We agree with your statement:

*It can struggle to ensure equitable access to limited resources, and health disparities persist. … finding new ways of working to deliver the services we need. (p1)*

We appreciate that there are limited resources to invest in the health sector and that this decision-making is complex. As above, we argue there is over whelming evidence of the cost effectiveness of investing in public health (Mearns, 2013; Mernagh et al., 2011; Owen et al., 2012; Shearer & Shanahan, 2006; Wright, Bates, Cutress, & Lee, 2001). Money invested in keeping people well leads to considerable savings in clinical treatment costs later. The invisibility of public health within this strategy is a potentially expensive omission ten years out.

To support both health investment and disinvestment decisions we would like to see mandatory use of the *Heath Equity Assessment Tool* (Ministry of Health, 2004) and/or the *Whānau Ora Impact Assessment* (Ministry of Health, 2007). This discipline would help ensure equity remains a core focus of the health sector.

We disagree with your statement “*New Zealand’s health system performs well*” (p. 2).

Marriot and Sim’s (2014) recent report and *Tatau Kahukura: Māori health chart book* (Ministry of Health, 2015) and before that the Hauora Māori health report series (Pōmare, 1980; Pōmare & De Boer, 1988; Pōmare et al., 1995; Robson & Harris, 2007) show entrenched heath inequities between Māori and other New Zealanders. This suggests that the health system is not working for all New Zealanders. For instance life expectancy rates sound high (p2) but when you look closer (p. 6) it reveals the inequities. We welcome the life expectancy gap between Māori and other New Zealanders becoming a core measure of performance of the health sector.

## Te Tiriti o Waitangi and Institutional Racism

Health inequities are frequently enabled by breaches of Te Tiriti o Waitangi. As of April 2011 there have been over eighty-nine separate Waitangi Tribunal claims related to Crown administration of the health sector. This is not satisfactory in the context of your plans to refresh our acknowledgement of the special relationship between Māori and the Crown through the Treaty of Waitangi (p9) within the NZHS.

As above we request you specify how you will address each article of Te Tiriti o Waitangi to enable monitoring.

We agree with your statement:

*Some funding arrangements contribute to stubborn disparities in access to services, and sometimes they widen the gap in unmet need*. (p. 7).

And support your vision:

*…reduce disparities in health outcomes, and make sure the health system is fair and responsive to the needs of all people — young and old, from all ethnic groups, and wherever they may live. (p. 8).*

Our research shows systemic institutional racism within the administration of the health sector by the Ministry of Health and district health boards in relation to the development of health policy (Came, 2014) and funding practices (Came, 2013; Came, Doole, Lubis, Garrett, McCreanor, Coupe, et al., 2015). To maintain the existence of systemic racism is a critical barrier to the achievement of health equity. We would like to see the acknowledgement of racism within the health sector as one of the challenges/opportunities (p. 5) facing the sector named in this strategy, made a health target and a commitment made to specific actions to address it.

As we have particular expertise in this area, we welcome dialogue around this and are happy to collaborate and offer specific evidence-based advice in relation to how inequities and/or racism could be addressed.

## Public Health/ Health Promotion

The role of public health is consistently invisible and/or minimised in this strategy. Public health is more than health education, health literacy and prevention, it is the art and science of improving holistic health through the organised efforts of society (Winslow, 1920). It involves community development, action research, social marketing, Māori economic development, advocacy, mobilisation, regulation and innovation. As noted above we welcome efforts to capture a more fulsome picture of the critical contribution of public health to population level outcomes.

We are pleased to see the inclusion and acknowledgement of the healthier homes and Whānau Ora programmes (p4).

Although health promotion and many public health professionals are not regulated health professionals we do align our work to competency documents (Health Promotion Forum, 2011; Public Health Association, 2011) and with ethical standards (Public Health Association, 2012). Many of us have specialised qualifications and/or significant experience working in our field. We welcome multi-disciplinary partners but believe health promotion and/or public health professionals should lead health promotion/public health work – rather than positioning this work as something any health professional can do.

## People-powered

Can this section be reframed so it allows for both individual and collective people-power?

It is pleasing to see innovation around the health sectors engagement in new technologies. However, lets ensure this is done in addition to people being able to access more traditional kanohi ki te kanohi (face to face) approaches which is the preference for some cultural groups.

## Closer to home

It is great to see specific mention of Māori providers (p. 14) and recognition of their expertise. Note our recent research findings (Came, Doole, Lubis, Garrett, McCreanor, Coupe, et al., 2015) that show some of the barriers faced by Māori providers operating in the heath sector. These include inequitable i) contract lengths across providers, ii) monitoring and auditing frequency, iii) access to cost of living and discretionary funding and iv) representation on advisory groups. To achieve your goal of ‘closer to home’ will require reconfiguring of Crown of behaviours to enable an equitable contracting environment.

We agree the provision of universal services is important (p. 16), but we would also like to see targeted services for specific communities. There is a significant body of work which suggests tailored approaches work best for Māori (Jansen, Bacal, & Crengle, 2008; Theodore, McLean, & TeMorenga, 2015; Wilson, 2008).

It is pleasing to see mention of Māori and Pacific health models (p. 17). Going forward can public health service specifications be reconfigured to enable Māori and Pacific providers to work with these frameworks.

## Value and high performance

We support your statements:

*transparent use of information to drive learning and decision-making for better performance.*

*strong performance measurement and a culture of improvement, in which we are open and honest about where we can improve (p. 18).*

Within the public health sector Crown funders have a range of mechanisms to monitor provider performance and the capacity to enable quality improvement (Ministry of Health, 2003). It is less clear how these same funders and policy makers embrace quality assurance within their own practice; or learn from mistakes. Certainly in our research (Came, Doole, Lubis, Garrett, McCreanor, Coupe, et al., 2015) we have identified a plethora of opportunities to strengthen the administration of the health sector that remain unaddressed. Many of these ideas could reduce health inequities and health spending, and improve health outcomes. However it is unclear how to feed these ideas into the Ministry and disseminate to DHBs.

We welcome efforts to remove the “infrastructural, financial, physical and other barriers” to robust service delivery. We maintain institutional racism and personally mediated racism are barriers to quality service delivery (Harris et al., 2012; Harris et al., 2006). Mono-cultural practice or what Morrison (2006) calls unconscious incompetence seems wide-spread within the administration of the health sector. Inequities in practice often seem invisible to those managing the health system. In terms of doing something different (p. 18) based on a review of the evidence we (Came & McCreanor, 2015) recommend the development of a systems-wide plan for identifying, transforming and preventing racism. Again, we have particular expertise in relation to this and are happy to enter into dialogue.

You acknowledge the need to address “the full range of factors that affect health outcomes” (p. 18) but are unclear what the health sectors contribution will be to addressing the wider determinants of health. As noted above we welcome articulation of specific action points to alleviate the negative determinants of Māori and Pacific health.

## One team

As indicated earlier the Ministry of Health’s leadership of the health sector will be more credible when they address institutional racism within their practice.

One team, sounds promising but what are the mechanisms to ensure Māori as treaty partners and Pacific providers as a minority perspective are heard within such a collaborative climate. The risk is a dilution of Māori, Pacific and ethnic minority viewpoints by the dominant majority.

We congratulate the Ministry on their ongoing investment in the Māori Public Health leadership programme. We think this is an outstanding programme with exceptional and consistent evaluations. If you are looking for a leadership and talent management programme (p. 47) look no further.

We maintain the leaders in the health sector need to have the relevant political and cultural competencies (Came & da Silva, 2011) to address health inequities. If public health practitioners (Public Health Association, 2007) need to be competent in everything from health systems to advocacy and planning and evaluation so should those that administer the public health system.

## Roadmap of actions

We agree that Te Tiriti o Waitangi should inform the training of health professionals and board members (p. 31). We reiterate that it also needs to be central in the ongoing professional development of Crown Officials and senior managers.

We maintain the strategic planning (p. 35) needs to occur both regionally and nationally. Advisory groups need strong Māori and Pacific representation, in addition to a more formal partnerships between Crown agencies and other health providers. Kaupapa Māori world views and evidence needs to be incorporated within the planning and prioritisation needs to use appropriate equity tools.

Partnerships need to be negotiated from a place of mutual trust and respect. The imposition of partnership (p. 37) from above is unlikely to engender trust. Best practice is a term widely used in the health sector and often refers to international best practice as generated in the Northern hemisphere in studies that include no indigenous analysis. If we don’t know what works best in a New Zealand context it seems smart to commission local research so we can ensure interventions serve to decrease rather than increase health inequities.

If the health sector is committed to addressing health inequities, we should not have to incentivise corners of the health sector to be proactive about working towards health equity (p. 40). This is an absurd use of public monies that could be better invested elsewhere.

We support the stream-lining of reporting, (p. 40), the introduction of transparent performance management approaches which make things publically available. We welcome the monitoring of quality assurance systems and processes rather than output focussed reporting. In saying that we want to be able to monitor all corners of the heath sectors service delivery in relation to Māori and Pacific health including levels of investment.

We welcome longer-term contracts for Māori and Pacific providers.

We welcome annual forms where providers and interested others including academics can participate in annual planning (p. 42). These forums could be an excellent opportunity to update the sector on progress on implementation of Te Tiriti o Waitangi, health equity and addressing institutional racism.

We support the regular review of DHB governance and management and welcome Maori provider and hapū involvement in this process (p. 43). The latter being uniquely placed to comment on DHBs engagement with Maori vis a vis Te Tiriti o Waitangi.

It is critical to keep accurate data to enable the performance of the health sector to be monitored (p. 45). It was disappointing in research we have done to find providers making up ethnicity data and not monitoring their service delivery to Maori (Came, Doole, Lubis, Garrett, McCreanor, & Coupe, 2015; Came, Doole, McCreanor, & Simpson, 2015). From a public health perspective, it is critical that Crown funders monitor all providers’ service delivery to Māori. This tracking data needs to inform future investment decisions.

## Other Feedback

Given the perpetual change within the health sector in the last two or three decades it is pleasing to see the retention of the core principles of the earlier *New Zealand Health Strategy* (King, 2000).

Thanks again for the chance to participate in this consultation.

Naku noa Na

Dr Heather Came and Claire Doole

For HEN: Health Equity Now

**References**

Came, H. (2012). *Institutional racism and the dynamics of privilege in public health.* (Unpublished doctorate), Waikato University, Hamilton, New Zealand. Retrieved from <http://researchcommons.waikato.ac.nz/handle/10289/6397>

Came, H. (2013). Beginning to address institutional racism within the public health sector: Insights from a provider survey. *Keeping up to date, 38*(Autumn/Winter), 1-9.

Came, H. (2014). Sites of institutional racism in public health policy making in New Zealand. *Social Science and Medicine, 106*(0), 214-220. doi:10.1016/j.socscimed.2014.01.055

Came, H., & da Silva, S. (2011). Building political competencies for the transformation of racism in Aotearoa. *Kotuitui, 6*(1-2), 113-123. doi:10.1080/1177083X.2011.615332

Came, H., Doole, C., Lubis, D., Garrett, N., McCreanor, T., & Coupe, N. (2015). *Benchmarking Crown practice: Public health contracting and funding- Preliminary report for public health providers*. Auckland, New Zealand: Health Equity Now.

Came, H., Doole, C., Lubis, D., Garrett, N., McCreanor, T., Coupe, N., & Berghan, G. (2015). *Benchmarking Crown practice: Public health contracting and funding- Preliminary report for public health providers*. Auckland, New Zealand: Health Equity Now.

Came, H., Doole, C., McCreanor, T., & Simpson, T. (2015). Refreshing public health providers' efforts to honour Te Tiriti o Waitangi. *Social Science and Medicine*.

Came, H., & McCreanor, T. (2015). Pathways to transform institutional (and everyday) racism in New Zealand. *Sites: Journal of Social Anthropology and Cultural Studies, 12*(2). doi:10.11157/sites-vol12isss2id290

Cram, F. (2014). *Equity of healthcare for Māori: A framework*. Retrieved from Wellington, New Zealand:

Harris, R., Cormack, D., Tobias, M., Yeh, L.-C., Talamaivao, N., Minister, J., & Timutimu, R. (2012). The pervasive effects of racism: Experiences of racial discrimination in New Zealand over time and associations with multiple health domains. *Social Science and Medicine, 74*(3), 408-415. doi:10.1016/j.socscimed.2011.11.004.

Harris, R., Tobias, M., Jeffreys, M., Waldergrave, K., Karlsen, S., & Nazroo, J. (2006). Racism and health: The relationship between experience of racial discrimination and health in New Zealand. *Social Science and Medicine, 63*(6), 1428-1441. doi:10.1016/j.socscimed.2006.04.009

Health Promotion Forum. (2011). *Ngā kaiakatanga hauora mō Aotearoa: Health promotion competencies for Aotearoa-New Zealand*. Auckland, New Zealand: Author.

Jansen, P., Bacal, K., & Crengle, S. (2008). He ritenga whakaaro: Māori experiences of health services. *Hospital, 200*, 30-37.

King, A. (2000). *The New Zealand health strategy*  Retrieved from Ministry of Health website:<http://www.health.govt.nz/publication/new-zealand-health-strategy> Retrieved from Ministry of Health website:<http://www.health.govt.nz/publication/new-zealand-health-strategy>

Marriott, L., & Sim, D. (2014). *Indicators of inequality for Māori and Pacific people [Working paper 09/2014]*. Retrieved from Wellington, New Zealand:

Mearns, B. M. (2013). Public health: Cost-effectiveness of various strategies for preventing RHD. *Nature Reviews: Cardiology, 10*(7), 366-366. doi:10.1038/nrcardio.2013.84

Mernagh, P., Coleman, K., Cumming, J., Green, T., Harris, J., Paech, D., & Weston, A. (2011). PCV97 cost-effectiveness analysis of public health interventions to prevent obesity in New Zealand. *Value in Health, 14*(7), A382.

Ministry of Health. (2003). *Improving quality: A systems approach for the New Zealand health and disability sector*  Retrieved from <http://www.health.govt.nz/publication/improving-quality-iq-systems-approach-new-zealand-health-and-disability-sector> Retrieved from <http://www.health.govt.nz/publication/improving-quality-iq-systems-approach-new-zealand-health-and-disability-sector>

Ministry of Health. (2004). *A health equity assessment tool (equity lens) for tackling inequalities in health*. Retrieved from Wellington, New Zealand: [http://www.moh.govt.nz/moh.nsf/0/24474C7464606A5ACC25700B0009D6F8/$File/heattool.pdf](http://www.moh.govt.nz/moh.nsf/0/24474C7464606A5ACC25700B0009D6F8/%24File/heattool.pdf)

Ministry of Health. (2007). *Whānau ora health impact assessment*. Wellington, New Zealand: Author.

Ministry of Health. (2014). *The guide to he korowai oranga: Māori health strategy*. Wellington, New Zealand: Author.

Ministry of Health. (2015). *Tatau kahukura: Māori health chart book* (3rd ed.). Wellington, New Zealand: Author.

Morrison, T. (2006). *Staff supervision in social care: Making a real difference for staff and service users* (3rd ed.). Brighton, England: Pavillion.

Mowbray, M. (2007). *Social determinants and indigenous health: The international experience and its policy implications: Report on specially prepared documents, presentations and discussion on the International Symposium on the Social Determinants of Indigenous Health*  Retrieved from World Health Organization, Commission on Social Determinants of Health website: <http://www.who.int/social_determinants/resources/indigenous_health_adelaide_report_07.pdf> Retrieved from World Health Organization, Commission on Social Determinants of Health website: <http://www.who.int/social_determinants/resources/indigenous_health_adelaide_report_07.pdf>

Owen, L., Morgan, A., Fischer, A., Ellis, S., Hoy, A., & Kelly, M. P. (2012). The cost-effectiveness of public health interventions. *Journal of Public Health, 34*(1), 37-45. doi:10.1093/pubmed/fdr075

Pickett, K., & Wilkinson, R. (2011). *The spirit level: Why greater equality makes societies stronger*. USA: Bloomsbury.

Pōmare, E. (1980). *Maori standards of health: A study of the 20 year period 1955-75: A report prepared for the Medical Research Council of New Zealand*. Retrieved from Wellington, New Zealand:

Pōmare, E., & De Boer, G. (1988). *Hauora:Māori standards of health: A study of the years 1970-1984*. Wellington, New Zealand: Medical Research Council and Department of Health.

Pōmare, E., Keefe-Ormsby, V., Ormsby, C., Pearce, N., Reid, P., Robson, B., & Watene-Haydon, N. (1995). *Hauora: Māori standards of health 3: A study of the years 1970-1991*. Wellington, New Zealand: Te Rōpū Rangahau Maori Research Centre.

Public Health Association. (2007). *Generic public health competencies implementation: Issues for consideration*. Retrieved from Wellington, New Zealand: <http://www.publichealthworkforce.org.nz/Articles/Competencies/11/20/Generic-Public-Health-Competencies-Implementation-Issues-for-consideration>

Public Health Association. (2011). Consultation on a code of public health ethics for Aotearoa New Zealand. Retrieved from <http://www.pha.org.nz/documents/PHA-Code-of-Ethics-consultation-draft-jul-11.pdf>

Public Health Association. (2012). *Te ture whakaruruhau: Code of ethical principles for public health in Aotearoa New Zealand*. Wellington, New Zealand: Author.

Robson, B., & Harris, R. (Eds.). (2007). *Hauora: Maori standards of health 4. A study of the years 2000-2005*. Wellington, New Zealand: Te Ropu Rangahau Hauora a Eru Pomare

Shearer, J., & Shanahan, M. (2006). Cost effectiveness analysis of smoking cessation interventions. *Australian and New Zealand Journal of Public Health, 30*(5), 428-434. doi:10.1111/j.1467-842X.2006.tb00458.x

Theodore, R., McLean, R., & TeMorenga, L. (2015). Challenges to addressing obesity for Māori in Aotearoa/New Zealand. *Australian and New Zealand Journal of Public Health*, n/a-n/a. doi:10.1111/1753-6405.12418

Wilson, D. (2008). The significance of a culturally appropriate health service for indigenous Māori women. *Contemporary Nurse, 28*(1-2), 173-188.

Winslow, C. (1920). The untilled fields of public health. *Science, 51*(1306), 23-33. Retrieved from <http://www.sciencemag.org/>

Wright, J. C., Bates, M. N., Cutress, T., & Lee, M. (2001). The cost-effectiveness of fluoridating water supplies in New Zealand. *Australian and New Zealand Journal of Public Health, 25*(2), 170-178. doi:10.1111/j.1753-6405.2001.tb01841.x

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| **56** | Submitter name | Jeanette Woltman-Black |
| Submitter organisation | The Physiotherapy Board of New Zealand |

 Submission on Draft Updated Health Strategy

1. The Physiotherapy Board (the Board) is the Responsible Authority for physiotherapists, established under the Health Practitioners Competence Assurance Act 2003 (HPCAA). The purpose of the Board is to protect the health and safety of the public by providing mechanisms to ensure physiotherapists and competent and fit to practise.

Included within the statutory functions of the Board are to specify scopes of practice, qualifications and experience. As such the Board has a key role to play within the shaping the future of the health and disability system.

2. Overall the draft updated health strategy is supported by the Board.

2.1 Specifically the Board support;

- The Strategy theme of *One Team* in particular, making the best and most flexible use of the health and disability workforce;

- The reference to the wider context and the interconnections between health and other aspects of people’s lives;

- Inclusion of cross agency way of working;

- The refreshed guiding principles;

- Regarding the section on *People – powered* acknowledgement that there are services provided now in community settings that are tailored to the population segments. This is not to say these should not continue and be expanded as required;

- Embracing the opportunities technology can offer including electronic health records to all significant health professions;

- The reduction of safe and appropriate legislative barriers for example streamlining the process for enabling physiotherapists to prescribe;

- The Road Map as a useful and clear way of seeing the actions that the Strategy propose.

2.2 Specifically the Board request:

- Acknowledgment and recognition of the role of physiotherapists within the health and disability system. Whilst the Strategy refers to Doctors, Nurses, Midwives and Pharmacists, Physiotherapists currently play an active part in the provision of health and disability services. Physiotherapists actively support wellness, prevention, provision of assessment and treatment and are a key health practitioner in the management of long-term conditions such as musculoskeletal health and acute illnesses. A word search identified on mention on page 15 only despite being a key profession in every community in New Zealand alongside GP’s, Nurses and Pharmacists;

- Demographic statistics on physiotherapists as per our workforce data provided to Health Workforce NZ are incorporated;

- Acknowledgement of the opportunities expanded or extended scopes of practice physiotherapy can provide. This would be most appropriate within the *Closer to Home* section and under the *Road Map Closer to Home - Action 4.* For example there are opportunities and efficiencies for physiotherapists in ordering MRI’s (currently not able to do so) and prescribing;

- Recognition of the Physiotherapy Specialist scope of practice within the *One Team* section;

- Addition of Global challenges in the blue box on page 5 – could add musculoskeletal conditions1 ;

- Providing services close to home (theme 2) could include examples of rehabilitation programmes for heart and lung disease2, as well as programs for arthritis conditions (hips and knees) to reduce the burden on surgical waiting lists;

- Page 35 “what do we want in 5 years?’ – suggest add *rehabilitation* to bullet point 3;

- Page 36 - Action 4a – suggest adding *dieticians and physiotherapists;*

- Page 39 “what do we want in 5 years?’ – suggest changing ‘Primary care services use teams ….’ to ‘Primary care *and community* services use teams….’ to bullet point 3.

1 Significant

Thank you for the opportunity to provide a submission. Should there be questions or areas of clarification required regarding this submission, please contact Jeanette Woltman-Black (Chief Executive) via email on j.woltman-black@physioboard.org.nz

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| **57** | Submitter name | [redacted] |
| Submitter organisation |  |

On a most basic high level my biggest feedback would be that in order for items 1-3 to happen we need items 4&5 and while I don't see that this says we must do them in any order without a one team vs 20DHB/60PHOs we wont achieve the outcome. For example the more detail action talking about commissioning and improving this, this will never happen if we are unable to break barriers, we have PHOs across DHBs and DHBs with multiple PHOs and while in principal may be right the competition model particularly between PHOs creates -perverse incentives to data sharing and working as one team



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action 1 - a) particular attention needed towards what works for  Maori and other difference between age groups ie youth

action 1 d.ii) not bold enough, should link to the items around the shared data record and should be at least all DHBs moving to electronic system for maternity & children

action 5 a) ensure this includes equity across ethnicities

action 14) needs clear direction that at key points the centre will direct especially where leaders of the systems views clash with the over arching principal of patient led

apart from these specific points the only other feedback is one where more than stating that all NZers get well and stay well, we have a system that actively hunts and eliminates inequities rather than providing and equal system we need one that is equitable

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| **58** | Submitter name | [redacted] |
| Submitter organisation |  |

Thank you for the opportunity to feedback on the above:

I fully support the approach of Government re promoting  greater interagency collaboration and information sharing.

* Allied Health Scientific and technical encompasses a diverse group of professions working across all sectors of society, both in large organisations such as DHBs and are already strongly linked especially through the disability sector in education and social services. There is a risk these services remain as the reactive services, often poorly understood by other professional groups and as such not working to the top of scopes. For example, physiotherapists First Surgical appointment, Women’s health,
* Allied Health has a role in prevention through education and work in primary care. Funding is required to ensure the best people and professions are situated in areas where the fullest impact can be made.
* There are some great examples of inter-agency and interdisciplinary efforts are having a positive outcome, e.g. Diabetes service and particular Gestational Diabetes.
* People powered –what great might look like in 10 years. Health literacy and socio economic implications mean certain groups are at risk of not being able to access and make informed choices. It is absolutely appropriate that individuals and cultural groups are able to access and determine their health choices---is this a western approach to healh management that is at risk of excluding other cultural norms.
* Closer to home is a great concept—use of Telehealth and technology to support this is paramount. The health consumer will need to have access to fast, multi tech facilities and  it is envisaged that in many rural areas this may prove an issue.
* Government having a clear knowledge of what Allied health  offers across multiple domains and a diverse work force is essential. Allied Health collectively has a role alongside medicine and nursing, and historically been a “nice to have”… in regards to closer to home, one team and people powered Allied Health has an important place.
* Inform and involve people.: In order to know current state and opportunities for innovation Allied Health needs to be included as an equal partner.
* I would seek assurance from government that clinicians are not just Doctors and Nurses but representative of all professions. To this end the descriptor on page 42 is very encouraging.

In general I feel this strategy is very constructive and the five focus areas absolutely appropriate,

*Nga mihi nā*

[redacted]

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| **59** | Submitter name | [redacted] |
| Submitter organisation |  |

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| This submission was completed by: *(name)* | [redacted] |
| Address: *(street/box number)* | [redacted] |
|  *(town/city)* | [redacted] |
| Email: | [redacted] |
| Organisation (if applicable): | [redacted] |
| Position (if applicable): | [redacted] |

Are you submitting this *(tick one box only in this section)*:

X as an individual or individuals (not on behalf of an organisation)

If you are an individual or individuals, the Ministry of Health will remove your personal details from your submission, and your name(s) will not be listed in the published summary of submissions, if you check the following box:

X I do not give permission for my personal details to be released.

(The above information will be taken into consideration if your submission is requested under the Official Information Act 1982.)

Please indicate which sector(s) your submission represents
*(you may tick more than one box in this section)*:

[ ]  Māori [ ]  Regulatory authority

[ ]  Pacific [ ]  Consumer

[ ]  Asian x District health board

[ ]  Education/training [ ]  Local government

[ ]  Service provider [ ]  Government

[ ]  Non-governmental organisation [ ]  Pharmacy professional association

[ ]  Primary health organisation [ ]  Other professional association

[ ]  Professional association

[ ]  Academic/research [ ]  Other *(please specify)*:

### Challenges and opportunities

The Strategy reflects a range of challenges and opportunities that are relevant to New Zealand’s health system. Some of these are outlined in I. Future Direction on pages 5–7.

1. Are there any additional or different challenges or opportunities that should be part of the background for the Strategy?

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| You reference workforce challenges. The Allied Health, Scientific and Technical (AHS&T) workforce encompasses over 50 professional groups working across all health and disability services, and employed in both the public and private sectors, comprising over 30,000 individual professionals. You have made no mention as to whether this workforce faces similar challenges to nursing, medical and midwifery or whether it offers opportunities to meet some of the challenges the other workforces embody (ageing, expense). |

### The future we want

The statement on page 8 of I. Future Direction seeks to capture the future we want for our health system:

So that **all** New Zealanders **live well, stay well, get well**, we will be **people-powered**, providing services **closer to home**, designed for **value and high performance**, and working as **one team** in a **smart system**.

2. Does the statement capture what you want from New Zealand’s health system? What would you change or suggest instead?

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| I think you could leave off “so that” and use sentences instead. I am also not sure that “people powered” has a clear meaning for people who haven’t read the supporting text.. Perhaps it could read “All New Zealanders live well, stay well, get well. People work as one team to power a smart system that provides services closer to home and is designed for value and high performance. |

A set of eight principles is proposed to guide the New Zealand health system. These principles are listed on page 9 of I. Future Direction and page 31 of II. Roadmap of Actions.

3 Do you think that these are the right principles for the New Zealand health system? Will these be helpful to guide us to implement the Strategy?

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| Principle 8 could read “Working/providing care beyond narrow…” or some equivalent action verb. “Thinking” doesn’t necessarily imply you expect behaviour change or action – and I think your intent is to make the strategy action oriented? |

### Five strategic themes

The Strategy proposes five strategic themes to focus action – people-powered, closer to home, value and high performance, one team and smart system (I. Future Direction, from page 10).

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| 4 Do these five themes provide the right focus for action? Do the sections ‘What great might look like in 10 years’ provide enough clarity and stretch to guide us?**1. People powered**a)Under “people powered” – the text seems to be contradictory –saying there is a move to a stronger customer-focus, but then saying there is a move away from the term customer to people. b)The AHS&T workforces work with patients to understand what matters to them so that they set goals together and work in partnership to achieve their outcomes. Outcomes can be anything from returning to work, to being able to walk the dog each day, or using aids to remember medication. This approach enables patients to be successful and live well in a manner that enables the individual to live as independently as possible, and able to manage their own health condition(s) as much as possible. c) There is a risk with the people powered theme as it is written that it could reinforce notions of blame for those with poor health outcomes. The ability to self-manage health presupposes a whole lot of other personal resources – a sense of self-efficacy and self-worth, the ability to plan, predict consequences, choose between competing priorities and have the self-belief that your actions make any difference. Added to that for a significant proportion of society, extra challenges of mental health conditions, trauma, low cognitive functioning, environments of abuse or neglect or poverty or disenfranchisement with society in general reduce their ability to action these ideals. The promotion of an individual responsibility message in the absence of a balancing context statement risks reinforcing value judgements . The idea that increased health literacy leads to better health outcomes is true for a portion of society, but makes others potentially further excluded.**2. Closer to home**Allied Health, scientific and technical  professionals, have a well established multi-professional and inter-sectorial approach and are very well placed to lead new ways of collaborative working designed around and with the person, their whanau and wider community. Many of the Allied Health teams in particular already work in community settings in close collaboration with NGOs and primary health organisations to support people with long term conditions such as mental illness.**3. Value and high performance**In order to provide value and high performance design, decision making and delivery there needs to be a comprehensive oversight of all facets of the system and the strategy refers to the need to ensure all parts of the team have high quality, effective deployment and efficient practice. The strategy is not in line with the Ministry of Health practice in this regard. Allied Health Scientific and Technical workforces (with the exception of pharmacy) are not represented at the senior strategic level at the ministry. Quality measures are generally focussed on medical treatment outputs and in fact much DHB reporting to the ministry with regard to Allied Health Scientific and Technical is optional. There needs to be a model within the Ministry, which enables clear understanding of all clinical and support systems and to allow all parts of the system to play their roles effectively and efficiently. Essentially the Ministry has a blind spot in this area and risks missing opportunities for gain. There has recently been indication from the Ministry of Health that including this perspective at the strategic level of the Ministry is not on the agenda – an approach which would seem at odds with the stated goal of this theme – and the One team theme 4. |

**4. One team**

The AHS&T workforces keep people well and intervene early to prevent the occurrence of long term conditions and associated complications.  Engagement of these workforces early and in conjunction with other key community and primary care based professions enables innovative and sustainable community centred models of care to be developed and implemented.

As the sector works towards new models of care, the significant scope and range of specific skills that the allied health, scientific and technical professions can offer provides a broad range of options for the health system to call on. Most health agencies, nationally and internationally, acknowledge that the future of healthcare lies in developing a cohesive, integrated multi-professional approach to care. The true benefits of the wide array of skills of the allied health, scientific and technical  workforces have  traditionally not been fully utilised. This is an untapped resource in providing truly holistic and joined up patient care.

**5. Smart system**

### In order to build on the work that we have begun, there needs to be clearer understanding, from central health leaders and DHB, PHO and NGO leaders of the urgent need for a coordinated multi-professional approach to new models of patient care. Improving patient outcomes in primary care will require a much more integrated policy approach encompassing not only health but also social care, education and justice.

### Roadmap of Actions

II. Roadmap of Actions has 20 areas for action over the next five years.

5 Are these the most important action areas to guide change in each strategic theme? Are there other actions that would be better at helping us reach our desired future?

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| I particularly support Action 8 Develop and implement a **health outcome-focused framework**, with its focus on moving from an input focus to an outcome measures focus. |

### Turning strategy into action

6 What sort of approaches do you think will best support the ongoing development of the Roadmap of Actions? Do you have ideas for tracking and reporting of progress?

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### Any other matters

7 Are there any other comments you want to make as part of your submission?

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| It is exciting to consider sophisticated technological solutions to current problems, but it is important to consider this in the context that many of our most vulnerable do not have access to technology or ability or confidence to utilise it.In addition, tight fiscal constraints mean that much of our health providers have outdated (if any) electronic and communications technology. An important aspect of planning for the future needs to be how to ensure broad scale access to basic technology and full utilisation of existing systems, in conjunction with aspirational aims to new and innovative technology solutions. |

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| **60** | Submitter name | Alison Quesnel |
| Submitter organisation | Natural Products NZ |

Submission on the New Zealand Health Strategy

Prepared by Alison Quesnel, Executive Director, Natural Products NZ

25 November 2015

Natural Products NZ (NPNZ) is a national industry organisation representing this country’s natural products, functional foods, complementary medicines, cosmeceuticals and nutraceuticals industries within New Zealand and internationally.

Our submission on the New Zealand Health Strategy encourages policy-makers to place more strategic emphasis on thinking outside the pharmaceutical square to include funding for more research and healthcare that focuses on integrative medicine – a medical model that an increasing number New Zealanders and health professionals are turning to.

By ‘integrative medicine’ we are referring to medical practice that draws on both pharmaceutical and ‘complementary’ therapies that include herbal medicine, phytotherapy, osteopathy, dietary supplements and acupuncture.

There is a growing consumer demand for complementary medicine worldwide and New Zealand is no exception. This is evidenced by recent research that NPNZ commissioned, which found this country’s natural products industry contributes around $1.4 billion per annum to the economy – a 40 per cent increase over the previous five years. Add complementary therapies such as osteopathy and acupuncture to the mix and the figure would be much higher.

This trend is mirrored within the health profession, with evidence of an increasing number of medical doctors and nurses using complementary medicines and practices themselves and routinely prescribing previously unconventional remedies such as fish oils, glucosamine, meditation and yoga to patients. In addition, many medical schools in North America now teach complementary medicine in their undergraduate courses and some hospitals offer acupuncture, meditation and massage.

The low risk nature of most complementary medicines means they attract a different regulatory framework than do higher risk medicines, which need many more safeguards. This lower risk means they can be more accessible to the public and are more appropriate for use in self-care.

This is significant because pharmaceutical drug costs are spiralling – and will continue to do so under TPP – so a continued focus on pharmaceutical medications presents an unsustainable healthcare model. The health system and the public would benefit if health research and practice also explored other options such as complementary healthcare with the view to integrating the best that pharmaceutical and complementary medicine has to offer.

Even though there is a need for affordable healthcare options that complement or replace pharmaceutical products, complementary and pharmaceutical medicine need not be mutually exclusive. An artificial barrier has been created between the two types of medical practice, which is doing patients and the health system a disservice.

We encourage policy-makers to ensure the New Zealand Health Strategy explores pharmaceutical and complementary medical practices that promote good health, prevent and treat disease, and ease discomfort by looking at how to integrate the best of both worlds rather than treating them separately.

It is also our hope that health researchers are encouraged to look further than randomly-controlled trials for guiding medical practice and information. Creating evidence through such trials is prohibitively expensive so the pharmaceutical industry has no incentive to fund expensive complementary trials due to lack of patent protection, while few complementary medicine producers or practitioners have the budget for this kind of research.

Evidence for all medicines is ever-changing and in a constant state of flux, including around well-known pharmaceutical medicines such as paracetamol, hormone replacement therapy, and over the counter cough and cold treatments.

In many cases there are centuries of traditional evidence that complementary medicines and healthcare practices work, which suggests there should be a change to what ‘evidence’ means. The new health research strategy should encourage researchers to treat randomly-controlled trials a tool – not the tool – in validating a medicine’s efficacy.

Major public health issues associated with obesity and an ageing population are here to stay. Cost-effectively and successfully addressing these issues requires health researchers, health practitioners – and their funders – to think outside the square.

The health system and its users will benefit if the Health Strategy’s mandate is widened to explore integrating pharmaceutical and complementary medicines in New Zealand’s health research and government-funded health care systems. Significantly, a new economic report in Australia shows that taking specific complementary medicines can provide significant positive health outcomes and cost savings by reducing hospitalisations and improving productivity.

Integrating complementary and pharmaceutical medicine has long been the elephant in the Vote Health room. It is our sincere hope that the Government’s Health Strategy will be bold enough to address it.

Natural Products would appreciate the opportunity to present a verbal submission in due course.

For further information contact:

Alison Quesnel

Executive Director

Natural Products NZ

Ph: (09) 531 5717

Mob: 021 415 888

Email: alison.quesnel@naturalproductsnz.org

Web: www.naturalproducts nz.org

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| **61** | Submitter name | Johan Van Schalkwyk |
| Submitter organisation |  |
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# A Better Health Strategy for New Zealand

L Hopley,[[1]](#footnote-1) J van Schalkwyk[[2]](#footnote-2)

## Executive Summary

We respond to an invitation to contribute to a new health strategy for all New Zealanders.[[3]](#footnote-3) We endorse its aims: empowering people, bringing health closer to home, improving ‘value and performance’ (progressively decreasing waste), working as a team, and optimal use of technology (“smart systems”). In [Section 1](#_1._Introduction) we present our credentials, explore the healthcare aims, and say why the NZ healthcare system is strong.

In [Section 2](#_2._Three_weaknesses), we examine three weaknesses of the current approach that impair success and predispose to failure. These are:

1. Insufficient accommodation of important drivers of population health. These drivers are largely out of the hands of the citizen and those helping her to achieve health. These high-level determinants of health are related to the flow of commodities—alcohol, poor quality food, and nicotine-containing products. Any healthcare strategy *will fail* if not integrated with management of flow of these commodities;
2. Excessively complex systems that by virtue of their complexity are unreliable, insecure and inefficient;
3. Actions that pervert measurement. A profound, bitter lesson from the architects of statistical quality control is that if process measurements—the measurements used to determine “how we are doing”—are set as targets, then those at the coal face will remove their focus from achieving quality. Their focus will shift to providing the desired numbers.

In [Section 3](#_3._Design_Principles), we describe principles that we believe will address the above issues. These are:

1. Any strategy must address the flow of commodities;
2. Good health is not achievable if you don’t get the basic science correct;
3. Measurement processes should be robust and unperturbed by reward and punishment;
4. Minimise complexity: provide simple, useful data to the clinician on the front line;
5. Software quality must be evident and free from legal constraints;
6. Design so that every participant has skin in the game, and feels part of the process;
7. Design in security from the bottom up. Security can’t be sprinkled over like a condiment.

The implications of the above *for empowerment of the individual* are noted.

We anticipate that neglecting the principles described will result in failure to stem the incoming tide of disorders such as hypertension, cancer, obesity, diabetes and mental illness. Effects on health and costs will be predictable.

To keep this document concise, we’ve minimised the number of references. Further information is available on request.

## 1. Introduction

New Zealand healthcare has many strengths. Outcomes are fairly good by OECD standards, and we spend just over 10% of our GDP on healthcare—somewhat more than Australia, and far more than e.g. Hong Kong or Singapore, but considerably less than the USA. We have near-universal computerisation of primary care practices. We are starting to vocalise a strong emphasis on integrated care, with optimal delivery of care at the right level. We seem to have the will to improve.

We have however moved from innovation—the first country to establish a National Health Index (NHI)—to relative stagnation. In addition, several major threats to long-term population wellbeing have become apparent. These include the “obesity epidemic”, notable mainly for its association with diabetes mellitus, with consequent vast consumption of healthcare resources; the majority of New Zealanders will develop high blood pressure, which is the major cause of heart failure, kidney failure and stroke; we have largely failed to contain and manage major organ cancers. In addition, inappropriate responses to the ageing of our population can also be considered a threat.

 In this document, we briefly suggest why we have stagnated, and how we can move from adequate healthcare to superlative health care. We wish to emphasise that “quick, easy solutions” will likely result in long-term pain, and that solutions with long-term value will require twenty-year planning rather than five-year fixes.

Lara Hopley is a practising specialist anaesthetist and clinical advisor to digital innovation at Waitemata DHB. Approximately half of her working hours are devoted to investigating and deploying digital solutions; she is currently devoting much of this time to the “Computerised Physician Order Entry” type solutions - eReferrals, eOrder and ePrescribing process taking place within CMDHB, WDHB and ADHB. Johan van Schalkwyk practises as a perioperative physician and general physician at Auckland DHB, and has also done his “ten thousand hours” in IT, with the ability to program in a variety of languages including Javascript, Perl, PHP, C/C++, SQL and extensive past experience with other languages down to the machine-code level. He gained a Diploma in Datametrics in 1991. He has written a mobile “paperless” application for the Acute Pain Service at ADHB, and this has been running for over seven years. He is conversant with the interrogation of healthcare databases, as shown in a recent paper published in the premier journal Anesthesiology.[[4]](#footnote-4)

We believe that the promise of healthcare computerisation has largely not been realised. The following attributes are obviously desirable, yet we seem to be moving in the opposite direction:

1. Health care computerisation should be empowering, yet it largely isn’t;
2. It should save clinicians valuable time. It doesn’t;
3. It should improve data integration and interpretation. It largely hasn’t.

Why are these problems present in almost all attempts at healthcare computerisation? We argue that there has been a failure to get the basics right, and that this failure has led to multiple systemic failures throughout most healthcare-related systems. We’ll explore how things can be done better, but first let’s look at the problems in more detail.

## 2. Three weaknesses

In our opinion, at least three glib “solutions” have conspired to prevent development and deployment of systems that improve the quality of healthcare. These are:

1. Healthcare has been put in a compartment. This has resulted in major drivers of health being almost completely ignored;
2. “Solutions” have been patched together, resulting in unworkable complexity. This is only getting worse;
3. Imposition of “targets” has perverted the very measurements on which adequate responses should be based.

The first and third points will not sit well (particularly with administrators eager for a quick fix) so we need to explore these in some detail.

### 2.1 The determinants of population health

In the final analysis, population health is about the reaction of individuals to their environment—an environment that may be deficient in some substances and provide harmful amounts of others. If the population intake of, for example, vitamin B12 is insufficient, then signs and symptoms of deficiency of the vitamin will result. In contrast if we “dose” the population with large amounts of alcohol, it has been well shown that there will be a predictable rise in the incidence of harm, including predictable societal damage, also resulting in the loss of billions of dollars in revenue.[[5]](#footnote-5)

It is equally obvious that there is an element of individual variation and individual choice here—individuals may be constitutionally unable to absorb vitamin B12, or may be intolerant of alcohol due to deficiency of a liver enzyme. However, *on a population basis*, the overall effects of deficiency or excess provision of a ‘resource’ are predictable.

Other influences modify population responses to such “dosing”. Certain substances like alcohol and tobacco are addictive, so once consumption is established in a population, there will be strong resistance to subsequent attempts to change consumption. Consumption is obviously strongly modulated by availability and by advertising.[[6]](#footnote-6) Now that we have stopped tobacco promotion, and to a degree have limited availability, consumption is slowly declining.

It can be seen that in terms of the population health of New Zealand, these factors are critical:

1. Tobacco consumption results in cancers at multiple sites, vascular disease, and obstructive airways disease;
2. Consumption of high-energy-density, carbohydrate-rich foodstuffs cause obesity and diabetes;
3. The combination of large amounts of salt combined with low intake of fruit and vegetables has resulted in an epidemic of high blood pressure[[7]](#footnote-7);
4. Alcohol consumption results in social disruption, trauma (including motor-vehicle-related injuries), cirrhosis, stroke and cancer (a 7% increase per glass per day).

It is important to realise the magnitude and preventability of the harms caused by these factors. About 30% of NZ adults aged 18–24 years are potentially hazardous drinkers.[[8]](#footnote-8) The lifetime incidence of high blood pressure in Westernised populations is estimated at 70%. Not only does diabetes consume about 10% of healthcare resources in Westernised populations, but the incidence is increasing as are the costs. In contrast, with wise management, smoking rates have declined to 17%.

The above considerations are critical to the understanding of where we are currently going wrong. It’s easy from the point of view of an advertiser or politician to place emphasis on “individual choice”, but from a population health point of view, this is irrelevant. We know that if a commodity like tobacco is made available and advertised at a certain level, a predictable population response will occur. There is no good reason why the same should not apply to other commodities like alcohol or high-energy-density food. This is particularly the case where the substances are highly sought after and available cheaply and in large quantities.

We also need to acknowledge the importance of economic competition between resources. If availability and advertising drive consumption of some resources, less money and desire will be available for other resources such as fresh fruit and vegetables.

We suggest that currently the management of this flow of resources has largely been neglected in preference to two other strategies. First, “individual choice” has been emphasised. Second, healthcare providers have been extensively recruited to “solve the problem”.

These approaches have been and will be largely ineffective. It’s not difficult to see why, from an economic point of view. If billions are invested in effectively promoting alcohol or harmful foodstuffs, unless billions are similarly invested in counteracting promotion and availability, it’s basically naïve to believe that the latter will prevail. Economic factors trump wishful thinking.

Similarly, once consumption is established within a society, particularly if the substance being promoted is addictive, it is naïve to believe that even vast inputs from healthcare providers will be effective. We see this with alcohol, where we ‘cure’ less than 5% of those dependent on the substance. We see this with smoking counselling, where a single ‘counselling’ intervention works transiently in just 1–3 % of people, with no effect at 20 years.[[9]](#footnote-9)

It should be clear at this point that healthcare professionals are truly “the ambulance at the foot of the cliff” when it comes to addressing the major determinants of population health. The fences at the top of the cliff need to be mended, and we aren’t particularly good at doing this at an individual level. Solutions need to be sought outside the artificially created “compartment” of “Healthcare”.

### 2.2 Unworkable complexity

It is obvious that our current computerisation of healthcare is a bit higgledy-piggledy. We currently have multiple, poorly-interacting systems that are loosely tied together. Our current emphasis is on documents, rather than data. Let’s take an example—allergies.

As part of the NHI system, we have the ability to document allergies, but the content has been poorly regulated. The centre for adverse reaction monitoring in Dunedin provides some quality checks; other data sources are largely unregulated. There’s the excellent MedicAlert system, but this does not feed into any part of the national system. Local district health boards have their own individual systems, some of which interact fully with the national system, and some of which don’t. Primary care usage of the NHI itself and recording of allergies is often totally distinct from the NHI system, and finally, with any given clinical exposure, a new allergy may be documented in the local notes without finding its way into any other system.

This is just a single example of “data denormalisation”—the presence of multiple representations of the same thing, often in quite different forms. Current solutions have been centred on integration of *documents*, for example, it may be possible to present most of the above conflicting data as distinct documents within a “portal” that more-or-less pulls the documents together.

It should be clear that this is unworkable in the long term for several reasons:

1. The clinician now has to reconcile multiple disparate data sources *every time*;
2. Workload increases, notably repetitive work (rather than one clinician doing the job correctly, once);
3. Cognitive load increases, predisposing to error;
4. The “integration engine” that pulls the data/documents together has to deal repetitively with multiple sources. This makes for a complex, slow and fragile system;
5. Errors in data representation are difficult to fix, even if they are identified. One has to go back to one or several sources, and fix the problem at source. This too increases complexity.

Even with this simple example, the complexity is evident. Now multiply this by ten thousand to obtain some idea of the magnitude of the problem.

### 2.3 The use of ‘targets’

We are acutely aware that “targets” are so embedded in New Zealand healthcare that any attempts even to point out the problem will likely be ignored or ridiculed by those with the ability to change things. We will still try.

It seems so obvious—set a good, well-thought-out healthcare target, and those “working on the floor” will meet the target, and healthcare will improve. Job done.

The problem is we’re dealing with a complex system. Although those who work in quality control have long known that tinkering with a complex system often has “revenge effects”, it’s only comparatively recently that this has entered the popular imagination. We’ve come up with terms like the “Streisand effect” where attempts to hide information highlight that information, and the “cobra effect”— attempts to eradicate cobras from Delhi using a bounty system resulted in the proliferation of cobra farms; when the bounty was scrapped, the farmers released their cobras.

Such “unintended consequences” are by definition unpredictable. It is however now clear that setting targets *predictably* causes harm *to the system as a whole*. W Edwards Deming pointed this out decades ago.[[10]](#footnote-10) One of his fourteen points for quality improvement (the 14 points that the Japanese used in their miraculous recovery in the 1950s) is:

*“Eliminate numerical goals, numerical quotas and management by objectives. Substitute leadership”.*

Why should harm result when we establish numerical goals? It’s tempting to cite examples that the authors have personally observed, but we will resist this temptation as the argument will inevitably be made “Yes but in your specific system things simply aren’t being done right. This can be fixed”.

The major point here is that if we are to determine the success or failure of modifications to a process, our *measurements must not be perturbed*. If the measured value becomes an end in itself, particularly if punishment/reward is attached, there is a near-infinite number of ways that users will “achieve the measurement”. Any negative consequences of these attempts will however be invisible because the measurements look better! The target has been met.

## 3. Design Principles

We believe that if any new healthcare strategy is to succeed, there are two major dangers to avoid. The first is “micromanagement”, where every design parameter is so finely specified that there is no room for evolutionary growth and adaptation to changing circumstances. The second is being so general and non-specific that “anything goes”. You’d struggle to move without a skeleton.

It is also possible to combine these two errors, over-specifying things that should be left vague, and ignoring fundamental design principles in an attempt to please everyone. We believe that the following seven principles strike the right balance:

1. Any strategy must address the flow of commodities;
2. Good health is not achievable if you don’t get the basic science correct;
3. Measurement processes should be robust and unperturbed by reward and punishment;
4. Minimise complexity: provide simple, useful data to the clinician on the front line;
5. Software quality must be evident and free from legal constraints;
6. Design so that *every* participant has skin in the game, and feels part of the process;
7. Design in security from the bottom up. Security can’t be sprinkled over like a condiment.

Quality will flow from the above. The following vignettes illustrate these points.

### 3.1 Address the flow of commodities

Cheap, aggressively promoted alcohol and high-energy density food are major current threats to the wellbeing of all New Zealanders. Unless price and distribution are controlled, it’s largely futile to expect clinicians to address the problem. Solutions will need to be integrated across multiple government departments.

### 3.2 Get the science correct

As already noted, high blood pressure is a huge problem that won’t just go away. More and more people are using home measurement of blood pressure, and will want to upload their data (with multiple other data) for inclusion in their EHR. If the devices they use are not traceably calibrated back to a standard, how can we trust these data? (If your supermarket used a home bathroom scale to weigh your potatoes, would you trust the weight?) Similar strictures apply to the recording and storage of *any and every* datum within an EHR. Getting this right is non-trivial.

### 3.3 Make measurements independent of rewards

In Medicine, it’s all too easy to focus on the symptom (e.g. high fever) and miss the underlying disease (e.g. a liver abscess). Symptom management should not take the place of treating the underlying cause. Danger arises if ‘symptoms’ are made a priority (focus on the treatment of the fever; focus on getting the patient out of the emergency department within an arbitrary target time). Even worse, symptomatic “fixes” may efface information about how the system is doing.

### 3.4 Minimise complexity

Some EHR providers assert that the clinical record, as presented to the clinician, contains about 80,000 elements. We’d suggest that *anyone* will drown in such complexity.

Simpler approaches have been known for decades. Foremost among these is the “problem-oriented record”, where any participant can identify problems such as fever, right upper quadrant pain and a very high white cell count; propose explanations (for example, that these problems are due to a new problem — a liver abscess); and suggest appropriate investigations (an ultrasound or CT) and solutions (for example, drainage of the abscess). Software should enhance this approach, allowing transparent linkage from a tentative diagnosis to the underlying thoughts and results that support or refute that diagnosis.

Clinicians are getting by, using wisdom, insight and a minimal set of data. They often know what data they require, but are increasingly being drowned in irrelevancies. Let’s adopt “solutions” that emphasise appropriate provision of the necessary minimum of quality data, rather than “big data”.

### 3.5 Software quality

Modern software is often vast. A typical EHR system may run into millions or even tens of millions of lines of code. Unfortunately, almost all modern commercial systems have this complexity. Even worse, it is customary for the providers of such software to use legal constraints to limit their liability and impede exploration of problems. We believe this needs to stop. Developers must open up their source code to inspection, and not limit the ability of those who find defects to draw attention to these issues. We appreciate that this needs to be an evolutionary process, where code is favoured based on its openness. We need a smarter, more transparent way to choose new and replacement software, instead of our current *ad hoc* approach.

### 3.6 Part of the process

In our perception, there is potential for an increasing divide between those who make and implement software (on the one hand) and those who use it (on the other). This will become a very real problem unless patients and clinicians feel part of the process. We believe that the software should primarily be there to help the clinician to help the patient—something it cannot possibly do if the clinician has no control over the way the software works in their environment.

The solution to this problem is not easy. Even where resources are vast enough to have clinician assistants walking around behind clinicians and entering data (as often occurs in US systems that have adopted EHR technology), clinical software often slows the clinician in his/her task. We see the solution as a progressive one with two main themes:

1. The software should be designed not only to ease the clinician’s task, but also to be easily configurable *by the clinician* to meet the needs of the clinician;
2. The data must nevertheless be adequately mapped to a robust, common data dictionary.

As we see it, the best way to achieve this is to “dual train” large numbers of clinicians, so that they have sufficient, insightful control to ensure software is helpful and not a hindrance. This won’t happen overnight, as there needs to be both an improvement in the software, and an improvement in clinicians’ computer literacy. We need to take advantage of the “digital natives” moving into medicine, making stewardship of electronic health a paid part of their job, training them up and giving them appropriate responsibility and rewards.

### 3.7 Security

Until recently, healthcare data have not been a great prize for hackers; things are now changing. There is now a substantial risk of major failures related to intrusions. A well-established principle of computer security is that security can’t be sprinkled over a system like magic fairy dust—it must be built into the system *from the ground up*. This has not happened, leaving our systems vulnerable whatever the assurances to the contrary. The major issues here have been described—lack of transparency,[[11]](#footnote-11) and excessively complex systems that are intrinsically vulnerable. The only long-term solution we can see is to progressively whittle away at these complex systems, eventually replacing them with simple systems where the source can be scrutinised, criticised and improved. This will not happen overnight, but it will not ever happen without the right motivation and incentives.

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| **62** | Submitter name | Dr Wendy Pattemore |
| Submitter organisation |  |

Submission Re Draft, Updated, New Zealand Health Strategy

|  |  |
| --- | --- |
| This submission was completed by: *(name)* | Dr Wendy Pattemore |
| Address: *(street/box number)* | Nurse Maude Community Palliative care15 Mansfield Ave |
|  *(town/city)* | Christchurch |
| Email: | Wendy.Pattemore@nursemaude.org.nz |
| Organisation (if applicable): |  |
| Position (if applicable): | Palliative Care Specialist Doctor |

Are you submitting this *(tick one box only in this section)*:

X As an individual or individuals (not on behalf of an organisation)

[ ]  on behalf of a group or organisation(s)

If you are an individual or individuals, the Ministry of Health will remove your personal details from your submission, and your name(s) will not be listed in the published summary of submissions, if you check the following box:

[ ]  I do not give permission for my personal details to be released.

(The above information will be taken into consideration if your submission is requested under the Official Information Act 1982.)

Please indicate which sector(s) your submission represents
*(you may tick more than one box in this section)*:

[ ]  Māori [ ]  Regulatory authority

[ ]  Pacific [ ]  Consumer

[ ]  Asian [ ]  District health board

[ ]  Education/training [ ]  Local government

X Service provider [ ]  Government

[ ]  Non-governmental organisation [ ]  Pharmacy professional association

[ ]  Primary health organisation [ ]  Other professional association

[ ]  Professional association

[ ]  Academic/research [ ]  Other *(please specify)*:

Everyone will die.

It does not matter how well our chronic conditions are cared for, nor how many years we live, with wellness or disability. We will all die.

This is not reflected in the new Health Strategy.

I am heartened that the approach that health is more than merely an absence of disease has been embraced, and that this involves cross discipline cooperation.

However that death, as a normal part of life, is never mentioned is a gross omission.

People are afraid of death - partly because it has been removed from the public sphere and partly because of our own too good PR work on the wonders of medicine. It is a reality of life. Despite calls for Physician Assisted Suicide, it cannot be controlled or tamed. It need not however, be the Bogey Man that leaves scars on those left behind and robs people of legitimate life as the end approaches.

This will only happen if it is talked about - if it takes its place within life and health. Leaving death out of a health strategy is heaping further problems on an already thinly spread health system.

Live every moment of your life until you die.

Live Well. Get Well. Stay Well. Die Well

Wendy Pattemore

MBChB, FRNZCGP, FAChPM

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| **63** | Submitter name | Michelle Robertson |
| Submitter organisation |  |

Working in child health this is becoming more and more an issue and I am still seeing more women admitting to alcohol use in pregnancy

 Firstly FASD needs to be recognized as a disability and should not go on IQ alone. 80% of individuals with FASD need lifelong support. Currently very few families receive respite care allowance.

 More diagnostic centres throughout all DHB’s in New Zealand. Currently there are only 7 and none in the south island. As a result many parents (who can afford it) pay for a diagnosis privately.

Employment of FASD coordinators similar to ASD coordinators who will support the family upon diagnosis and advocate for them throughout the journey and the contact they will have with various agencies along the way.

 Education across all sectors on the impact of FASD in the community and the support that is required.

Michelle Robertson

Clinical Nurse Manager

Children and Youth Service

Hawkes Bay Regional Hospital

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| **64** | Submitter name | [redacted] |
| Submitter organisation |  |

[redacted]

[redacted]

24th November, 2015.

**Submission New Zealand Health Strategy: Response to Action 6:** The Ministry of Health will continue to collaborate across government agencies, using social investment and life course approaches to improve and make more equitable the health and social outcomes for all children, families and whānau, particularly those at risk.

**H. Lead the development of a plan to improve the health systems response to children and families who are living with fetal alcohol spectrum disorders.**

We would like to tell our story as we believe that our families’ wellbeing is seriously compromised through the current chronic lack of professional training and funding for services across all Government departments to support individuals and families living with FASD which has led to us being denied access to service provision. Therefore, we welcome the development of a plan to support those affected by FASD. We hope by sharing a small portion of our circumstances it will emphasis the importance of developing services which are responsive to the individual needs of families living under the immense stress caused by FASD. Any plan needs to take into consideration that FASD babies grow into adults who will need ongoing services throughout their lifespan.

We are parents to an adopted child of 10 who has FASD. Diagnosing FASD using internationally accepted diagnostic criteria is limited in New Zealand. Our district health board does not have a multi-disciplinary team trained in this area and when they heard our daughter was adopted, despite our insistence that her behaviour was congruent with FASD and we had evidence of prenatal exposure to alcohol their focus was on attachment. However unless you deal with the primary disability and make accommodations for the neurological impairment, interventions will be oppressive as they are going down the wrong track and based on the premise of neuro typical functioning. We ended up paying privately to receive a correct diagnosis, adding the cost of this to our mortgage.

We have walked into a CYFs office from the street asking for support. We went through a strengthening families meeting (which the social worker forgot to attend) only to be told that there were no services to support us as it is not recognized as a disability so funding is not available to support us all.

This year we were also denied access to CAMHS as our daughter did not fit their criteria for service provision. We are unsure what criteria is required as our daughter was threatening us with knives, throwing anything to hand at us and attacking us each day leaving bruises. The advice we were given was to make sure we took some time out for each other before we attended to the children each evening and to call the police every time our daughter attacked us. We were also denied access to a psychiatrist to discuss medication as the occupational therapist who interviewed us did not think that medication would be effective. Subsequently we are paying to see a psychiatrist privately again adding the cost to our mortgage. The medication has helped our child to cope better as it was not bad behaviour that she was displaying but a symptom of her brain damage that was causing the violent outbursts.

From our experience the response of the MoH to our family’s situation demonstrates inexperience of FASD and the many challenges that accompany this disability. We are really shocked with how our family has been treated by the MoH as we were in crisis. It has been documented over the last 3 years that our daughter can be aggressive and we often struggle to manage her behaviour, are frequently physically assaulted and verbally abused. However, when our doctor asked for an emergency appointment with CAMHS we still had not had a response 6 weeks later. We were exhausted and broken as we had been dealing with rages for months and we only got the appointment when we rang our doctors and said we were in crisis and our child may have to go into care unless we received some support. After an interview with an occupational therapist we were then denied all access to service provision.

As our child suffers with sensory processing and central nervous system damage everyday living and tasks present with challenges. Examples include mealtimes which are fraught as the sound of chewing is amplified and leads to rages. We are sworn at most mealtimes, have been spat at and had food thrown. If we feed our daughter earlier, this does not alleviate the problem as she will not go into another room when the rest of the family eat as she is sociable and demands attention. She will not watch the television.

Getting dressed, having a shower, brushing her hair or teeth can lead to rages. Overheating suddenly can send her into orbit. The damage of prenatal exposure to alcohol has led to a life of heartache for her and for those who love her and live her struggles alongside her.

Weekends are hard. In the morning she will ask us what we have planned for her for the day. If she only has horse riding she will go into a rage and follow us around, standing in front of us not allowing us to pass, backing us into corners, swearing at us, hitting us constantly in the face but just stopping short of hitting us. She tells us that if we take her out and buy her something she will stop.

Our cat got run over a couple of years ago. Often she will attack the dog and tells us that she will stop hurting him when we tell her she can get a cat. We will never get a cat under these circumstances as it would not survive. However, she has obsessive traits and this theme has continued since the cat died with repetitive cycles and irrational reasoning and threats.

My husband and I can never go out together for some quality time as she has meltdowns and gets very aggressive making it impossible to leave the house. She did have a mentor but she left stating that she did not feel safe.

All areas of our family’s lives are affected by FASD. Holidays are a nightmare as her stress levels go through the roof leading to massive meltdowns which are very aggressive. We do not live a normal life, have few friends and do not get invited anywhere anymore and are becoming increasingly isolated as our child matures. Our lives are not equitable compared with many other New Zealand families as we get no support.

Our daughter does have some amazing strengths, she is a great artist, plays the piano, is doing well at horse riding and has a great sense of humor and can be very kind. She wants to be liked and fit in and is very aware that she is falling behind her peers at school despite being held back a year. We are committed to raising our child as our love for her is immense. We have educated ourselves on our child’s disability and are making the necessary accommodations in order to parent her according to her needs. However, we need support to do this to the best of our ability. After being turned down twice for carer support days, after our last disaster visit to CAMHS we were given 28 days. However, we have struggled to use them as we do not know where to go for support as we are not entitled to disability services.

Unless services develop to support families such as ours, we are unsure if our daughter will be able to remain in our care as she gets older. This is heartbreaking as we love our child and as any parent we want her to have the best possible life. This cannot be achieved without wrap around support to help us all achieve this. Services need to be evidence based from other models that are being used in countries such as Canada who are leading the way in support/interventions. We need key workers to work alongside us - as families such as ours soldier on for a long time but when we hit crisis we need access to services NOW.

Unless Government take persuasive action with media campaigns to highlight the dangers of alcohol to the unborn child, innocent children will continue to be born with brain damage. We have to question the Governments apathy behind this given New Zealand’s obsessive drinking culture. The alcohol industry needs to pay a ‘harm’ tax and have mandatory warning labels on all bottles.

A person does not outgrow FASD, it is a lifelong disability caused by prenatal exposure to alcohol. However, as our child has an IQ within the normal range, she does not qualify for disability services despite 3 areas of her brain domain operating in the bottom 3% of the population, suffering from sensory processing issues, central nervous system damage and having adaptive and executive functioning disabilities. This is discriminatory as she will need ongoing services to support her throughout her lifetime.

FASD needs to be recognized as a disability to overcome this inequity.

The MoH cannot afford to half-heartedly develop services for FASD individuals and their families as the long term cost of ignoring us means that many of our young people come into contact with the law with 35% of FASD sufferers incarcerated at some point in their lives despite the fact that they are living with the disability of brain damage. Research shows that early intervention and support leads to better outcomes. This is cost effective long term for Government.

MoH needs to work with other agencies so silo services do not emerge and we do not have to repeat our story to every service provider. Our children need support from all services including MoE and MSD so their life outcomes are positive and they are able to contribute productively to society. Professionals need training as they will encounter FASD in all areas of service provision with most service users presenting with incorrect diagnoses.

FASD-CAN is a New Zealand based non-profit society made up of parents, caregivers, extended whanau and professionals. They have the largest collective knowledge base of FASD in New Zealand. Therefore we would like to see all agencies collaborate with them so services can emerge that are responsive to the diverse needs of this cohort.

As part of this submission we include:

1. The FASD in New Zealand: A Time to Act; Call to Action Consensus Statement 2014 which was formulated as a result of information shared at the Fetal Alcohol Spectrum Disorder Symposium and the FASD Policy and Research Roundtable hosted by the University of Auckland’s Centre for Addiction Research and Alcohol Healthwatch. It identifies areas of priority to prevent FASD and to address the gaps in service delivery.
2. ‘A Parents Wish List’ which provides valuable information into what parents have identified as needs within service provision.

We want our submission published but given the sensitive nature we ask that our names and address be removed.

FASD: A PARENT’S WISH LIST © Claire Gyde 2014

**From Government and Policy Makers:**

1. Funding for WHO prevalence study so, as a nation, we understand the size of the problem.

2. Increased training for diagnostics country-wide and funding to provide key worker assistance to

families post diagnosis AND into adulthood (see expectations of Assessment Teams below, all

will need increased Health sector funding).

3. FASD in the professional curricula for teachers, health, mental health, addiction counselling and

professionals within the justice sector.

4. Caregiver funding for parents to allow them to make the choice between working or staying at

home to provide adequate supervision. Alternatively, a funded caregiver arrangement so that

parents can go to work without worry.

5. Funding for a national support organisation.

6. Recognition of FASD as a disability to be linked to specific funding for education and

independent living services and allowances – recognising that services and funding are

necessary across the life span not just in childhood. Access to services and funding should NOT

be hinged on IQ scores but rather on adaptive functioning scores.

7. A nationwide awareness campaign not only aimed at prevention but also how communities and

employers can help understand and support those with FASD.

**From Assessment Teams:**

1. Allow enough time to deliver the diagnosis in broad terms. There is nothing worse than feeling

like you have used up your 15 minutes and others in the room are clock watching and fidgeting

because they need to be somewhere else.

2. Provide some written material or internet resources for parents to take away with them and

research. If they struggle to read or do not have access to internet then provide a key worker to

walk them through what FASD is.

3. Provide the full diagnostic report within two weeks.

4. Schedule a follow up meeting within two weeks of giving diagnosis. This should coincide with

diagnostic report and give professionals the opportunity to go over their findings with the parents

in detail. Often parents will have questions after doing research, speaking to extended family

and absorbing the information that has been given to them.

5. Provide a key worker who is trained in FASD to assist the family as they go out into their

communities (school, family, work place) to explain the diagnosis and the support that their child

is going to need to taste success. *Do not think that doing this once is enough.* You need to be on

hand for transitions as they progress through different stages in their life.

6. Meet as regularly as the family considers necessary. In their home environment would also be

helpful to paint a picture for you of how this family lives and interacts.

7. Set up an immediate Strengthening Families meeting with as many agencies as necessary (given

age of child). Start this inter-agency support early, before the family reach crisis point.

8. If a Strengthening Families meeting is not considered necessary then provide assistance to

highlight HOW agencies work together. Eg; How does mental health interact with other DHB

services? How does Special Education work with your school? What services do you need

referrals for and which ones are just walk in’s?

9. Make sure the child’s strengths are highlighted in your report so that parents have something

positive to focus on.

10. Direct the family to a support group.

11. Families need a key support person / social worker who understand FASD and their situation

intimately. This person needs to be prepared to work with the family for an elongated period of

time.

12. Remember that children with FASD become adults with FASD. Think about support over entire

life span and help set that support in place before “signing off”.

FASD: A PARENT’S WISH LIST © Claire Gyde 2014

**From Other Service Providers:**

13. *Believe* the diagnosis. You are working with a family who is raising a child with permanent brain

damage that manifests itself in cognitive and behavioural deficits.

14. *Understand* the diagnosis*.* Do the research before meeting with the family.

15. *Acknowledge* the diagnosis. Parents need to hear that you believe and understand the issues

they are dealing with because of FASD.

16. Make no assumptions. ASK the parents to walk you through their day, week, month. Really

LISTEN to them. FASD is individual.

17. Go to the home environment, or ‘Gemba’ (this is a Japanese term meaning ‘the real place’). Do

not always meet in a clinical setting. Get to know the family. Observe. The ambiguity of a

dysfunctional child in a functional household will challenge traditional beliefs that behaviours are

the result of poor parenting.

18. Crisis management – make sure there is an immediate response path for families. Issues can

escalate quickly and families need immediate interventions and support. Do not question the

parent’s need for support. Remember that they have probably been managing behaviours and

issues for quite some time. If they are asking for help it is because they have reached their

breaking point. Their stress can be immense and this can jeopardise the safety and well-being of

the entire family.

19. DO NOT blame the child or expect the child to change their behaviours just because you say so.

DO NOT hang anti-social labels on them!

20. Understand that if you agree to work with this family or child that you will need to commit to a

long term approach. There is no quick fix. There is no silver bullet. There is no sprint to the finish

line. Understanding this will help you empathise with the position the parents are in.

21. Mental Health – anxiety, depression, self-harm, acting out, addictions – all secondary difficulties

associated with FASD. Believe it. Help, understanding and support from within the mental health

community is essential, especially through adolescence.

22. Offer respite that ensures adequate support and supervision of the child/adult with FASD.

Parents need to know their child/loved one is safe and in competent hands.

23. If you don’t know the answer then don’t try and make something up that “might work”. Talk to

the parents about the aspects of the child or presentation that you are struggling to understand.

LISTEN to them. Work collaboratively with parents and extended family too, if necessary.

Formulate some plans together and check progress regularly. Seek expert opinion as required.

24. Be very careful what you say in front of the young person with FASD. Make sure parents are

clearly supported in your comments.

25. Be positive. Often parents are weary and cannot see the good in their child after a run of bad

behaviours. Talk about what the child CAN do rather than focusing on what they CAN’T do.

Encourage parents to remember BRAIN not BLAME. Have them revisit the issue or incident with

brain damage as the driver. FASD is not an excuse, it is a REASON. Parents need to feel like there

is some hope or they will become over-whelmed by the problems.

26. DO NOT apply ‘normal’ behaviour modification strategies to the situation.

27. Remember that the behaviours that are born of FASD are not the result of poor parenting. They

are the result of a damaged brain.

FASD in New Zealand: A Time to Act

Call to Action Consensus Statement September 2014

“This Call to Action is for urgent strengthened efforts to improve the lives of individuals with Fetal Alcohol Spectrum Disorder (FASD) and their families and prevent this brain-based disability. FASD demands shared responsibility with committed cross-government and cross-sector policy and service delivery working together in a coordinated, funded and effective strategic direction.”

This Consensus Statement is based on information shared at the Fetal Alcohol Spectrum Disorder (FASD) Symposium and the FASD Policy and Research Roundtable hosted by the University of Auckland’s Centre for Addiction Research and Alcohol Healthwatch on 5th and 9th September 20141. It identifies areas of priority to prevent FASD and to address the gaps in service delivery to those affected by FASD. It is underpinned by a commitment to the Treaty of Waitangi. It recognises New Zealand’s obligations under a range of United Nations charters.

FASD Prevention Policy and Practice

• Reduce the environmental influence of alcohol known to increase harm including reduction in availability, increase in price and restriction of promotional marketing.

• Strengthen consistency and effectiveness of non-stigmatising messages to not drink preconception, during pregnancy or when breastfeeding, including on the product and point of sale.

• Require screening and brief intervention with women of childbearing age by primary health and addiction services, and referral to specialist services for those at increased risk.

• Ensure FASD prevention is taught across the education curriculum and in specialist courses.

FASD Screening, Assessment and Diagnostic Training and Practice

• Direct health funding to support FASD training in integrated diagnosis and care planning with child health, mental health and other services across the lifespan.

• Provide for the establishment of a Centre of Excellence where expertise can guide and maintain consistency of evidence-based practice and continuing education across services.

• Together with FASD experts, develop guidelines and referral pathways for children and youth with FASD similar to that for Autism Spectrum Disorder.

1 Disclaimer: This FASD Call to Action Consensus Statement has been developed in good faith and places no obligation on any individual attending on behalf of their organisation.

• Screen children for FASD at point of entry into Children’s Teams, Gateway or other child health programmes.

• Ensure children in care who are at very high risk of having FASD are screened and if positive, receive timely diagnosis, care and education adapted to their special needs.

• Provide for Specialist FASD Advisor in schools.

• Screen for FASD in youth justice, care and protection residences and alcohol and drug services and provide appropriate intervention pathways to reduce the risk of recidivism.

FASD Intervention Policy, Training and Practice

• Ensure that the parent/caregiver voice is included and heeded in regard to FASD specific policy around health, education and justice.

• Prevent discrimination by recognising FASD is a lifelong disability with significant unmet need that is not explained by poor parenting practice or other circumstances.

• Recognise the fiscal, emotional and time-consuming demands on those caring for a child or adult with FASD by ensuring their eligibility for financial and respite care support.

• Ensure those diagnosed with FASD are eligible for disability and education supports that are not predicated on IQ alone but equally consider deficits in executive and adaptive function.

• Fund and mandate experts to deliver integrated intervention training and support programmes in mental health, justice, addictions, education, police etc. that will assist individuals with FASD to reach and maintain their potential.

FASD Research

• Build a research network to guide and conduct FASD-related research.

• Fund a World Health Organisation national prevalence study which New Zealand has been invited to participate in to ascertain the scale of FASD.

• Conduct a Youth Justice FASD prevalence and intervention study.

• Develop a national database for the collection and analysis of FASD clinical data.

• Conduct a cost benefit analysis to determine the cost of FASD in New Zealand.

• Research the outcomes of FASD and the cost-benefit of intervention strategies.

Background to this FASD Call to Action

Fetal Alcohol Spectrum Disorder (FASD) is a range of physical, cognitive and behavioural impairments caused by alcohol exposure during fetal development. Alcohol is a teratogen that interferes with normal cell growth and function during development. Impairments may include facial and organ malformations but primarily FASD is about multiple brain deficits that substantially impair day-to-day functioning and communication across the lifespan. These pose major challenges for individuals with FASD, their families and the broad range of service providers they encounter, that are amenable to appropriately directed support.

Alcohol, being almost universally available is pervasive in New Zealand society, making FASD prevention particularly challenging. In the developed world FASD is recognised as the leading preventable cause of developmental disabilities, yet in New Zealand, no reliable data has so far been gathered, no comprehensive government plan of action has yet been established and babies continue to be born adversely affected by alcohol.

Based on overseas studies and drinking patterns, New Zealand could have 3,000 babies a year or more born with FASD. Better information is vital to develop effective policy and health and other sector responses to reduce the prevalence and societal impact of FASD.

Babies born with FASD don’t outgrow the problems. On the contrary their difficulties grow as they grow. Individuals with FASD are more likely to experience adverse outcomes than the general population particularly in adolescence and adulthood. Referred to as secondary disabilities, these adverse outcomes include mental health problems, addictions, education failure, trouble with the law and becoming victims of crime.

Maori are disproportionately harmed by alcohol. The damage alcohol (waipiro) causes to unborn babies was recognised by Maori when it was first introduced in the 1800s. Recognising FASD and re-orienting existing services toward improved outcomes for the FASD-affected population will reduce the cost burden of secondary disabilities and increase prevention. The earlier in life that FASD is recognised and responded to appropriately, the greater the chance of successful living and protection of the next generation. Neglecting this has dire long term consequences, especially for our most vulnerable children.

Currently many individuals with FASD are behaving inappropriately in the community without appropriate support structure and are over-represented in the justice sector. This is a cost to society as well as an ineffective way to manage FASD disability. Caregivers are crumbling under the strain of preventing further harm from occurring by building the child’s strengths and are doing so in isolation of effective supports or recognition. Many parents are simply blamed for the problem – as indeed often are their disabled children -when it is the teratogenic effects of alcohol and misunderstanding to blame. That must change.

FASD has complex lifelong implications that no one agency or family can address alone. FASD prevention and intervention is a societal responsibility requiring Government and cross-sector commitment and collaboration that has the backing of Government funding. The cost of neglecting FASD is far too great.

Some of the action points identified in this FASD Call to Action represent work already begun by front-line professionals and families as demonstrated at the FASD Symposium and Roundtable. Much of this work has occurred in the absence of specific funding or structure. To ensure FASD planning and practice is well informed and funding is effectively directed, existing FASD experience and expertise must be recognised and more fully engaged in the process.

These matters form the substance of this Call to Action. They are consistent with the ‘FASD Call to Action’ from the delegates attending the 2013 Australasian FASD Conference in Brisbane [http://www.phaa.net.au/AFASDC\_2013.php], the recommendations made by the New Zealand Parliamentary Health Select Committee in their Inquiry Into Improving Child Health Outcomes and Preventing Child Abuse (2013), and subsequently agreed to by the Government and ‘The International Charter on the Prevention of FASD’ [The Lancet Global Health, Volume 2, Issue 3 -e135 -e137, March 2014].

The ‘FASD in New Zealand: A Time To Act’ Symposium on 5 September and the ‘FASD Policy and Research Roundtable’ on 9 September 2014 were hosted by the:

The symposium presentations and panel discussion can be viewed on www.fan.org.nz

For further information contact Christine Rogan Health Promotion Advisor and FASD Project Coordinator for Alcohol Healthwatch / Email: christine@ahw.org.nz / Tel: 09-5207037

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| **65** | Submitter name | Richard Handley |
| Submitter organisation |  |

Dear Strategy Team,

I think the emerging strategy is developing good robust strategic challenges and direction.

It does though totally miss the important work being emphasised on making gains in Maori health and closing gaps between Maori and non-Maori.

We at Taranaki have a very well developed Maori Health Strategy which is showing encouraging results.

Taranaki DHB is committed to further progress.

Can I submit that greater emphasis be placed on the improvement of Maori health in the Strategy.

With Regards

Richard Handley

Elected Member Taranaki DHB

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| **66** | Submitter name | Eleanor Bensemann |
| Submitter organisation |  |

|  |  |
| --- | --- |
| This submission was completed by: *(name)* | Eleanor Bensemann |
| Address: *(street/box number)* | [redacted] |
|  *(town/city)* | [redacted] |
| Email: | [redacted] |
| Organisation (if applicable): |       |
| Position (if applicable): |       |

Are you submitting this *(tick one box only in this section)*:

X[ ]  as an individual or individuals (not on behalf of an organisation)

[ ]  on behalf of a group or organisation(s)

If you are an individual or individuals, the Ministry of Health will remove your personal details from your submission, and your name(s) will not be listed in the published summary of submissions, if you check the following box:

[ ]  I do not give permission for my personal details to be released.

(The above information will be taken into consideration if your submission is requested under the Official Information Act 1982.)

Please indicate which sector(s) your submission represents
*(you may tick more than one box in this section)*:

[ ]  Māori [ ]  Regulatory authority

[ ]  Pacific [ ]  Consumer

[ ]  Asian [ ]  District health board

[ ]  Education/training [ ]  Local government

[ ]  Service provider [ ]  Government

[ ]  Non-governmental organisation [ ]  Pharmacy professional association

[ ]  Primary health organisation [ ]  Other professional association

[ ]  Professional association

[ ]  Academic/research X[ ]  Other *(please specify)*: Family member

### Challenges and opportunities

The Strategy reflects a range of challenges and opportunities that are relevant to New Zealand’s health system. Some of these are outlined in I. Future Direction on pages 5–7.

1. Are there any additional or different challenges or opportunities that should be part of the background for the Strategy?

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### The future we want

The statement on page 8 of I. Future Direction seeks to capture the future we want for our health system:

So that **all** New Zealanders **live well, stay well, get well**, we will be **people-powered**, providing services **closer to home**, designed for **value and high performance**, and working as **one team** in a **smart system**.

2. Does the statement capture what you want from New Zealand’s health system? What would you change or suggest instead?

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| I don’t like the term “Smart system.” It should be a “caring system.” |

A set of eight principles is proposed to guide the New Zealand health system. These principles are listed on page 9 of I. Future Direction and page 31 of II. Roadmap of Actions.

3 Do you think that these are the right principles for the New Zealand health system? Will these be helpful to guide us to implement the Strategy?

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### Five strategic themes

The Strategy proposes five strategic themes to focus action – people-powered, closer to home, value and high performance, one team and smart system (I. Future Direction, from page 10).

4 Do these five themes provide the right focus for action? Do the sections ‘What great might look like in 10 years’ provide enough clarity and stretch to guide us?

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### Roadmap of Actions

II. Roadmap of Actions has 20 areas for action over the next five years.

5 Are these the most important action areas to guide change in each strategic theme? Are there other actions that would be better at helping us reach our desired future?

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### Turning strategy into action

6 What sort of approaches do you think will best support the ongoing development of the Roadmap of Actions? Do you have ideas for tracking and reporting of progress?

H. \*Lead the development of a plan to improve the health system’s response to children and families who are living with Fetal Alcohol Spectrum Disorders”

Add children, **adults** and their families....

In my experience, the transition to adulthood and independence can be very difficult for those living with fetal alcohol spectrum disorders, especially young males. My family member has fallen foul of the justice system, and because of queries over fitness to plea has had many psychological assessments. Unfortunately some of these challenged his diagnosis of Intellectual Disability (first diagnosed at age 10 years.) At present, people who have FASD but not Intellectual Disability are not entitled to any support through the Health System. Even though my family member has high and complex needs and at times severe behavioural symptoms, all support through the local NASC was instantly withdrawn, in spite of appeals to the Ministry of Health for an exemption to be made. He was left to fend for himself, was homeless and without support. It is hardly surprising that this resulted in him reoffending. His latest assessment once again confirms his FASD and ID.
For people and their families dealing with FASD it is imperative that the Ministries of Health, Social Development, CYFs, Education and Justice work together for the best outcomes for these children, young people and adults. Many families are at breaking point as they attempt to deal with challenging behaviours with little or no support. FASD must be recognised by the government as a disability and appropriate training of health professionals, educators and social workers be made a priority. Otherwise the future we want “So that **all** New Zealanders **live well, stay well, get well...”** will fail to be a reality for an increasing sector of the population.

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### Any other matters

7 Are there any other comments you want to make as part of your submission?

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| We must tackle in a more robust way the issue of drinking alcohol during pregnancy. It is well recognised now in most medical circles that any amount of alcohol consumed during pregnancy **at any time** is unsafe for the developing baby. Please get more robust advertising out there, so that there is no doubt in pregnant women’s minds that no alcohol consumption is safe for their babies’ developing brains. |

Thank you for taking the time to provide feedback.

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| --- | --- | --- |
| **67** | Submitter name | Jude Bignell |
| Submitter organisation |  |

**[redacted]**

Please find attached a document which I sent through to several MPs and govt ministries, including MoH, in July 2014.

Since then, I have formed a charity – Rainbows Charitable Trust – [www.rainbowspeople.org.nz](http://www.rainbowspeople.org.nz/) and have been in regular contact with Nathan Guy’s office – our local MP. I have recently had an assurance from him that he will speak with Minister Jonathan Coleman in regard to the need for MoH to provide funding for quality children’s respite services/centres across NZ – not just in Akld.

I have also recently made a submission to the MSD in regard to their ‘Disability Action Plan 2014-2018’ and, as I understand it, the feedback they are receiving shows an **overwhelming need** for respite services for special needs children.

This MUST be a major consideration to be tabled urgently. There are vulnerable children at risk and families at breaking point. I would welcome the opportunity to speak further regarding this pressing issue to a Ministry representative.

Thanks and regards

Jude Bignell

Question – What does a car without wheels and...



...a Rainbow have in common?



Very little, it would seem. But for some of us, they symbolise a very real need for the parents and carers of children with disabilities and special needs.

The Need?

To have access to a safe, professional and reliable respite facility where we can take our precious children for short to medium term stays, in order to allow us the break that so many of us never get, but so desperately need – while feeling reassured that our children are being well cared for and above all, are happy.

This is not about the allocation of funding for the provision of that respite care as a service. It is about the actual ‘bricks and mortar’ – the physical place itself – and the provision of the service itself. At present, such places are virtually non-existent in New Zealand. Certainly any existing establishments of this type are not capable of providing the level of service – both in terms of quantity *and* quality – that parents of these special kids expect and deserve.

Many of these kids have funding ‘allocated’ to them (via the NASC or ACC) to allow their parents/carers to have respite breaks, but there is often little or no uptake of that funding by many, because of the lack of a suitable facility.

So the state (I won’t say ‘the government’ because the situation, as it is, has evolved through many governments) acknowledges this need for respite, because the offer to fund it is already there – as mentioned. For the parents, that is very reassuring. To know that we don’t have to fight that battle – to prove that we have this need – that is a given. Thank goodness. But this is where the car with no wheels comes in...Imagine this scenario...

...You have no transport. No way to get from A-B and because of your need, you are offered a very nice car. In addition, you are given a ‘Fuelcard’ to use as often as you need – you have unlimited use of this car which is just what you need! But there’s a catch...the car has no wheels. So the offer of ‘unlimited use’ of the car and the fuel means nothing – because you can’t actually use the car to drive anywhere.

This analogy describes the funding ‘offers’ currently in place for respite care of special needs kids...They are just what we so desperately need...if only we could actually *use* them.

Fact – There are currently around 900 children in the Kapiti/ Horowhenua region alone who receive the ‘Child Disability Allowance’. How many of those kids are ‘NASC’ funded I am unsure as Supportlinks, despite many requests from me for stats on this, have never come back to me with numbers. But even if only half of them were eligible for funded respite care, that’s still 450 odd kids who are **not catered for**. There is NO respite facility in this region for kids.

So what *is* available?

* **IHC** have 2 facilities - one in Porirua that takes up to 6 kids at a time.

It has only one caregiver for every 3 children, it’s not fenced off from a very busy road and the doors are left unlocked due apparently, to Health & Safety regulations...??? How safe can that be for severely retarded, fully mobile kids? My experience of this place was that the staff seemed more interested in whether or not my child was “fully funded” for respite and whether or not he was a fussy eater. They asked not one question about him and his likes and dislikes, medical condition etc. etc.. I have never been back and would never put our dearly loved son in the care of those people. IHC’s other facility is in Palmerston North – where sadly, a 16 year old boy,Nathan, recently drowned in the bath while in the CARE (....?????) of others while his mother had a respite break. I believe that investigations into Nathan’s death have proven that it was avoidable and due to the negligence of the staff on duty at the time. This is beyond unacceptable and is the reason why so many parents of disabled/special needs kids are reluctant to want to put their beloved child into respite care.

* **‘Kara Hands’** is a wonderful respite care facility for kids in the Hutt Valley. But this is a rarity and has come about solely due to the kindheartedness of two wonderful women who chose to dedicate their lives to providing parents with a much needed break from their severely disabled children. Being 2 women in one house, there is a limit to how many kids they can care for at one time. I believe that the service they now offer is even more limited as one of the 2 women have poor health. There is a waiting list to get in.
* **CCS Disability Action** offer ‘Home to Home’ respite care – or so they say...In the 10 years that we have been ‘on their books’, they have NEVER once found anyone for us. My experience of CCS is unfortunately “lots of talk but not much action”! (We did find our own respite carers once and CCS did help with ‘vetting’ and police checking them etc..Our son went to their home for care. However, that didn’t last long as the couple were not adhering to some of the basic rules – like no smoking, no visitors – and also, the woman had mental health issues. This was all uncovered by us – not CCS who were supposed to be monitoring things.)

Home to Home care can also be where a carer comes into your own home to care for your child. That can be ok occasionally – like for an hour or two a day but most of us parents feel uncomfortable with a stranger caring for our child in our own home. It is really not a break at all as the carer will inevitably end up asking questions or needing your help. The alternative is to vacate your own home. But where are we supposed to go? Ok – sometimes when you need a wee holiday and are happy to spend money on that, then that would be fine. But the reality is that most of the time you need a respite break so that you can get on with jobs around home (that can’t be done when you have a very high maintenance child) or...just ‘blob out’ and get some desperately needed rest, watch a movie etc. – in the comfort of your own home. We really don’t want to have to pack a bag and ‘shift out’ just to get a break...and why should we?

A Ministry Of Education employee (Group Special Ed. Division) who works with special needs kids and their families, recently made an interesting comment to me about the respite option of a caregiver coming into the child’s home. She pointed out that often it is the “child’s home which is the problem” and that it could be greatly beneficial for the child to have ‘time-out’ in a purpose-built respite facility with other kids and caring people, away from their home environment. This is another perspective on the situation - one not previously considered by me but it certainly supports the need for respite facilities.

Interestingly, CCS are currently campaigning to secure a repeal of Section 141 of the CYPFs Act, 1989, which they believe to be discriminatory against disabled children as it allows them to be placed into residential care indefinitely. This is admirable and certainly great that they advocate for the child’ rights. But the disabled child’s parents and siblings have rights too and I do not believe that CCS are looking at this matter with a balanced perspective. Jenny Wyber, the head of CCS’s Intensive Family Service is quoted as saying “ *It simply doesn’t seem fair that disabled children shouldn’t be given the same chances to be included in a normal home-like environment. Ultimately professionals are no real substitute for family.”* She cites Paula Bennett’s ‘Children’s Action Plan’ and the Vulnerable Children’s Bill as relevant to CCS’s desire for change...Well so do we!! We agree with what she says in principal and in part...**But the big problem with CCS’s ideals is that there needs to be many, many kind caring and willing families wanting to take on the thousands of disabled children around New Zealand whose parents need regular respite breaks, and the reality – as CCS are fully aware - is that this just simply isn’t the case!**

I believe the **NZ Care Group** have run ‘respite care’ trials in the Marlborough region. But I also believe that, under direction from the Ministry of Health, the focus has been on ‘Home to Home’ care. For some unknown reason there seems to be an avoidance on the part of the MoH to consider the possibility of purpose built respite centres. This may be due to developments within the disability sector over the past few years that have brought about the concept of ‘Enabling Good Lives’ and MoH’s ‘New Model’and the idea that a shift from residential care facilities is needed. But if you look at the model of The Wilson Centre, Takapuna, Auckland, you will see that this type of respite for disabled children is favoured by many parents and is very well utilised. In fact, that is an understatement as I understand that there is a waiting list to get in and there is a great need for many more centres of this type in just the Auckland region alone.

The Current Problem?

What *is* available does not come close to catering for the level of need and for the most part, is unsuitable and/or unattainable for the majority.

So there are thousands of families around the country who care for and share a home with a child who may have very high needs, very challenging behaviour etc. and who never get a break from that often heartbreaking and soul-destroying situation. Parents feel despair, become worn-out, angry and unable to cope. Siblings miss out on their own needs being met. Under these circumstances, the situation can escalate into one of volatility and ultimately – tragedy.

What happens if a disabled/very high needs child’s only caregiver becomes ill or has to have an operation and is unable to care for the child? Where do they go? Many people do not have family or friends that they can rely on for help in a circumstance such as this. This is a common occurrence and a problem that there is still no solution to.

As mentioned above, ‘Home to Home’ care is not ideal for many and it is very challenging to find suitable carers. For example, our son can walk but he has severe brain damage and is partially blind. He has the cognitive ability of a toddler and no sense of danger. So any home that he goes to must be fully and safely fenced, free of obstacles that he can fall off or over. In our case, we have ACC cover and they would do housing modifications like handrails, fences etc. to a prospective caregiver’s home. But to me, that is an appalling waste of public funds as there is no guarantee that the caregivers will continue in that role.

And that is the other main problem that is inherent with ‘Home to Home’ Care...The caregiver’s circumstances can change for many and varied reasons and the arrangement can end at any given time. Reliability cannot be guaranteed. So a family like ours can spend a great deal of time and emotional energy getting to know a prospective caregiver and vice versa and educating them on behavioural management and medical care issues etc., only for it to all end when things don’t work out or they get another job or move or get sick or whatever! It is not fair on us as parents and not fair on our child. As parents we deal with a lot of guilt at putting our child into the care of another. We must overcome feelings of anguish and fear and it can be quite soul-destroying going down that road only for it to come to an end – again.(Personally, we gave up trying that option 4-5 years ago. We have actually never had proper respite care in the almost 11 years that we have been caring for our severely retarded son - apart from the odd night or two when aging grandparents have helped us out. It shouldn’t be their job at their age. We also have a 7 year old son who is autistic and we have never had respite, other than grandparents, for him either(and he *is* funded for respite via NASC). Sometimes I am amazed that our marriage has withstood this and that I have not ended up needing psychiatric attention myself!)

If anything, CCS’s ‘push’ for more ‘Home to Home’ care is contravening the rights of Disabled children and quite contradictory to the cause of protecting the vulnerable children of NZ. **Because CCS cannot guarantee the safety of the children who go into their ‘Home to Home’ care programme**  - and that is the bottom line for most of us parents! Let’s face it – vetting, Police Checking etc. does not always uncover a potentially unsafe environment for a child to be in. Many of our kids are non-verbal which makes them an even easier target for would-be predators – and the sad reality is that these vermin are everywhere. A child who cannot report any wrong-doing against them is a *very vulnerable child.*

The only alternative to Home-to-Home care is actual respite care facilities - which are virtually non-existent or certainly geographically unattainable for most of us. Any facility that does exist is more often than not sub-standard in the level of safety and care that it offers. This is simply just not an option for parents like us who love and cherish our children and want them to be *very* safe, *very* well cared for and most of all...*very, very* HAPPY when they are not with us. In other words – we only want for our children the same thing that most other parents want...

The Solution

...this is where the Rainbow comes in...

Rainbows Respite for Special Needs Children

...the vision

A much needed, “home away from home”, purpose-built respite care facility that caters for special needs children under the age of 16, predominantly, but also for young adults . We see a warm, happy, safe, nurturing and fun loving environment run by the sort of people who our kids will come to love and think of as nothing less than angels!! They will include Paediatric Nurses, qualified nannies and well trained, big-hearted caregivers who have all been thoroughly vetted, including police checked, and carefully selected to ensure their total devotion to special needs kids and their appropriateness for this type of role. They will be given a set of 10 Commandments to adhere to!

We see a fabulous play area similar to Lollipops playland or Junglerama, with music, dancing and laughter. A lounge area with access to movies/TV/games/books etc.. A craft and activity area. A dining area capable of catering for kids with disabilities and possibly special dietary requirements. Bathrooms specifically set up to meet the needs of those with disabilities. We see quiet, time out space with lava lights and swings and soft music – a ‘Snoezelen’ Multi-sensory Room. A safe, outdoor play area with lots of space to be a kid, and enjoy nature and lots of sensory experiences. We see bedrooms set up to make kids feel happy and cosy when it comes to sleep time. This is a facility that caters for short to medium term respite care (1 hour – 6weeks), and is based in the Horowhenua/Kapiti region initially, with a view to being modelled all around the country. The day to day operation would be partially funded via Carer Support days (Supportlinks/Enable) and ACC relief care where available. Parents also have the option of funding their child’s respite care too.

The criteria for a child to be eligible for respite would be that their parent or caregiver is receiving the government funded “Child disability allowance” for them.

Each Rainbows ‘client’ will have a detailed record kept securely on a nationally accessible database. This will include all relevant information about them such as meds needed, dietary requirements, likes and dislikes, how they communicate, things their parents want all carers to know about them, favourite toys/songs/movies etc. – in other words everything that needs to be known about them for them to be well-cared for and happy. The theory behind this database being nationwide is that the child is able to be cared for in any Rainbows Respite Centre in NZ. This will assist when families are travelling away or when parents/caregivers live apart and take turns with caring for a child.

An ‘out-service’ will be available for emergency situations when a parent or caregiver suddenly finds themselves unable to care for the child and with no way to make arrangements for the child to be cared for. (Such as a medical emergency during the night)

We also see a separate wing of this facility dedicated to providing respite for special needs young people in need, over the age of 16 - and possibly up to age 65 – but too young to be placed into care at a care centre for the elderly. Activities and crafts etc would be available.

Most of all – this is a place where the caregivers/parents/family/whanau, can take their loved ones and feel 100% assured that they will be safe, very well cared for, happy and want to return.

<https://www.facebook.com/Rainbowsrespite>

Please take some time to have a look at this Facebook page if you can. In a few short months I have gained over 800 ‘likes’ and heard from some very, very desperate parents in need of respite care for their child/ren. Attached to this are some of the posts from this Facebook page that provide further insight into the reason for this proposal. There are also separate sheets attached that are responses from a small survey conducted 3 years ago.

The RRSNK Team

We are the ‘Rainbows Respite for Special Needs Kids’ Team and are a small group of parents with special needs kids who are willing to set ourselves up as a Charitable Trust if that is what is needed. Ideally, we seek a collaborative approach between the Government Ministries involved namely, Health – and the Disability Support Services, Education and Social Development and also, ACC in terms of funding this project.

We respectfully refer the readers/recipients of this proposal to  **Article 33 of the United Nations Convention on the Rights of Persons with Disabilities** and the need for disabled children to be given respite care in a safe and caring environment which caters to their specific needs and contributes to their well-being and happiness.

Also, **The NZ Carers’ strategy Action Plan for 2014-2018** states that the **Government’s vision is that “carer’s voices will be heard”** and that

* the top priority for carers is being able to take a break when required
* respite options need to be flexible, whānau-, aiga- and carer-friendly, and available to all carers
* whānau, aiga and carers need good information about what respite options are available to them

Some of us are parents of children who have severe brain injuries as a direct result of ‘medical misadventure – failure to treat’ situations. Our children are therefore ACC clients. **We believe that the government and ACC have a responsibility to provide respite centres.** That it has not been done before now is appalling and adds insult to injury – quite literally – for the parents who live with the heartbreaking consequences of serious breaches by employees of the State.

So thank you for the car – but it is no good to us without wheels...

Please put the wheels on and get them turning immediately. 

This needs to happen ***NOW***. There are desperate parents all over NZ who cannot wait much longer for this.

Who Wins?

For every child eligible to be placed in respite care, there are usually parents, siblings, grandparents, aunties, uncles and many other people who are part of their extended family/whanau/circle of support and who are often also affected by the need for the child to have access to decent respite care. So there are tens, perhaps hundreds of thousands of New Zealanders that will in one way or another either benefit directly or see the benefit, from the establishment of nationwide respite facilities.

For the present government to make this happen in an election year can only be a good thing.

When parents are able to have a break from a very challenging and high-needs child, they ‘recharge their batteries’ and are better able to cope with the demands of their special parenting role. So the child’s home environment will be more likely to be safe, calm and nurturing and one which is less likely to result in the occupants becoming another ‘statistic’ or a future burden on society/the health system. Society has an obligation to help these families and to ensure that everything possible is done to maintain a functional family unit when there is a disabled child involved. Everyone wins.

How will this be achieved?

We understand that there are limits to the amount of funding that can be allocated to this project. We therefore do not necessarily expect ‘new’ funding but a review of all existing allocation of funds. After 4 years of researching this area, I have no doubt that such a review will uncover poor use of government funding in some areas that can then be re-allocated into purpose-built respite facilities.

Perhaps investors could be sought and funding from charitable trusts such as The Lion Foundation/Lotteries Commission etc.. The key to ensuring profitability is to ensure maximum occupancy rates – and this has proved difficult in the past. This adds weight to the need for these centres to be fun, happy, warm and inviting places that parents *want* to take their children to. Then, with a proper marketing plan, I believe we can make these centres successful to at least a ‘break-even’ point.

*PLEASE – we have already seen too much bureaucracy and ‘red tape’ around this issue. We need this to happen NOW.*

More about Rainbows Respite Sanctuaries...

The 10 Commandments

* Everyone here is equal and is valued and shall be treated with the greatest respect
* See and nurture the spirit within and not just the physical embodiement – you will see things that you never knew were there!
* Anger, aggression , neglect or cruelty do not and will never have a place here
* Work together for the benefit of all who dwell here
* Show compassion, patience and kindness always
* Do what you know to be right and shine a light in the lives of those less fortunate than yourself
* Be truthful and honest at all times
* Be responsible for your own actions
* Be light-hearted, have fun and laugh a lot
* Always keep your halo on!

Mantra

“The Human spirit is not disabled”. My physical being may not function like most others, but my spirit is strong.

(I would like to see this up on the wall of the entrance way to every Rainbows Respite Home)

From the Rainbows Facebook page

My dream is to start up a 'purpose built' facility where special needs kids can go and spend some time away from their usual home which will enable their parents/ carers to have the break that they so desperately need. At present in our region, there is one such facility in Porirua which can take max of 6 kids per night - there are more than 900 kids in the Kapiti and Horowhenua region alone on the Child Disability Allowance. Many of us have the funding approved for respite but we have nowhere for our kids to go to use that funding. All that can be offered by the various agencies is 'home to home' care where your child goes to someone elses home...all the police checks in the world will NEVER make me comfortable with that. You never really know what goes on once you have left your child in someone else's home. Anyway, all the agencies (IHC/IDEA services, CCS etc.) admit that they permanently struggle to find homes to place kids in for respite.

I have a vision of a Lollipops Playland kind of place but with 'kid friendly' accommodation, disabled facilities, sensory 'wonderland' rooms, lots of room to roam around outside and play and lots of thing to occupy kids... and lots of angels and cuddly grandmotherly types waiting to give unlimited love and attention to our precious children.
Each child registered will have a profile recorded on a database - so that caregivers know everything they need to know about them. This is so incredibly important for our kids - especially where autism is a factor.

Parents need peace of mind that their precious kids are getting everything they need to feel loved, secure and happy while they are away from home. We need our kids to WANT TO GO BACK in other words!
This is not a want, but a desperate need in our community and I need as many people as possible to like this page so that I can post updates, gain feedback etc. to help me on my journey to see this dream become a reality. If successful, this could be modelled around the country and with database info on each child, parents could seek respite NZ wide when travelling and know that their child will be given the very best TLC wherever they are in NZ.

Really good point made by Gina - her gorgeous son Ben, doesn't have a 'voice' like many of our kids. It is a sad reality that there are predators out there everywhere - often the most 'unexpected' people in the most unexpected places. You only have to watch the 6 o'clock news to know that to be true. Being non-verbal, a child has no way of reporting any wrongdoing against them and so are particularly vulnerable when in the care of others. The Rainbows Respite way will mean the most rigorous vetting of any potential staff and constant monitoring procedures in place - that is a 'non-negotiable'! Everything possible will be done to ensure that our precious kids are in a 100% safe environment.

On the Rainbows Respite 'To Do' list is the Ministry of Social Development and specifically, their boss, Paula Bennett. Like her or loathe her she has the thumbs up from me for her desire to protect the 'vulnerable kids' of this country. Ok, Paula Bennett, time to put your money where your mouth is, we are the parents and caregivers of some of the most vulnerable kids in New Zealand. We are tired, at our wits end and in DESPERATE need of a break. Surely to continue to deny us that may put our kids at risk? Many parents simply cannot cope 24/7 with the stress that caring for an intellectually and/or physically challenged child brings. But putting them into the care of a complete stranger may put them equally at risk. We need nationwide, purpose-built respite centres with very carefully selected, caring staff and a database of our kids with all of their relevant info to ensure they are properly cared for and HAPPY.
Rest assured - Rainbows has you, Ms Bennett, and all of the other 'movers and shakers', firmly in our sights.

So it's been a wee while since the last update on this page...Because for those of us who parent or care for special needs kids, the world just has to 'stop' during the school hollies. If you're like me, you'll love having them home and spending some quality time with them...but it's hard yakka! 24/7 care for 2 solid weeks (6 weeks at Christmas!) is exhausting for many of us. We can't send our kids on those awesome sounding kids holiday programmes, can we? The sad reality is that we really don't live in an 'inclusive' world - these kids holiday programmes are simply not set up to cater for kids with special needs. Seems a wee bit discriminatory from where I'm sitting...how about you? Aren't we the parents/caregivers who need help the most? So...a local respite facility for kids - that is a FUN place for them to go - is what is needed. This is what RAINBOWS is all about - keep spreading the word and keep the 'likes' coming!

**‘Parent Posts’**

**[redacted] -** my son is nearly 9 autistic and a handfull this holidays his disapeared for half an hour, we found him at a neighbours. He put two holes in the walls of our rental house drove his siblings crazy ive had food thrown at me, been bitten and punched. im so tired i dont have the energy to cry i have nowhere to send my son for respite care.

**[redacted] -** We have a 3yrold boy who has a chromosome deletion, epilepsy with
Brain damage, we also have another son 8yrs whom is fine.
We haven't been on holiday in years we struggle on my husbands wage and just manage to keep a float so going on holiday is defiantly out of the question, our son is not mobile and
Becoming very heavy, and having to take his chair and everything else is

Exhausting. My oldest son misses out as we all love to go to the beach but it's impossible to push a wheelchair in the
Sand so one of us has to stay home.

[The Angelman Network](https://www.facebook.com/theangelmannetwork?ref=stream&hc_location=stream)

**We would be very keen to get involved with this. Our Angelman-families are all in desperate need for more respite for their angels, in a quality/caring environment.**

Sandy -  **Teacher Aide from** [Rosehill Special School Staff - Papakura NZ](https://www.facebook.com/RosehillSpecialSchoolPapakuraNz)**, also parent to two teenage HF Autistic son and daughter with PDD-NOs. All the time when my son was young, never could I find such a service, were hard years when he was younger. I wish you all the very best... Would love being involved in someway to help you make this dream possible.... Kia Kaha xx**

Lisa H - **Maybe respite centre's need to be small, purpose built residential homes? Respite services, like healthcare will never be a profit making venture- its about caring.**

**[redacted] -** We're the same Lisa, desperate for a respite facility! We have a fantastic carer but my daughter and I have to go out when she's here which is a bit of a pain. And we need overnight respite where my son goes to give us time away from him. Very tricky!

**[redacted] -** Everyone has such different needs. At present there is usually always people available to the sort of in-home care you are wanting( although it is difficult to retain these people in my experience, especially once you have found a good carer) but the gaping hole in this sector from my point of view is
out of home respite. Like you, when meg was young, we wouldn't have dreamed if letting her go anywhere. She is very vulnerable too, and has very high medical needs. But as she has gotten older and bigger, our needs have changed. We are desperate to give out 3 other daughters some "normal" family time. I am tired of living in grand central station with people constantly in my home. We don't want to have to go away every time we have organised respite for meg but currently that is the only option. Have someone come in to our home and care for meg. That is a big ask and one that I find hard to switch off from. Having someone here looking after my child, while I am under the same roof too? That's almost impossibly to relax Nd switch off. Sending her to someone else's home, a trusted friend or family member has now become incredibly difficult because if the physical limitations and challenges of having to use a hoist for transfers and a full wet floor bathing/showering facilities. People's homes are just not set up for that. The only option left for families like us is a dedicated facility where she can go and be well cared for and to be happy and most of all safe.

##### **[redacted]** - Here is the feedback you wanted [Jude](https://www.facebook.com/jude.bignell), on the NZ care Respite trial in Nelson. There so-called proposal, at this meeting was for 3 options which turned out to be 2 options. The third option was supposed to be "out of home respite"- in a facility. That was the option we were interested in and desperate for. Meg is bigger now and needing specialized equipment, hoists, wet floor shower areas or raised bath. Wheelchair accessible accommodation. Medical care is a big part of her daily needs. She has fragile health. I asked the NZ care people about that option and all they could offer me was their "overflow bed" in an existing facility used to house adults fulltime? WTF? They call that an option? Outrageous. I left in disgust. Many parents at the meeting had severely Autistic kids that needed specialized accommodation too, but there was nothing on offer either. They were offering nothing new at all. The other 2 options were the usual- finding host families to have children- I asked how many host families they had on their books with wheelchair accessible houses? The lady I spoke to said she had no idea. The other option was for someone to come to our home and offer respite- quite frankly, that is not respite. It means we have to take our other 3 kids and go away somewhere? That's not respite and all fine if you can afford to go away every few weeks? They spoke about carers being able to come and take the kids out to the park or the movies or go to town with our kids, for respite. That will work for the less severe kids and the higher functioning, but it most definitely does not meet our needs or the needs of the severely austistic.

**[redacted] -**  Thanks heaps for this post too Lisa. When I spoke to Jo from NZ Care in Nelson she also talked about the 3 options saying that 'option 3' wasn't a popular option and had only been utilised once. It didn't surprise me when she told me about what was available. The thing is Lisa, is that we feel exactly as you do about where we would want Sian (and possibly Jack our autistic boy) to go - they need so much more than a *bed* in an old people's home! We're also not happy about having to clear out of our own home just to get a break! I feel as though I have said that a million blimmin’ times to people and yet they all seem to make me feel like I am the only one who feels this way!! Arrrrrggghhhh!! I cannot tell you how rapt I am to read what you've written THANK YOU!! It has not and will not fall on deaf ears. PLEASE ANYONE ELSE WHO FEELS THIS WAY - POST ON THE RAINBOWS PAGE. I am committed to ensuring that your voices are heard.

**[redacted] -** Hi we have 3 little boys, our oldest is 10 years old and has ADHD and Autism and our twins who are 6 years old have Globlel Developmental Delay. We did have respite care when we lived in Hastings but now we live in tiny Otane there has been no respite care available through lack of people down here to do the respite care, even though our provider has been trying and been very helpful. It is very hard as our oldest boy is very busy and on the go all the time, he has had to go off all medication as of serious side effects. The twins are easier to manage as the GDD effects their speech and they are behind their peers. My husband and I haven't been away or taken the children on holiday for 10 years. We've lived here for 2 and a half years and there has been nothing available in that time unless we will travel a long way, which is out of the question as hubby works long hours and I'm the main caregiver. I wish the government would help out us that live in tiny country towns, some times you feel like you've been forgotten!!

**[redacted] -** We have two kids with special needs but our younger child is only 19 months so its not a big issues right now for her. She shares one set of grandparents with my step son. But she only has the one set.
My step son (who lives with me and his father full time) is severely autistic, aged 9. Like most with autism, he thrives on routine and has only a handful of people he will allow to care for him, including his father and I. The longest we feel safe leaving him with his elderly grandparents is one night as they cannot handle him anymore: he is tall, strong and wilful. He doesnt often sleep well when and has selective eating issues. His routines would be far more rigid if it werent for the fact that we refuse to teach him how to tell the time.. If we did it would mean fixations with time and routine even more then now..
Having a facility for respite would be amazing for families such as ours to get a much needed break.

**[redacted] -**  Hey i have 3 children. My oldest son is 12 he has adhd autism and intellectual disability he is violent and agressive behaviour he is such hard work my other son is 10 yrs he has autism and obsessional behaviour he runs away then i have my daughter she is 8 yrs she struggles to understand her brothers the thought of a holiday is exhausting my mum has been our greatest support but we need more. Life is so isolated and i cry so much wanting my sons to wake and b ok i struggle with life its so hard we need help thanks for listening

**[redacted] -** Ok this is wrong on so many levels , I haven't ever shared a story on my daughter but here it is.lucy has a rare chromosome disorder , she is mostly non verbal, deaf, delayed. She has severe "behaviour" needs. A few years ago Lucy was recieving some home care , she was not able to go to the respite or go on holiday programme with ihc as I found out they would mostly sit them in a room and watch DVDs or take them on random drives in the van to pass time and they would only have Lucy there she also had a one on one person.... Anyway Lucy had a good caregiver for a while who went on a long holiday . Ihc knew 6 months before she left and I had told them how concerned I was. I trained the caregivers daughter to provide Lucy's care she was excellent even though she was young , ihc refused to employ her. For a period of ten weeks Lucy had 10 different carers. I could not leave Lucy with any of them and it caused her and me and the ret of our kids allot of stress . In week 10 Lucy was having a very bad day and she attacked one of her sisters , the caregiver was standing in the kitchen pretty much just watching no attempt to help. It was dinner time and my husband was just walking in the door. He walked past the girl straight to Lucy and took her to her room. As Lucy was in full agression it was not a pretty sight. 3 days later cyps showed up . No word from ihc... None of the workers they sent me knew anything about what they were coming to and none had any training , it was the most awfull time not knowing if these people were at school collecting my kids or sending the police to pick up my husband. After investigation and explanation cyfs ruled on my side and contacted the Nasc, we changed to individualised funding. And have never looked back. My carers I send to first aid training and sign language classes and I train them all into how to help Lucy . I don't believe anyone can train carers to look after our children other than us and I think care plans are a waste of paper because people don't read them...

**[redacted] -** We had multiple carers who mostly only ever lasted 1 stay. Long story short our girl was too hard to handle. Well doh why did they think we needed the break.

**[redacted] -** There so needs to be somewhere safe and secure for our amazing children. I have 2 children on the spectrum but only get respite for 1 as didnt bother with getting our son hours, as i cant find people for 1 let alone 2!! Have no close family around so struggle. And my husband is very very fussy who we leave our children with (ie a centre could do proper police/reference checks etc) We get so run down ourselves that we get ill and are a hinder on the health system, so this would be a blessing! Thanks so much for being our voice Jude  x

**[redacted] -**  Our family are from Rotorua. A purpose built care facility with well trained staff is so needed here. We have traveled to Hamilton on occasion to have a break and we leave our daughter at Te Whare poi poi. It is very difficult to have her so far from us and she does not travel well. Our daughter has very high needs and she is six. We get 40 x 8 hr resprite per year through support net and our carer gets $76.00 for a 8 hour shift.This is not enough time for me to have adequate rest which is so important so I may be the best Mum for our precious daughter. We are a family of seven. Husband, myself and 5 children. I wish you luck. I do hope the government pays attention to this. We are starting to feel desperate around this plight

**[redacted] -** Just got through a problem with the help of my son's grandparents not a good option as they are infirm. Problem: Have not yet got respite care, now that I work my son needs to be taken care of during the holidays. There are no school holiday programmes that will take special needs children in Opotiki. What is a working mother to do with an autistic child?

**[redacted] -**  This is the problem I have .......my son has ASD, ADHD,ODD and dysbraxia and was kicked out of holiday programme and cant cope in the large group situation. I asked for more repite days to try and get a carer to have him as I cant take all the holidays off and was told I can not use them for someone to care for him while I work as they are for me to have a break ..... so what am I supposed to do with him??????????

**[redacted] -** no respite but have a carer for 20 days per year - not enough as a single working Mum! get any changes you want to the Minister of Disability now before she resigns

**[redacted] -** I am one of the lucky few it took over 2 years but I now have a great respite carer..without the ability to have that time out when we need it I truly believe my family would disintegrate. Our gurl has multiple challenges which consume eveyone in our house, even getting a decent nights sleep is a luxary. To have a safe, secure place she could be cared for would be a dream.

**[redacted] -** It should be a given. Keep fighting the good fight. I wish you well.

**[redacted] -**  I don't get respite. So I signed her up at daycare, 7hrs x 3 days a week. It only has public holidays off. We get by with just that but it is tiring. Double whammy I'm a blind (VIP) parent & care for our daughter most of the time coz husband works long hours. We live in Porirua.

**[redacted] -** I wish you well....I've always used family to care for my sister when I've needed a respite break

**[redacted] -** Our son goes to a respite facility in christchurch, however it is mainly intellectually disabled people. Marshall is purely physically disabled and has other complex medical needs (one quite serious). We have had several problems with the wrong feeding, toileting etc...some ending in hosital stays due to his condition not being handled correctly. We only send him there as he is bright and very capable of letting us and others what happens or doesnt happen (he is ok and we are not far away!!). We and a lot of other parents in Christchurch would dearly love a purpose built place for young people with purely physical disabilities....there are NONE in Christchurch.

**[redacted] -** Hi [Jude](https://www.facebook.com/jude.bignell), pretty sure you have heard from me in the past but incase you haven't, or it has disappeared- here is a quick summary of us and our needs for your document. Thank you for trying to advocate for so many families who struggle to keep their heads above water everyday. Who are so burnt out with the constant un-ending job of caring for their treasured kids but who are unable to access decent, safe respite care. We live at the top of the South island. Nelson Marlborough DHB area. Our daughter Meg has severe CP and fragile health. Her medical issues/needs are high and ongoing, compromising her constantly. She has little or no function physically so depends on us for everything. She is often in hospital, which seems to be the only place equipped to care for her. This of course is not a respite option as staffing levels are not sufficient for us to leave her. She requires direct care 24/7. Now that she is 20kg and 7years old, she needs to be hoisted in and out of equipment and requires regular changes of position. Everything needs to be modified. There is no appropriate respite facility in the entire area. No place where she can go and be safely cared for. Finding competent, carers who can be valued by way of a decent wage and proper training is non existent. Currently we are lucky to have my sister who takes Meg for one weekend a month. This is not a long term solution and I worry when it will end. We constantly fight burn out and the level of stress on our family and Meg's 3 other sisters is significant. It is all well and good for a so-called respite trial run by NZ Care, here in nelson/Marlborough to offer families respite options for the last 2 years. When we went along to the first meeting we found out the only options were respite in our own homes (carers coming into our homes)- as we all know, this isn't a new option and doesn't work for all of us all of the time. The second option was for our kids to go to "host families". When I enquired about that option no one at the meeting from NZ care had thought about the problem of finding host families with wheelchair accessible homes, wet floor bathrooms and hoists??? HOPELESS and disheartening. Putting aside the "politically correct" version of respite where kids get to go and stay in "normal" homes and get out into the community and go to the movies etc etc some of us need a proper FACILITY, bricks and mortar, hoists and hospital beds, feeding pumps and Oxygen supplies. A bathroom big enough to be hoisted into a warm bath or have a shower. Quiet rooms for those who have sensory issues. A music room or play room.....a garden where the sun shines. Its doesn't have to complicated. Small residential facilities, that look an feel like home but have the capability to care for our most vulnerable and fragile kids. Hope this helps. I am wishing you all the luck in the world. XX

**[redacted] -**  Im the same as nat, no respite, but need it. I have signed my son to full time day care, we are both on disability allowances as i have graves disease. But home help would be such a help so i can get my illness under control. Im tired 24/7...and its worse wen he gets sick...meltdowns galore. I am grateful for the fulltime daycare...but maintaining a home and cooking meals can drain the last bit of energy.

**[redacted] -** We have just been given an extra lot of Carer support hours from 12 days to 36 but we have NO family nearby NO person who ever agrees to babysit for longer than a day so we just cope. Have had NO luck getting respite carers either

**[redacted] -** Hello we use respite in Auckland for three nights a month - so far it has been alright . My only concern would be around food what they get to eat lots of sugar ect , and we cant choose when he goes. Some times I would like to know what really goes on at the house. I think they to be more parent friendly . In our case our boy does not speak.. so I worry about that too.

**Sue G** Hi Auckland is no better. One service charged us 1.5 days carer support cos Gabi was in a wheelchair. Interestingly she was less work than the majority of other children.

[2 hrs](https://www.facebook.com/groups/complexcaregroup/permalink/322347134588270/?comment_id=322629921226658&offset=0&total_comments=4) · [Like](https://www.facebook.com/groups/complexcaregroup/322347134588270/?notif_t=group_comment)

**Sue G** The last one I used was totally inappropriate & the carers were heavy smokers. It was full of middle-aged people. We gave up in the end. Gabi would rebel & refuse to go cos she found them boring.

[2 hrs](https://www.facebook.com/groups/complexcaregroup/permalink/322347134588270/?comment_id=322630257893291&offset=0&total_comments=4) · [Like](https://www.facebook.com/groups/complexcaregroup/322347134588270/?notif_t=group_comment) · [1](https://www.facebook.com/browse/likes?id=322630257893291)

**Gail**   Throughout our daughter's life it has been almost impossible to find respite in any facility. It's hopeless if you live in a small town or if your child has high or very high needs especially as they become adults.

**[redacted] -** Good luck in your mission, Jude. This continues to be a major issue for families and the single most important support that the Government can provide to ensure that family carers don't burn out and can continue to provide love and support for all members of their family. Respite must be a positive and safe experience for the disabled person Jan

|  |  |  |
| --- | --- | --- |
| **68** | Submitter name | Clare Randall |
| Submitter organisation | Arohanui Hospice |
| This submission was completed by: *(name)* | Clare Randall |
| Address: *(street/box number)* | P O Box 5439 |
|  *(town/city)* | Palmerston North |
| Email: | clare.r@arohanuihospice.org.nz |
| Organisation (if applicable): | Arohanui Hospice |
| Position (if applicable): | Chief Executive |

Are you submitting this *(tick one box only in this section)*:

[ ]  as an individual or individuals (not on behalf of an organisation)

[x]  on behalf of a group or organisation(s)

If you are an individual or individuals, the Ministry of Health will remove your personal details from your submission, and your name(s) will not be listed in the published summary of submissions, if you check the following box:

[ ]  I do not give permission for my personal details to be released.

(The above information will be taken into consideration if your submission is requested under the Official Information Act 1982.)

Please indicate which sector(s) your submission represents
*(you may tick more than one box in this section)*:

[ ]  Māori [ ]  Regulatory authority

[ ]  Pacific [ ]  Consumer

[ ]  Asian [ ]  District health board

[ ]  Education/training [ ]  Local government

[ ]  Service provider [ ]  Government

[x]  Non-governmental organisation [ ]  Pharmacy professional association

[ ]  Primary health organisation [ ]  Other professional association

[ ]  Professional association

[ ]  Academic/research [ ]  Other *(please specify)*:

### Challenges and opportunities

The Strategy reflects a range of challenges and opportunities that are relevant to New Zealand’s health system. Some of these are outlined in I. Future Direction on pages 5–7.

1. Are there any additional or different challenges or opportunities that should be part of the background for the Strategy?

|  |
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| The lack of visibility of results is compounded by a lack of shared/integrated information system for health professionals to access. There are inefficiencies due to this lack of access to shared information. I think we need a more visible IT focus in the solution and a greater investment in training in the health sector. |

### The future we want

The statement on page 8 of I. Future Direction seeks to capture the future we want for our health system:

So that **all** New Zealanders **live well, stay well, get well**, we will be **people-powered**, providing services **closer to home**, designed for **value and high performance**, and working as **one team** in a **smart system**.

2. Does the statement capture what you want from New Zealand’s health system? What would you change or suggest instead?

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| --- |
| Death and dying are a part of life. The strategy would be strengthened by adding a reference to dying well (or respectfully, and for people to be supported at this time). The people-powered approach is interesting and would need to be backed with education/resource and support. Self responsibility is good. The smart system required to improve technology so that inefficiencies and inequities are addresses is a good aspiration to have. One team – again, a good aspiration – the challenge will be to reduce silos. Sharing of information such as care plans is vital. |

A set of eight principles is proposed to guide the New Zealand health system. These principles are listed on page 9 of I. Future Direction and page 31 of II. Roadmap of Actions.

3 Do you think that these are the right principles for the New Zealand health system? Will these be helpful to guide us to implement the Strategy?

|  |
| --- |
| The principles seem sensible.      |

### Five strategic themes

The Strategy proposes five strategic themes to focus action – people-powered, closer to home, value and high performance, one team and smart system (I. Future Direction, from page 10).

4 Do these five themes provide the right focus for action? Do the sections ‘What great might look like in 10 years’ provide enough clarity and stretch to guide us?

|  |
| --- |
| The themes are appropriate. They need to be backed up with resources to ensure they are achieveable. |

### Roadmap of Actions

II. Roadmap of Actions has 20 areas for action over the next five years.

5 Are these the most important action areas to guide change in each strategic theme? Are there other actions that would be better at helping us reach our desired future?

|  |
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| There are some great actions – particularly 5f; 4a; 10d and 11. Somehow we need to reduce drug and alcohol abuse in our communities |

### Turning strategy into action

6 What sort of approaches do you think will best support the ongoing development of the Roadmap of Actions? Do you have ideas for tracking and reporting of progress?

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| --- |
| Integration of national organisations so that information is shared and silos reduced- eg HWNZ, NHB, DHBNZ, MOH |

### Any other matters

7 Are there any other comments you want to make as part of your submission?

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| I would like to see integration of care of the dying into the strategy. Also, make care of the elderly a focus please. |

Thank you for taking the time to provide feedback.

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| --- | --- | --- |
| **69** | Submitter name | [redacted] |
| Submitter organisation | [redacted] |

|  |  |
| --- | --- |
| This submission was completed by: *(name)* | [redacted] |
| Address: *(street/box number)* | [redacted] |
|  *(town/city)* | [redacted] |
| Email: | [redacted] |
| Organisation (if applicable): | [redacted] |
| Position (if applicable): | [redacted] |

Are you submitting this *(tick one box only in this section)*:

X[ ]  as an individual or individuals (not on behalf of an organisation)

[ ]  on behalf of a group or organisation(s)

If you are an individual or individuals, the Ministry of Health will remove your personal details from your submission, and your name(s) will not be listed in the published summary of submissions, if you check the following box:

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Please indicate which sector(s) your submission represents
*(you may tick more than one box in this section)*:

x Māori [ ]  Regulatory authority

[ ]  Pacific [ ]  Consumer

[ ]  Asian [ ]  District health board

[ ]  Education/training [ ]  Local government

[ ]  Service provider [ ]  Government

[ ]  Non-governmental organisation [ ]  Pharmacy professional association

[ ]  Primary health organisation [ ]  Other professional association

[ ]  Professional association

[ ]  Academic/research [ ]  Other *(please specify)*:

## Consultation questions

These questions might help you to focus your submission and provide an option to guide your written feedback. They relate to both parts of the Strategy: I. Future Direction and II. Roadmap of Actions.

### Challenges and opportunities

The Strategy reflects a range of challenges and opportunities that are relevant to New Zealand’s health system. Some of these are outlined in I. Future Direction on pages 5–7.

1. Are there any additional or different challenges or opportunities that should be part of the background for the Strategy?

|  |
| --- |
| **1) Add the challenge of real and meaningful actioning of Te Tiriti in the Health system.**Currently the different relationships and mechanisms in place to action Te Tiriti in the NZ health system are variable in their effectiveness. As tangata whenua we acknowledge the whole Tiriti document and emphasise the First Tiriti in te reo Maori – preamble and all articles. However we are aware that the Crown does not at this time acknowledge or entertain conversation and exchange on the basis of the full TOW instead has substituted the Principles of the Treaty. As such we will base this submission on the full Tiriti but converse with the MOH using the principles of Te Tiriti. **2) Demonstrate your acknowledgement of Te Tiriti from start to finish within document.** This requires that every section and strategy of the document is explicit in providing the tangata whenua viewpoints and themes. This includes specific tangata whenua actions and strong alignment with He Korowai Oranga. **3) Refer to Mäori as tangata whenua within the document.** We are ethnically Mäori and from our world view we are **tangata whenua**. This recognises our unique position as the indigenous people of Aotearoa New Zealand and the partner to Te Tiriti.This document should not replace He Korowai oranga but should aim to improve the conditions within the NZ health Sector so that He Korowai Oranga can be implemented effectively. |

### The future we want

The statement on page 8 of I. Future Direction seeks to capture the future we want for our health system:

So that **all** New Zealanders **live well, stay well, get well**, we will be **people-powered**, providing services **closer to home**, designed for **value and high performance**, and working as **one team** in a **smart system**.

2. Does the statement capture what you want from New Zealand’s health system? What would you change or suggest instead?

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| --- |
| **Te Tiriti as found document of Aotearoa is missing****The whole person is missing from this direction** **The whanau is missing from the direction and from the whole document****Life Course approach is needed so that all of the attention is not on older people with little flow of resources to young people and prevention.** |

A set of eight principles is proposed to guide the New Zealand health system. These principles are listed on page 9 of I. Future Direction and page 31 of II. Roadmap of Actions.

3 Do you think that these are the right principles for the New Zealand health system? Will these be helpful to guide us to implement the Strategy?

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| --- |
| On reading the updated version of the strategy, we notice that the Tiriti principle has dropped from first to nearly last in the list of principles. This strongly signals a reduced priority that the Ministry of Health has for Te Tiriti and its special relationship with tangata whenua. In order to provide a more balanced document with adequate priority and meaningful engagement with Te Tiriti and tangata whenua we recommend:1. **Return the principle for Te Tiriti to its position as the first principle of the Strategy as it was in its predecessor.**
2. **Change the wording of the principle referring to Te Tiriti to:**

***Acknowledge and action the special relationship between tangata whenua and the Crown under the Treaty of Waitangi*** |

### Five strategic themes

The Strategy proposes five strategic themes to focus action – people-powered, closer to home, value and high performance, one team and smart system (I. Future Direction, from page 10).

4 Do these five themes provide the right focus for action? Do the sections ‘What great might look like in 10 years’ provide enough clarity and stretch to guide us?

|  |
| --- |
| 1. **Add one more Strategic theme called Actioning Te Tiriti in the New Zealand Health Sector.**
 |

### Roadmap of Actions

II. Roadmap of Actions has 20 areas for action over the next five years.

5 Are these the most important action areas to guide change in each strategic theme? Are there other actions that would be better at helping us reach our desired future?

|  |
| --- |
| Currently Tangata whenua are largely not included in this roadmap. To make the point again - his action plan should not replace He Korowai oranga but should provide the necessary conditions and developments so that He Korowai Oranga can be implemented in the New Zealand Health Sector. 1. **Select 5 – 10 vital actions that will make the biggest difference to bringing to life te tiriti in the health sector and make a difference to tangata whenua wellness.**

Suggestions to be included as actions* An honest evaluation is required to ascertain how well Te Tiriti is being acknowledged and actioned in the New Zealand Health sector. Partnership, Participation and Protection of tangata whenua health in many areas is being eroded and diminishing. Just look at this strategy and ask yourself if this document is a true reflection of the intention of Te Tiriti o Waitangi? There are many threads to this work and much of it is sitting ready to be brought together in a single picture. Other areas may need some work.
* Develop an investment Plan for tangata whenua health
* Create a regular monitoring report to measure and disseminate information on progress on actioning Te Tiriti in the New Zealand Health system utilising RBA and infographics that are meaningful to the sector and to tangata whenua .
 |

### Turning strategy into action

6 What sort of approaches do you think will best support the ongoing development of the Roadmap of Actions? Do you have ideas for tracking and reporting of progress?

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| --- |
| See section above to create a TOW in action report and add case studies and vignettes about the reality for tangata whenua. Not only the feel good stories as the reality is many tangata whenua have negative experience and outcomes. Show true leadership by being willing to learn from reality.  |

### Any other matters

7 Are there any other comments you want to make as part of your submission?

|  |
| --- |
| We cannot see ourselves in this document – save for the disparity statements which talk about Maori inequalities. Consider Sharing our innovations and evidence of Maori health gains.  There is no proactive response to improving Maori health. Draw upon and recognise traditional Maori wisdom and frameworks as valued as part of the body of knowledge of wellness in Aotearoa NZ.  |

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| --- | --- | --- |
| **70** | Submitter name | [redacted] |
| Submitter organisation |  |

I am a mother of an adopted child who has Foetal Alcohol Syndrome.  Thankfully we were lucky to receive a diagnosis at 6yrs of age which is very rare as most DHB's do not have diagnostic capacity or experience to diagnose FASD.  I am also lucky as he has an Intellectual Disability which qualifies him for financial assistance through the NASC agency in our area.  Again this is not across the whole of New Zealand and FASD needs to be recognised as disability.   80% of individuals who grow up with FASD need life long support in order to succeed.  This is currently not the case in many areas of New Zealand.

Attached is a discussion document that a friend of mine and myself wrote as parents of children with FASD which we hope will help in your goals for a better health system for all New Zealanders.  FASD is at epidemic levels due the shocking drinking culture we have in New Zealand.  The Government are doing very little to address this and more and more babies are being born every year with severe brain damage which is totally preventable.  WE need a huge media campaign similar to family violence and smoking.  The costs associated with FASD support is huge and to that I suggest that a levy of 10% from the taxes received from alcohol  go towards paying for the much needed services that we so desperately need to diagnose and give life long support to these affected individuals.

My son is now 18yrs of age and pushing for independence but he will not cope and there is very little specifically in our area to assist.  He has no job and there is no training suitable for him. We are struggling with his behaviour and at times do not feel safe in our own home.  Our worry is that before long he will go down the road of the justice system and land up in prison like many of FASD youth due to lack of sustained support and supervision.

Many families are desperate for help and totally exhausted caring for their child with FASD

I am happy to tell my story at any level if it will help formulate realistic policy and support.  We are hard working, educated parents who have done our best but still feel let down by the lack of support systems that are out their to specifically help us.

Regards

A very exhausted parent

[redacted]

------------------------------------------------------------------------------------------------

Accompanying attachment: *FASD Discussion document* noted

|  |  |  |
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| **71** | Submitter name | [redacted] |
| Submitter organisation | The Podiatry Board |

Hi

Below are the comments provided by the Podiatry Board at its meeting on 19 November.

Important points to note - only a few had read the strategy and the Board's interest was focused on providing detailed comments on the presentation, strategy and roadmap rather than the consultation questions. Hence have typed up comments rather than filled in the form.

Key points raised:

* had difficulty with the claim in presentation that 90% claim to be in good health given other stats in strategy and their own clinical practice
* telehealth not always appropriate eg on East Coast, North Island people prefer face to face and the telehealth service that was set up is not supported as patients are suspicious of it. It doesn't meet patients' needs
* believe issues facing NZ health system same as 30 years ago but for many the gaps are bigger including workforce gaps (both capacity and capability) and health outcomes
* more focus needed on retaining continuity of care with new models such as IFHCs where patients don't necessarily see the same practitioner all the time; the whole sense of wellbeing includes the strong relationship patients have with their health practitioner
* patient portals could potentially mean the language used by health practitioners may need to change
* not all over the age of 50 will be comfortable with new technology - how will we be coping with health technology literacy?
* nothing in the roadmap directly about addressing health inequalities
* a lot more needs to be done to link health with broader policy settings including education, employment, social support etc.
* behaviour change very complicated - a comprehensive behaviour approach is needed
* keen to see strong allied health involvement in both engagement and implementation of next steps
* in relation to dietetics workforce - a number of issues including: a number have been successfully trained but now can't get jobs as there isn't the funding for positions despite the focus on good nutrition advice in LTC prevention; very small Maori workforce.
* more recognition and acknowledgement needed in strategy about disease prevention approach at a community level.

regards

[redacted]

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| **72** | Submitter name | Samantha Bennett |
| Submitter organisation |  |

|  |  |
| --- | --- |
| This submission was completed by: *(name)* |  Samantha Bennett     |
| Address: *(street/box number)* |  Private Bag 93503     |
|  *(town/city)* |  Takapuna, 0740     |
| Email: |  Samantha.Bennett@waitematadhb.govt.nz    |
| Organisation (if applicable): |  Waitemata and Auckland District Health Boards     |
| Position (if applicable): |   Asian, migrant and refugee health gain manager (Waitemata and Auckland DHBs)     |

Are you submitting this *(tick one box only in this section)*:

[ ]  as an individual or individuals (not on behalf of an organisation)

[x]  on behalf of a group or organisation(s)

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(The above information will be taken into consideration if your submission is requested under the Official Information Act 1982.)

Please indicate which sector(s) your submission represents
*(you may tick more than one box in this section)*:

[ ]  Māori [ ]  Regulatory authority

[ ]  Pacific [ ]  Consumer

[x]  Asian [x]  District health board

[ ]  Education/training [ ]  Local government

[ ]  Service provider [ ]  Government

[ ]  Non-governmental organisation [ ]  Pharmacy professional association

[ ]  Primary health organisation [ ]  Other professional association

[ ]  Professional association

[ ]  Academic/research [ ]  Other *(please specify)*:

## Consultation questions

These questions might help you to focus your submission and provide an option to guide your written feedback. They relate to both parts of the Strategy: I. Future Direction and II. Roadmap of Actions.

### Challenges and opportunities

The Strategy reflects a range of challenges and opportunities that are relevant to New Zealand’s health system. Some of these are outlined in I. Future Direction on pages 5–7.

1. Are there any additional or different challenges or opportunities that should be part of the background for the Strategy?

|  |
| --- |
| * Greater details about the super diversity and Asian population growth in the Auckland region should be emphasized as a challenge, in particular the health disparities experienced within Asian subgroups due to barriers such as accuracy of ethnicity data, access and utilisation of health services in particular primary care, language and a culturally competent health workforce. The real and emerging need to focus on Asian health in the Auckland region is immediate with a broaden lens beyond Maori and Pacific when discussing inequities in the document.
* Reference to Asian as falling under ‘Other populations’ needs to be more explicit in using the term ‘Asian’ populations given the projected growth in the Auckland region
* There is no reference to ‘refugee’ populations throughout the document, given their high needs and barriers to access and utilisation of services, language and complex health needs.
 |

### The future we want

The statement on page 8 of I. Future Direction seeks to capture the future we want for our health system:

So that **all** New Zealanders **live well, stay well, get well**, we will be **people-powered**, providing services **closer to home**, designed for **value and high performance**, and working as **one team** in a **smart system**.

2. Does the statement capture what you want from New Zealand’s health system? What would you change or suggest instead?

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| * The term ALL New Zealanders must take into consideration those groups whom are new migrants, refugees and asylum seekers who are eligible for publically funded healthcare but may not consider themselves in their identity as a ‘New Zealander’.
 |

A set of eight principles is proposed to guide the New Zealand health system. These principles are listed on page 9 of I. Future Direction and page 31 of II. Roadmap of Actions.

3 Do you think that these are the right principles for the New Zealand health system? Will these be helpful to guide us to implement the Strategy?

|  |
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| * The eight principles are sound. The concern is when overlaying the principles to Asian, migrant and refugee population needs is how will this Strategy work to address the barriers of access and utilisation of services, language and cultural barriers, financial constraints, poor experiences within the health care system which is not culturally appropriate, sensitive or responsive with competing funding models and finite resources often allocated to other priority populations.
 |

### Five strategic themes

The Strategy proposes five strategic themes to focus action – people-powered, closer to home, value and high performance, one team and smart system (I. Future Direction, from page 10).

4 Do these five themes provide the right focus for action? Do the sections ‘What great might look like in 10 years’ provide enough clarity and stretch to guide us?

|  |
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| See below updated headings:1. **Convenient & timely access** - Closer to home will suit those hard to reach groups and ‘at risk’ groups whom do not access centralised services within the DHBs2. **Community centred** rather than people powered – we must ensure we capture the feedback and needs of Asian, migrant and refugee groups whose voice may not be captured across mainstream engagement platforms. The NGOs, community groups, and ethnic associations are key players in their ability to ensure the needs of Asian, migrant and refugee groups are incorporated into the co-design of interventions, programmes and services , particularly those where language is a barrier. 3. **Value and high culturally responsive performance** -we must consider that cultural concepts of health vary across ethnic groups, and mainstream services should be delivered in a process that does reflect individual cultural and linguistic needs. How do we ensure that all populations are receiving equitable access to care? It is imperative to ensure existing mainstream services are culturally responsive and the workforce upskilled in CALD, which is promoted amongst the community whom have had poor experiences in the past.4. **Achieve Equity rather than ALL New Zealanders –** does the Strategy really incorporate the future needs of migrants, asylum seekers and refugees whom may not consider themselves New Zealanders yet, but are eligible for publically funded healthcare.5. **Workforce development**- need to have a health workforce who are culturally competent to effectively address the cultural needs of Asians, migrants, and refugees who are well supported by their organisation/s. |

### Roadmap of Actions

II. Roadmap of Actions has 20 areas for action over the next five years.

5 Are these the most important action areas to guide change in each strategic theme? Are there other actions that would be better at helping us reach our desired future?

|  |
| --- |
| Action 5: Tackle long-term conditions and obesitye. With regards to population segments, greater effort must be directed to high risk Asian population groups such as Chinese and South Asian in targeted prevention, promotion and early interventions for diabetes and CVD.Action 11: Target investmentsa. The Asian population in the Auckland region is growing rapidly and is increasingly diverse with health disparities experienced within Asian subgroups. Greater financial investment and effort directed at techniques, standards and guidance for health investment cases targeted at Asian subgroups should be considered. e. If greater health investment cases are directed at Asian populations in areas with high domiciled populations i.e the Auckland region, the findings can guide review of results and learnings which can then be extended/generalisable across the country for the selected Asian ethnic population groups.Action 16: Build system leadership, talent and workforceb. There are a number of Auckland based NGOs and smaller community-based providers targeting populations from Asian and refugee backgrounds which are delivering services with minimal funding, and whom require greater opportunities for access to funding and workforce development opportunities. Consideration of greater support should be given to smaller run NGOs who lack the capacity to attend capacity building trainings, whom are often working in dual roles and require financial support to take time off to upskill.Action 18: Strengthen national analytical capability a. Ensure that Stats NZ and the MoH provide ongoing opportunities for the DHBs to input into the Ethnicity Data Protocols without resistance or delay, so as to ensure that accurate data on ethnicities are recorded and reported by services to guide future planning and targeted funding to segmented Asian and refugee populations. People are increasingly able to interact with the health system online – this requires online functionalities to provide information to users in their preferred language with funding earmarked for ongoing support. English should not be the only language option available to individuals who wish to access information about the health system online.The Immigration NZ website – NZ Now website should be available in multi-languages for prospective and new migrants.Future considerations:How will the Strategy capture the growing needs of the Asian population as it continues to expand with an estimated growth to 31% by 2026 in Auckland? How does the Strategy reflect the complex needs of refugee populations including asylum seekers?  |

### Turning strategy into action

6 What sort of approaches do you think will best support the ongoing development of the Roadmap of Actions? Do you have ideas for tracking and reporting of progress?

|  |
| --- |
| * Consistent engagement with Asian, migrant and refugee populations across the country where incorporation of co-design principles are imperative.
* Funding support available to the NGO sector for smaller ethnic organisations whom have reach and influence into their communities but lack the funding to be able to provide ongoing effort and engagement based on lack of capacity.
* Benchmark health outcomes for Asian subpopulations globally, in order to identify potential emerging areas that may impact on the health of specific Asian groups in DHB catchments. The findings can guide planning of health outcomes, important risk factors, health service use, and policy framework which can guide the Roadmap of Actions.
 |

### Any other matters

7 Are there any other comments you want to make as part of your submission?

|  |
| --- |
| * A key challenge in the wider Auckland region is reflecting Asian population growth and super-diversity within our services. The health disparities experienced within Asian subgroups due to barriers such as accuracy of ethnicity data, access and utilisation of health services (in particular primary care) are important. Opportunities in this area include language and progress towards a culturally competent health workforce. There is a real and emerging need to focus on Asian health as a key priority group alongside Māori and Pacific, rather than consideration under ‘Other populations.’ We also note that there is no reference to ‘refugee’ populations throughout the document, given their high needs and barriers to access and utilisation of services, language and complex health needs.
 |

Thank you for taking the time to provide feedback.

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| **73** | Submitter name | [redacted] |
| Submitter organisation |  |

Hello, I have also filled in your survey and made some comments on the website. I believe you absolutely need to consider this if this strategy is to last 20 years. The first of the “ baby boomers” turned 65 in 2011 so they are now 69, in 20 years they will be 89, and the baby boomers born in 1961, the year of NZ’s highest birth rate (and also the year I was born, so very relevant to me personally) will be 74, by the 10 years after that they/we will be 84. Presumably this strategy will at least morph into the next one after that, and the number of people dying is likely to be greater in the next 20 years than in any other period of our country’s history except for perhaps 1918 WW1 and influenza epidemic.

Thanks [redacted]





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| **74** | Submitter name | [redacted] |
| Submitter organisation | South Island Alliance |

 New Zealand Health Strategy

South Island Alliance - feedback

1 CHALLENGES AND OPPORTUNITIES

The Strategy overall is heading in the right direction. The concept of ‘investment funding’ and cross government focus is good to see.

However, we think that the DHBs should be taking a leadership function in the integration of social services for a population. Evidence is strong that local determination of service delivery in a public sector is more effective at reducing inequity. DHBs have roles: to support the most vulnerable; leveraging their organisational capability in commissioning (Planning and Funding); and the reality that DHBs are the only Government agency accountable for every person from before birth to death. “People powered” as a concept risks excludes people who are not in a position to participate in their own health care and need the support of the system, it sounds individualistic rather than a partnership and loses the quality focus of “person centered” which guides how a system needs to be designed and function.

The strategy doesn’t reflect the need to use data to design the system in a flexible way that can respond to the needs of individuals. The increased use of data appears to be more about providing information for clinical care rather than using that data to design and plan systems. There is a risk in the strategy and the action plan that we will continue to function in silos rather than an integrated person centered system. There is little recognition in the document of the capability that already exists in DHBs and regions that can be leveraged to create local responses with true community engagement. The Productivity Commission Report was quite clear about the opportunities available using a collaborative approach built around DHBs and their alliances. The MoH’s role is to provide leadership and enable the DHB to deliver to their populations. The MoH needs to take a leadership role with other Government agencies on health and social service integration as health has the largest workforce, already functions in an integrated way , has the best access to data about populations and people, and the most to gain given the known impact of the social determinants on health outcomes .

Financial pressure in health has shown that the DHBs are capable of delivering significant efficiency gains, in real terms delivering more with the same. Stepping into the social service integration space really helps DHBs as the opportunity exists to get ahead of demand and reduce long terms impacts on the system.

Noting also there is no recognition of the challenges of:

* providing services over distance to rural areas;
* providing for multimorbidity and the generalist approach required for this;
* the poor person and family/whānau experience, and often high costs, when people’s end of life isn’t in their place of choosing.

2 THE FUTURE WE WANT

2.1 FUTURE DIRECTION STATEMENT

*So that all New Zealanders live well, stay well, get well, we will be people-powered, providing services closer to home, designed for value and high performance, and working as one team in a smart system.*

The ‘Live well, stay well, get well’ by-line doesn’t include dying well, as noted above. Suggest ‘Live well, stay well, get well, end well’.

2.2 PRINCIPLES

**The best health and wellbeing possible for all New Zealanders throughout their lives**

Agree

**An improvement in health status of those currently disadvantaged**

Agree

**Collaborative health promotion and disease and injury prevention by all sectors**

Agree but this is too limiting as a principle. We would be seeking a collaborative approach to all parts of health and social services including the care and support of people with ill-health and disabilities including disability due to aging. The principle is to support people to live the best possible lives.

**Acknowledging the special relationship between Māori and the Crown under the Treaty of Waitangi**

Agree

**Timely and equitable access for all New Zealanders to a comprehensive range of health and disability services, regardless of ability to pay**

Suggest ‘timely and equitable *access* for all New Zealanders to a comprehensive range of health and disability services, regardless of WHERE PEOPLE LIVE OR THEIR ability to pay ‘. Access however is a poor measure for equity we need unequal access to support equitable outcomes. Access should be according to need and ability to benefit.

**A high-performing system in which people have confidence**

Good aim – hard to measure, this is about how the people working in the system feel about working in the system. If they feel enabled and trusted they will work in a way that instils confidence.

Active partnership with people and communities at all levels

Good principle but could be interpreted as a partnership with individuals only – not clear on alternative wording

**Thinking beyond narrow definitions of health and collaborating with others to achieve wellbeing**

Agree

2.3 ALIGNING BEHAVIOURS

The core behavior trait required is trust. The MoH needs to move from a monitoring and regulator role to an enabling role. Adaptive leadership is required and the role of the leader in this model is to clarify the problem and support the solutions created by the people.

Dot point 4 suggest changing – from fragmented health sector silos to integrated HEALTH AND social service responses.

3 FIVE STRATEGIC THEMES

In general, the following are missing: good end of life care; a recognition that multimorbidity requires more than better disease specific care pathways; and the need for a generalist approach to providing care for these people are missing. Taking into account the aging population there is limited focus on the needs of older people and how we might provide support that is holistic and targeted at keeping people well as possible, in their own homes and communities and out of institutions (including age residential care and hospitals). This will take a whole of system response and is not disease specific. Without this focus a significant amount of resource will be expended on services that the people themselves would prefer to avoid. It is quite clear that no society can afford to institutionalize its aging population at the rate we currently are so without this focus healthcare in New Zealand will become unaffordable.

We also noting also the triple aim (Population health, Experience of care and Sustainability) has been 'demoted' to within one of the 5 high level themes rather than the overarching high level outcomes.

3.1 PEOPLE POWERED

The term ‘people powered’ is interesting wording but we would like to suggest this theme reflects the partnership with the person/family/whanau/carer/and health professional. We recognise that this theme is designed to put the emphasis on people owning and engaging in what is important to them / their needs and goals for their healthcare (along the lines of Advanced Care planning approach) and ensuring those needs are an integral part of the equation and not the health professionals determining what the best outcome.

The patient’s journey is now articulated strongly throughout the document. There is, for example, under the heading ‘People Power’ strong emphasis towards technology and infrastructure. The strategy needs to balance itself between IT being made available to support clinical needs versus people under the heading of ‘People Power’ still accessing health care in a traditional manner (walk ins or pre-booked appointments) of which there is little or no mention.

It should also be recognised that there are a group of people who will continue to need support to access healthcare at the level which meets their need. These people miss out if the system does not actively seek to engage and support them.

10 year view

This focuses entirely on individual level care, misses community based aspects of health promotion, illness prevention and patient empowerment. The view is largely casting people as passive rather than active partners in decision making. This also links to a preventative model. Health literacy is missing and technology is only one way to empower people. We need a broader multi-channelled approach that starts before school that empowers people to understand (in whatever way works for them) what will keep them well and how to access the support the need.

The core advantage that health has is the population approach which enables the delivery of services in a way that is aligned with the specific needs of the population and the resources of the community.

3.2 CLOSER TO HOME

The notion of ‘Closer to Home’ is a good however this strategy needs to be forward thinking in its projections

What this section should is explore is whether the existing community models of care are the right type of services to be offered in a changing world and where population behaviours are different. It’s good to see there is a focus on Maori and Pacific models and approaches, however, ownership of improved health outcomes for these communities must be seen as the responsibility of all health services and Maori/Pacific NGO being seen as key contributors towards population and service performance. “Closer to Home” should also mean focusing on building primary and community capacity and capability to support people to stay in their own home even when unwell so we can reduce the demand on the most expensive part of the health system. Managed correctly a strategy of people only being in hospital when they need hospital level care will ensure that we make best use of scarce workforce resources and avoid large future capital expenditure.

10 year vision.

Palliative care is missing, integrated care for multimorbidity not single disease approaches missing. Is the comment on public-private partnerships the thin edge of a wedge? Could add a bullet ’People die in their place of choosing’ or something similar.

How does the ‘Closer to Home’ 10 year view look for communities? The description is more about systems and infrastructure. What specific actions will address the early onset and advancement of long term chronic conditions for Maori and Pacific? We know that these conditions are starting 10 years earlier and in some cases these conditions are intergenerational.

3.3 VALUE AND HIGH PERFORMANCE

The fundamental key driver to a ‘Value and High Performance’ will depend on the types of models that are in play across the sector and the measurement of their performance. What we do have is national health targets. What we don’t is a very clear focus on measurable outcomes and a service improvement culture rather than a win/lose punitive target driven culture. Although Triple Aim gives a basis for moving this forward, we need to get serious about right sizing existing services gradually to show better performance overtime. That may mean disinvestment and reinvestment in activities that show benefit realisation overtime. Many things look good on paper, but how do we know changes have been great for our community/people.

3.4 ONE TEAM

There is a great deal to support in this section however the overall focus becomes one of the Ministry’s role as leader rather than reinforcing the concept of organising around the needs of the people and the multiple roles required in a team. The one team concept needs to be more person centered and less organisational centric in its articulation.

Although Whanau Ora, Integrated Family Care and other ideas have come forward, many cars up a person’s drive still happens. The strategy should be bold and set out a clear direction on what a One Team should be. This part of the strategy talks about IT and infrastructure - these are big investment calls and the resources spread across the section are very thin now.

Need to include a focus on generalism to meet needs of future multimorbidity. It is becoming clearer that a disease focus is not the solution to the challenges faced by the health system as the real challenges are with the combination of complex medical and social issues that prevent people from living well. This is even more support for an integrated approach that is tailored to meet the needs of the person in the context of their whanau and their community.

The box at the bottom of p.22 should include: need for generalist integrated approach for multimorbidity management and support.

10 year vision

Add - ‘We invest in the capability and capacity of our workforce, including the in NGOs and the volunteer sector, and make sure that it fosters leadership, A GENERALIST APPROACH, flexibility and sustainability’

3.5 SMART SYSTEM

Integration can be enabled by sharing data within the local ecosystem. National systems can act as backbone but local integration of data and observation is required to create that insight that enables innovation. There is a lack of recognition in the document of using information to plan and design services and to underpin a culture of continuous service improvement.

Shared care plans box – Shared care plans do not have to involve a health navigator. Integrated/coordinated care CAN involve a health navigator but depends on individual circumstances.

We must avoid using technology for technology’s sake we need to design our services and use technology to support.

10 year vision

10 year vision – electronic health pathways agreed; and overcoming distance with technology so same quality of care regardless of location missing

4 TURNING STRATEGY INTO ACTION

Overview of NZ health and disability system – district Alliances’ role, 4 regional DHB groupings role, and PHOs existence in the system, all with accountabilities (and funding flows) not mentioned.

5 ROADMAP OF ACTIONS

Note we have not included any actions based on the changes suggested earlier in this feedback document. In general the lack of mention of Alliances and PHOs is a bit concerning. I acknowledge that this document is to be taking a strategic view, but significant work has gone in to alliances over the last couple of years and the silence leaves a vacuum.

5.1 PEOPLE POWER

*Action 1*. Improving people’s ability to be informed and therefore self-manage better is not just about digital technologies. What actions will promote health literacy?

5.2 CLOSER TO HOME.

Need to promote career choices that are generalist in nature, e.g. GPs, rural hospital medicine doctors, generalist and community based nurses, general allied health roles.

This theme should also recognise that allowing people to die in the place of their choice improves the quality of their terminal phase of life, the experience for their loved ones, and can reduce costs.

Need an urgent focus on reducing hospital and aged residential care admission or we will run out of resource before the strategy is implemented.

*Shift services.*

*Action 3a)*: need to engage with health alliances, regional structures, not just DHBs

*Action 4* could speak more to promoting/enabling service integration more

*Tackle LTC and obesity*.

*Action 5b* is disease silo based, rather need to embed a generalist based multimorbidity approach, rather than disease specific approaches, to cope with the health needs of the future (approaches such as self-management support, life coaching and navigation). Needs to include Advance Care Plans being widely in place by 5 yrs time for end of life care.

5.3 VALUE AND HIGH PERFORMANCE

Second sub bullet point of final main bullet point – providers use a health investment approach – FUNDERS also need to have a health investment approach

*Align funding*

Equity model - funding model issues. There is so much more that can be offered in the community that is “free” when you access the hospital system and therefore reinforces the care away from home (not closer to). Under the ACC funding model people can access physiotherapists (and many others) directly for early intervention and prevention strategies ongoing. Others wanting access for early (non-accident) education/ advice / rehabilitation are required to pay (not subsidised). Cost is a barrier to preventative healthcare for many from an equity point of view. An exception to this would be the Pharmacists whereby people can walk in off the street and seek advice as a first step for straight forward ailments etc. The pharmacist ensures that pathway to the GP or other health professional is clear to the person should something change or not improve.*Target investments*

*Action 11 b* – this should be approached with caution. It risks competition that destabilises core services, potentially allows cherry picking and fragmentation of service provision. I know this sounds like circling the wagons, but experiences in UK would suggest caution.

5.4 ONE TEAM

*Clarify roles, responsibilities and accountabilities*.

*Action 14 b.* This casts the DHBs in the passive role. Wording should reflect active involvement of DHBs in development of changes.

*Build system leadership, talent and workforce.*

*Action 16e and f.* These two points are the main ‘workforce’ parts of the actions. Given the issues facing health workforce, regulated and unregulated, this seems light. Also could include promoting focus on generalism.

5.5 SMART SYSTEM.

Paragraph 2 – Not everybody will want/be able to have online access. The system should not become so focused on digital solutions that alternatives aren’t available, as risks designing in inequities.

There are three aspects to health information”

* Health information that the patient holds
* Health information that the health professional holds
* Health information across agencies / government

Smart technology will likely be an important enabler going forward for consumers and we also need to keep sight of equity issues with $ costs in terms of any IT devices (phones / apps etc).

*Use of electronic records and patient portals*.

*Action 19 a* – assume they are meaning create the ability for existing systems to talk to each other, rather than developing a whole new national system?

19c – why wouldn’t primary care providers be included in this action as well?

6 ANY OTHER MATTERS

* The plan lacks any real comment about access and actions to improve the health and wellbeing of Maori, Pacific and vulnerable populations like the Asian community.
* The strategy does not place a significant emphasis of the Maori relationship or its alignment to achieving He Korowai Oranga and Pae Ora. Although there are fleeting comments throughout, is the sector and New Zealand now saying that Maori health is no longer a priority nationally?
* The actions within the document don’t always synchronise with the statements made under the five themes. For example, ‘Closer to Home’ actions talks about the system. But
* when will actions include people at the centre of the care? It’s all about doing it to ‘them’ but limited about work ’with them.’
* The plan has a five and ten year focus. How is the planning building natural decline in populations in 10, 20 or 30 years? What we do know from demographers that there will be real pressures on all government services if we don’t plan for the bubble burst for those aged 70 years plus and non-Maori. There is a significant concern about this strategy which is more about meeting the demand now and this leaves population like Maori, Pacific and Asian in a vulnerable situation where their population demographics are younger and fertility/birth rates are higher to non-Maori.
* It would be good for this strategy to have bold statements. Why not say by 2020 Maori will enjoy the same level of health as Non-Maori and show this through the national health targets. It’s time to move the intent and become more proactive in making things happen and measuring this collectively.
* What I would like to see is data that shows where we are at now (our baseline and using babies born in 2015 as our start point) and where we should be in five or ten years. Let’s put the stake in the ground now.
* Throughout the document there is sparse reference to workforce development and changing requirements. For example page 5-6 talks of the issue of the ageing workforce but not the growing demand on the health system that will also lead to an increased need in health workforce numbers.
* It would be good to see markers that include education recruitment to tertiary centres, prioritisation about investment strategies and managing the transition points from a youthful workforce to a maturing/ aging workforce through to their exit or retirement.
* The type of health care professional we need is evolving and we need to ensure that we are growing and training the appropriate workforce to provide appropriate care. The mix and range of specialist vs generalist is key to this, particularly in the rural sector.
* There is a general lack of strategic vision or expectation in regards to local, regional and national collaboration or alliancing processes. Effective one system / integration / seamless patient journey is enabled by collaboration as much as integrated IT systems.
* The major theme that is woven through about IT enablers is great, but this is not the only way of ensuring all our population receives relevant health information or connection to the system. Some folks simply don’t have IT access, and as identified, what about health literacy.
* Improving care closer to home isn’t just about shifting services. There needs to be a focus on the development of appropriate and comprehensive models of care that support more complex care being provided in the community…..this takes me back to bullet points 1 & 2

|  |  |  |
| --- | --- | --- |
| **75** | Submitter name | Jane Newton |
| Submitter organisation |  |
| This submission was completed by: *(name)* | Jane Newton |
| Address: *(street/box number)* | [redacted] |
|  *(town/city)* | [redacted] |
| Email: | [redacted] |
| Organisation (if applicable): |       |
| Position (if applicable): |       |

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(The above information will be taken into consideration if your submission is requested under the Official Information Act 1982.)

Please indicate which sector(s) your submission represents
*(you may tick more than one box in this section)*:

[ ]  Māori [ ]  Regulatory authority

[ ]  Pacific [x]  Consumer

[ ]  Asian [ ]  District health board

[ ]  Education/training [ ]  Local government

[ ]  Service provider [ ]  Government

[ ]  Non-governmental organisation [ ]  Pharmacy professional association

[ ]  Primary health organisation [ ]  Other professional association

[ ]  Professional association

[ ]  Academic/research [ ]  Other *(please specify)*:

### Challenges and opportunities

The Strategy reflects a range of challenges and opportunities that are relevant to New Zealand’s health system. Some of these are outlined in I. Future Direction on pages 5–7.

1. Are there any additional or different challenges or opportunities that should be part of the background for the Strategy?

|  |
| --- |
| The biggest drain, cost or need on the health system is meeting the needs of older people – they need to be cared for – ie, not get well at that time. This strategy missed the need to support older people to be independent for as long as possible and ‘die well’ |

### The future we want

The statement on page 8 of I. Future Direction seeks to capture the future we want for our health system:

So that **all** New Zealanders **live well, stay well, get well**, we will be **people-powered**, providing services **closer to home**, designed for **value and high performance**, and working as **one team** in a **smart system**.

2. Does the statement capture what you want from New Zealand’s health system? What would you change or suggest instead?

|  |
| --- |
| Yes |

A set of eight principles is proposed to guide the New Zealand health system. These principles are listed on page 9 of I. Future Direction and page 31 of II. Roadmap of Actions.

3 Do you think that these are the right principles for the New Zealand health system? Will these be helpful to guide us to implement the Strategy?

|  |
| --- |
| Yes |

### Five strategic themes

The Strategy proposes five strategic themes to focus action – people-powered, closer to home, value and high performance, one team and smart system (I. Future Direction, from page 10).

4 Do these five themes provide the right focus for action? Do the sections ‘What great might look like in 10 years’ provide enough clarity and stretch to guide us?

|  |
| --- |
| People drivenCoordination via primary care, family services in the communityIT enabledWell-funded |

### Roadmap of Actions

II. Roadmap of Actions has 20 areas for action over the next five years.

5 Are these the most important action areas to guide change in each strategic theme? Are there other actions that would be better at helping us reach our desired future?

|  |
| --- |
| Yes, but there are no outcomes to measure by |

### Turning strategy into action

6 What sort of approaches do you think will best support the ongoing development of the Roadmap of Actions? Do you have ideas for tracking and reporting of progress?

|  |
| --- |
| Local outcomes shared |

### Any other matters

7 Are there any other comments you want to make as part of your submission?

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| --- |
| This system needs to evolve not be restructured. |

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| **76** | Submitter name | [redacted] |
| Submitter organisation |  |

|  |  |
| --- | --- |
| This submission was completed by: *(name)* | [redacted] |
| Address: *(street/box number)* | [redacted] |
|  *(town/city)* | [redacted] |
| Email: |       |
| Organisation (if applicable): |       |
| Position (if applicable): |       |

Are you submitting this *(tick one box only in this section)*:

[x]  as an individual or individuals (not on behalf of an organisation)

[ ]  on behalf of a group or organisation(s)

[x]  I do not give permission for my personal details to be released.

Please indicate which sector(s) your submission represents
*(you may tick more than one box in this section)*:

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[ ]  Asian [ ]  District health board

[ ]  Education/training [ ]  Local government

[ ]  Service provider [ ]  Government

[ ]  Non-governmental organisation [ ]  Pharmacy professional association

[ ]  Primary health organisation [ ]  Other professional association

[ ]  Professional association

[ ]  Academic/research [x]  Other *(please specify)*: **Older persons**

### Challenges and opportunities

The Strategy reflects a range of challenges and opportunities that are relevant to New Zealand’s health system. Some of these are outlined in I. Future Direction on pages 5–7.

1. Are there any additional or different challenges or opportunities that should be part of the background for the Strategy?

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| --- |
| Why do people come into hospital receive the medication that is right for them and then when they visit their GP it is changed. |

### The future we want

The statement on page 8 of I. Future Direction seeks to capture the future we want for our health system:

2. Does the statement capture what you want from New Zealand’s health system? What would you change or suggest instead?

|  |
| --- |
| Current restrictions on assistance care givers can give makes it inefficient (ie, can’t clean windows, ceilings etc) |

A set of eight principles is proposed to guide the New Zealand health system. These principles are listed on page 9 of I. Future Direction and page 31 of II. Roadmap of Actions.

3 Do you think that these are the right principles for the New Zealand health system? Will these be helpful to guide us to implement the Strategy?

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### Five strategic themes

The Strategy proposes five strategic themes to focus action – people-powered, closer to home, value and high performance, one team and smart system (I. Future Direction, from page 10).

4 Do these five themes provide the right focus for action? Do the sections ‘What great might look like in 10 years’ provide enough clarity and stretch to guide us?

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### Roadmap of Actions

II. Roadmap of Actions has 20 areas for action over the next five years.

5 Are these the most important action areas to guide change in each strategic theme? Are there other actions that would be better at helping us reach our desired future?

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| --- |
|       |

### Turning strategy into action

6 What sort of approaches do you think will best support the ongoing development of the Roadmap of Actions? Do you have ideas for tracking and reporting of progress?

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### Any other matters

7 Are there any other comments you want to make as part of your submission?

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| It is concerning that health system cannot meet all needs. Eg, hip replacements and this means repeat visits through the system and added costs to both. Feels like those at the top need a reality check and should visit to see what is actually happening patient and system |

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| **77** | Submitter name | [redacted] |
| Submitter organisation |  |

Tuesday 1st December 2015

[redacted]

[redacted]

FORMAL SUBMISSION DRAFT OPEN LETTER

Dear Sir/Madam

My submission is on an individual basis primarily, but also indirectly in support of MECFS sufferers.

I didn’t know about this submission process, as I don’t have a computer for financial reasons, and because my health makes learning a computer a major hurdle for me. I type this – one finger style. Sandra Forsyth kindly sent me her info off her computer today so that I can be in time by mail. The only newspaper I receive is the Hutt News, and I didn’t see any mention of the process in it (community newspaper). My submission is as a consumer, but as MOH does not recognise MECFS in NZ, I am not receiving any real help with my illness.

I have had MECFS for about 20 years, after a sandfly bite on the inner calf of my left leg turned septic, partly as a result of poor/incorrect GP treatment, which later had to be dealt with at Hutt Hospital A&E department etc. For a number of years I could not get a proper diagnosis for MECFS because of GP bias and because I didn’t know exactly what my condition was/is medically etc. (I was treated as a mental case instead!) At that stage, I felt that I could not approach WINZ for a disability allowance as I didn’t have GP back-up. I was on an invalid benefit then, but am on the pension now.

I pay most of my bills at NZ post by cash or cheque, as I can’t remember pin numbers for ATMs or eftpos etc. (I don’t wish to write down pin numbers for security reasons.) I am not on any medication for mental disorders, which I don’t have anyway!

People say how healthy I look, because my condition is largely invisible! If I mow my garden, I get accused of not being unwell. They don’t see me in bed afterwards! I can’t work, as I don’t have enough physical or mental energy to be available for employment on an ongoing basis, as I can’t sustain my energy levels. My poor health tends to isolate me from joining clubs etc, socially. I am semi-house bound with all my disabilities. Not being able to work puts pressure on my budget also. Not enough people know or understand about MECFS – on one occasion, I told a man that I suffered with M.E. and he replied, “Is that a sexually transmitted disease?”!!!!

I only get home help now, because I have osteoarthritis in my right knee. I was told that there is no home help for my main medical condition – MECFS in NZ! That is blatant illegal medical discrimination!!! It appears that I have to be happy that I have arthritis, so that I can get home help! The World Health Organisation recognises MECFS as an illness-related DISABILITY! What’s wrong with NZ MOH? It is imperative that MECFS sufferers get accepted/recognised in NZ formally. We are entitled to a formal accepted legal diagnosis and treatment options; in theory only in NZ. In reality, it is imperative that we be accepted by MOH etc in NZ. We should also be entitled to receive research funding for MECFS! If our Health could be improved we would have a better quality of life and public and medical acceptance etc. Further, we would be able to help ourselves more and help others also, and also possibly be able to earn money and reduce taxpayer burden etc.

I strongly urge MOH to please take note of my comments, and stop discriminating at MECFS sufferers anymore. I also have severe fibromyalgia in my feet and lower legs etc. Now, Wellington hospital has discharged me from haemotology outpatients as they claim my other anemia condition is too low to act on!!! Long story!

Yours sincerely,

[redacted]

P.S. MECFS is like having a permanent flu in body!

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| **78** | Submitter name | Drew Tata |
| Submitter organisation |  |

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| This submission was completed by: *(name)* | Drew Tata |
| Address: *(street/box number)* | [redacted] |
|  *(town/city)* | [redacted] |
| Email: | [redacted] |
| Organisation (if applicable): | [redacted] |
| Position (if applicable): | [redacted] |

Are you submitting this *(tick one box only in this section)*:

* as an individual or individuals (not on behalf of an organisation)

[ ]  on behalf of a group or organisation(s)

[ ]  I do not give permission for my personal details to be released.

Please indicate which sector(s) your submission represents
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[ ]  Non-governmental organisation [ ]  Pharmacy professional association

[ ]  Primary health organisation [ ]  Other professional association

[ ]  Professional association

[ ]  Academic/research [ ]  Other *(please specify)*:

### Challenges and opportunities

The Strategy reflects a range of challenges and opportunities that are relevant to New Zealand’s health system. Some of these are outlined in I. Future Direction on pages 5–7.

1. Are there any additional or different challenges or opportunities that should be part of the background for the Strategy?

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| --- |
| 1. Working with the Ngati Ranginui Marae community I have found it hard to navigate positive health outcomes because of the competitive nature in Health funding. This needs to be addressed if we want Māori Health providers to work together for the betterment of the communities participating in health initiatives.
2. Tick box systems can also play a huge role in defining the way health providers can and can’t support community driven initiatives that address current issues that are prominent to them aside from a general lens that does not accommodate the needs to make significant progress.
 |

### The future we want

The statement on page 8 of I. Future Direction seeks to capture the future we want for our health system:

So that **all** New Zealanders **live well, stay well, get well**, we will be **people-powered**, providing services **closer to home**, designed for **value and high performance**, and working as **one team** in a **smart system**.

2. Does the statement capture what you want from New Zealand’s health system? What would you change or suggest instead?

|  |
| --- |
| “YES” – If this statement is going to be acknowledged and applied across the board fairly and equally; I feel this will be a great step into positive future health outcomes.  |

A set of eight principles is proposed to guide the New Zealand health system. These principles are listed on page 9 of I. Future Direction and page 31 of II. Roadmap of Actions.

3 Do you think that these are the right principles for the New Zealand health system? Will these be helpful to guide us to implement the Strategy?

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| “Yes” – an addition could be; Improved rules of engagement and approach methodologies that can be transformative, unique, acknowledged and ultimately fine-tuned for greater understandings of what is working and what may not be working so well. For example Kaupapa Maori theory can be set as a holistic approach that could provide a process of integrated services from all sectors. Kaupapa Māori key values underpin the how’s, who’s, why’s, where’s all positive and currently successful approaches if understood. Downfalls would be the misuse of this approach, or known as tokenism.  |

### Five strategic themes

The Strategy proposes five strategic themes to focus action – people-powered, closer to home, value and high performance, one team and smart system (I. Future Direction, from page 10).

4 Do these five themes provide the right focus for action? Do the sections ‘What great might look like in 10 years’ provide enough clarity and stretch to guide us?

|  |
| --- |
| Yes  |

### Roadmap of Actions

II. Roadmap of Actions has 20 areas for action over the next five years.

5 Are these the most important action areas to guide change in each strategic theme? Are there other actions that would be better at helping us reach our desired future?

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### Turning strategy into action

6 What sort of approaches do you think will best support the ongoing development of the Roadmap of Actions? Do you have ideas for tracking and reporting of progress?

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| **Ngati Ranginui Iwi stands by Kaupapa Māori as successful tool:**1. Community driven initiatives
2. Being open minded
3. Small achievable steps
4. Being open to holistic cultural progress instead of contract driven (losing sight of what’s important and current)
5. Cultural alternatives to be highlighted as contributing advantages to improved health – whakapapa, tikanga, kawa etc.

**Kaupapa Māori Principles** **Tino Rangātiratangā “The Principle of Self-determination** - *Tino Rangātiratangā relates to sovereignty, autonomy, control, self-determination and independence. The notion of Tino Rangātiratangā asserts and reinforces the goal of Kaupapa Māori initiatives: allowing Māori to control their own culture, aspirations and destiny. (Kaupapa Maori, 2015)***Taonga Tuku “The Principle of Cultural Aspiration** - *This principle asserts the centrality and legitimacy of Te Reo Māori, Tīkanga and Mātauranga Māori. Within a Kaupapa Māori paradigm, these Māori ways of knowing, doing and understanding the world are considered valid in their own right. In acknowledging their validity and relevance it also allows spiritual and cultural awareness and other considerations to be taken into account. (Kaupapa Maori, 2015)***Ako Māori “ The Principle of Culturally Preferred Pedagogy** *- This principle acknowledges teaching and learning practices that are inherent and unique to Māori, as well as practices that may not be traditionally derived but are preferred by Māori. (Kaupapa Maori, 2015)***Kia piki ake i ngā raruraru o te kainga “ The Principle of Socio-Economic Mediation** - *This principle asserts the need to mediate and assist in the alleviation of negative pressures and disadvantages experienced by Māori communities. This principle asserts a need for Kaupapa Māori research to be of positive benefit to Māori communities. It also acknowledges the relevance and success that Māori derived initiatives have as intervention systems for addressing socio-economic issues that currently exist. (Kaupapa Maori, 2015)***Whānau “The Principle of Extended Family Structure** - *The principle of Whānau sits at the core of Kaupapa Māori. It acknowledges the relationships that Māori have to one another and to the world around them. Whānau and the process of whakawhānaungatanga are key elements of Māori society and culture. This principle acknowledges the responsibility and obligations of the researcher to nurture and care for these relationships and also the intrinsic connection between the researcher, the researched and the research. (Kaupapa Maori, 2015)***Kaupapa - The Principle of Collective Philosophy** - *The 'Kaupapa' refers to the collective vision, aspiration and purpose of Māori communities. Larger than the topic of the research alone, the kaupapa refers to the aspirations of the community. The research topic or intervention systems therefore are considered to be an incremental and vital contribution to the overall 'kaupapa'. (Kaupapa Maori, 2015)***Te Tiriti o Waitangi “The Principle of the Treaty of Waitangi** *- Pihama (2001) identified another principle to be taken into account within Kaupapa Māori theory: Te Tiriti o Waitangi (1840) is a crucial document which defines the relationship between Māori and the Crown in New Zealand. It affirms both the tangata whenua status of whānau, hapū and iwi in New Zealand, and their rights of citizenship. The Tiriti therefore provides a basis through which Māori may critically analyse relationships, challenge the status-quo, and affirm the Māori rights. (Kaupapa Maori, 2015)***Ata - The Principle of Growing Respectful Relationships** - *The principle of āta, was developed by Pohatu (2005) primarily as a transformative approach within the area of social services. The principle of āta relates specifically to the building and nurturing of relationships. It acts as a guide to the understanding of relationships and wellbeing when engaging with Māori. (Kaupapa Maori, 2015)* |

### Any other matters

7 Are there any other comments you want to make as part of your submission?

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| --- |
| Very pleased with the many approaches described and cannot wait to attend the draft health strategy on the 8th of December, I leave with a Whakatauki I use as the Pae Ora coordinator for Ngati Ranginui Iwi; **“Ko nga pae tawhiti whaia kia tata, ko nga pae tata whakamaua kia tina”“The potential for tomorrow depends on what we do today”** |

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| **79** | Submitter name | [redacted] |
| Submitter organisation |  |

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Feedback on Update of the New Zealand Health Strategy

**The Updated New Zealand Health strategy requires:**

* A stronger consumer focussed co-design element associated with all developments of the evolving health systems i.e. pro-active joint intention partnership with communities.
* Stronger emphasis/incentives to support both the health and general populations to view health interventions in the acute setting to be less desirable than other health interventions. Hospital/secondary health care is sexy and avoidance is not.
* A greater focus on informing health professionals and public to plan end of life choices to enable a “die well” emphasis which will avoid inappropriate use of costly secondary care resources when primary care and less interventionist focus would enable better outcomes. Advanced Care Planning is the perfect conduit.
* A more and stronger incentivised focus on prevention of disease and poor health condition rather than expensive treatments i.e. loose weight rather than knee replacement. Clear ambitious targets, health sector goals to change legislation i.e. sugar drinks tax.
* More emphasis to support clinical outcomes rationalising public health policy and developments i.e. poor dental outcomes/costs for the population versus sugar drinks tax.
* A greater focus on the young and early interventions with incentivised clear health targets to reduce overweight/obesity rates.
* A stronger workforce development focus is required in all sectors of health to develop many scopes/roles of practice from Pharmacy to unqualified health care workers. i.e. the scope of the practice nurse needs supported development and number of nurses in General Practice Teams needs to be inverted in proportion to the number of GPs.
* A clearer focus on joining health and social sector capability with joint appointments/IT enablers, incentives etc Social, housing and education prime areas…a health professional associated and routinely spending time in every school.
* An increased IT enabling focus in every stream of development of the health system to ensure reduced duplications, improved integration, efficiency gain, outcome monitoring etc
* An increased focus on a national programme of care quality indicators across the health system additional to health targets.
* A greater focus on improved health system integration which must be incentivised, promoted and enabled to ensure both the population and the health and social sectors understand what diverse range of resources are available to support the health of the nation…..

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| **80** | Submitter name | [redacted] |
| Submitter organisation |  |

[redacted]

3rd December 2015

New Zealand Health Strategy Update Consultation

To whom it may concern,

**Re: New Zealand Health Strategy Consultation**

Thank you for the opportunity to provide feedback on the proposed New Zealand Health Strategy Update (Future Directions and Roadmap of Actions). I acknowledge what has been a considerable amount of work to prepare these for consultation.

I have opted not to answer your specific questions but provide you with over-arching feedback and specific feedback relating to the dietetic workforce. I trust the comments made in my submission will be given due consideration.

**Introduction**

Dietitians are registered health professionals who meet standards required by the NZ Dietitians Board under the Health Practitioners Competency Assurance Act (HPCA) 2003. In New Zealand, by law, dietitians must be registered with the Dietitians Board and hold a current practising certificate, work within a specified scope of practice, participate in a continuing competency programme and adhere to a Code of Ethics.

Additionally, registered dietitians can undergo further training to be legally qualified to prescribe nutrition supplements. Dietitians are the only registered and suitably qualified profession in New Zealand able to prescribe and manage therapeutic diets for patients and provide the nutrition supplement that will have the best outcome for the patients.

**Closer to Home**

I am concerned that there is a fundamental lack of reference to nutrition professionals in the Roadmap of Actions document, who I believe are pivotal to the Ministry of Health (MOH) fulfilling the principle of services being delivered ‘Closer to Home’. The Roadmap of Actions talks about health professionals [namely nurses] being trained in tasks that they have not traditionally performed and altering their scope of work. Whilst this may be necessary in some areas, particularly in rural areas where there is a definite need; there is currently already a near 600 strong dietetic workforce who are skilled and qualified to carry out many of these tasks but to date have not been harnessed even close to their full potential.

Further, I am concerned that to ‘continually invest in training’ when there are a lack of jobs for new graduates, is not an incentivizing career pathway. This is worsened if overseas trained or other health professionals [namely nurses] are trained to fill a nutrition role when a capable dietetic workforce exists. I see an investment in dietetic roles, particularly in primary care, as a more currently pertinent priority than an investment in training.

The Roadmap of Actions document also refers to the need to ‘fully utilise health skills and training by removing legislative barriers to allow health practitioners such as ‘pharmacists and nurses’ to prescribe’. It is disappointing that the MOH has not considered utilising the many other professional groups such as dietitians, optometrists, psychologists and other professions who already have or who are in the process of working towards prescribing scopes of practice.

There is no doubt that an integrated ‘wrap around’ approach to dealing with chronic health conditions such as diabetes could significantly benefit from the expertise of a number of health practitioners other than Doctors many of whom have not just prescribing rights but are highly skilled in their particular field of expertise.

**Tackle Long Term Conditions and Obesity**

The Roadmap of Actions document refers to the need for health professionals to reorient planning guidance and performance management to either diabetes or mental health or cardiovascular disease. I strongly assert that these conditions are connected, multi-factional and driven by social factors that cannot be siloed.

The document also refers to health providers implementing a package of initiatives to prevent and manage obesity in children and young people up to the age of 18 years. There is, however, no reference to how these programmes will be resourced, supported and managed and as there are currently a number of initiatives that are working very successfully around the country, how existing programmes that have been evaluated and have international credibility could be compulsorily rolled out across the country to prevent reinvention of the wheel.

I believe that in order to ‘make primary care more accessible and affordable’, to provide ‘more and better access to community services’ and for people to ‘access practical evidence-based health advice that makes it easier for them to make healthy choices and stay well’, significant integration of allied health services at a primary care level is required. With only 20 FTE dietitians employed in primary care nationally we consider this an area of untapped opportunity.

**One Team**

The Roadmap of Actions document references the need to develop an established, integrated, advisory framework that supports the shared future direction. To date, the MOH has not provided a formal avenue for the allied health sector to provide feedback and policy advice and to develop such an advisory framework, to do so without the allied health voice would be a retrograde step.

Further, I am concerned that the Future Directions document focuses too heavily on the traditional doctor nurse model of care and that there is a lack of recognition of other health professionals who may be the more appropriate service provider or lead care provider. Nor has there been sufficient attention to the need for central health coordinator to assist patients in navigating the health system.

**Value and High Performance**

The 50 different allied health professional groupings, including dietetics, could bring a myriad of services and professional, regulated skills to primary care services teams who want to increase the value they bring to their community. Allied Health professionals are able to deliver a wider range of core services, develop more integrated care plans, better co-ordinate with specialists and hospitals, increase access and work in a raft of different community environments.

I am pleased the MOH has acknowledged the need to ensure funding and information systems support providers to improve their services and it is encouraging that a health investment approach is being considered. However, I am concerned the document does not provide enough of a mandate for providers to invest in systems that are for the good of the nation and will assist health delivery services to be joined up across both care sectors and professional groupings.

I would also argue that purchasing from non-government organisations (NGOs) and commissioning services at a local level requires sound contract management to ensure deliverables are clear and outcomes are met.

**Improve Performance and Outcomes**

I am keen to reinforce that if the MOH want to increase and improve equity of health outcomes, quality and value, allied health services must be incorporated into the primary care delivery model and for this to work there needs to be a health investment approach that is supported by a complete overhaul of the funding model. As long as Doctors remain the financial gatekeepers to the way services are devolved, we will continue to get the same outcomes for patients.

**Some Overarching Concerns**

The MOH has acknowledged in the document that many of the recommended actions do not deviate far from the existing strategy. Whilst I acknowledge the difficulty in proposing solutions that are overly prescriptive, I would argue that there is a fundamental lack of detail in how the strategy is going to be resourced and implemented and we may well find that in five years’ time we are no better off.

Furthermore, until there are significant changes made to the way in which capitated primary care services are purchased and funded, the type and location of services delivered and the health outcome measures expected we will not realise any effective change from what we currently have.

There are a number of examples where the Roadmap of Actions document refers to solutions being delivered ‘over time.’ This is not a measurable outcome, does not provide healthcare providers with a blue print for expectations around timely outcomes, what it is expected they deliver or how they should interface with other providers and this lack of connectivity we believe will once again result in siloed and inefficient health care delivery.

Furthermore, ‘Promoting to service users and clinicians the benefit of having access to a patient portal’ we would argue is not sufficiently robust if we are going to realise the health outcomes that we aspire to. Such an initiative needs to be more than promoted, but mandated by the MOH, sufficiently resourced and uptake regularly measured as General Practitioners become more IT savvy.

I wholeheartedly agree that the obligations under the Treaty of Waitangi should be a fundamental principle in guiding the general direction of the strategy. However, where the document refers to the Treaty of Waitangi underpinning the design of training for health workers and ‘board members’, it is not clear who these board members are, whether they be District Health Boards, Regulatory Authorities, or both.

I support self-management of healthcare through the use of digital technologies and the use of social media particularly in the area of Type 2 Diabetes Mellitus (T2DM). However, it has been raised with the MOH before that many of the high needs populations that are most at risk of chronic long term diseases, such as T2DM do not have access to smartphones or know how to use social media apps.

**Summary of Interventions**

Dietitians are pivotal to the delivery of a number of the actions outlined in the Roadmap of Actions Document. We urge the MOH to consider how dietetic services may be better utilised in the development of future primary care models and future funding arrangements.

Thank you for the opportunity to provide feedback, we ask that our comments be given due consideration as part of the consultation process. I am happy to be consulted further.

Yours Sincerely,

[redacted]

[redacted]

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| **81** | Submitter name | [redacted] |
| Submitter organisation | New Zealand LAM Trust |

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| This submission was completed by: *(name)* | [redacted] |
| Address: *(street/box number)* | [redacted] |
|  *(town/city)* | [redacted] |
| Email: | [redacted] |
| Organisation (if applicable): | New Zealand LAM Trust |
| Position (if applicable): | Director |

Are you submitting this *(tick one box only in this section)*:

[x]  on behalf of a group or organisation(s)

Please indicate which sector(s) your submission represents
*(you may tick more than one box in this section)*:

[ ]  Māori [ ]  Regulatory authority

[ ]  Pacific [x]  Consumer

[ ]  Asian [ ]  District health board

[x]  Education/training [ ]  Local government

[ ]  Service provider [ ]  Government

[x]  Non-governmental organisation [ ]  Pharmacy professional association

[ ]  Primary health organisation [ ]  Other professional association

[ ]  Professional association

[x]  Academic/research [x]  Other *(please specify)*: Patient support and advocacy organisation specifically representing: women in New Zealand, diagnosed and suffering from the Rare Lung Disease (LAM Lymphangioleiomyomatosis)

### Challenges and opportunities

1. Are there any additional or different challenges or opportunities that should be part of the background for the Strategy?

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| The challenge for the NZ Health Strategy update is for government to take real and focussed responsibility to ensure equity, fairness, consistency and inclusion in respect of all New Zealanders suffering from RARE CONDITIONS.The Strategic Framework Update must take this long overdue opportunity to address and include all New Zealanders living with a rare disease and must accept,embody and provide an equitable share of funding and resources for this group. \*\*The internationally accepted incidence of a person diagnosed and suffering with a rare condition is fewer than one person per two thousand in the population ( 1 per 2000); There are between 7000 and 8000 known rare diseases representing approximately 8% of the New Zealand population.The New Zealand LAM Trust advocates on behalf of 26 diagnosed women with the rare and invariably fatal lung disease Lymphangioleiomyomatosis ( known as LAM). Please refer to www.lam.org.nz |

### The future we want

So that **all** New Zealanders **live well, stay well, get well**, we will be **people-powered**, providing services **closer to home**, designed for **value and high performance**, and working as **one team** in a **smart system**.

2. Does the statement capture what you want from New Zealand’s health system? What would you change or suggest instead?

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| Patients with rare disorders are often unable to be “people powered” or to have a voice within “a smart system”. Those who advocate for the thousands of New Zealanders who do not have “a voice within a smart system” are left out.The New Zealand LAM Trust, on behalf of women suffering from LAM asks for a future that embraces a “changing mindset”; this means that at all levels of our health system, the Strategy must signal a new direction, where “putting the patient in the middle of the health equation”, means exactly that. Part of this changing mindset must include all New Zealanders who suffer from rare conditions and who are not always able to advocate for themselves; the NZ LAM Trust is particularly aware of the constancy of some LAM patients “not being”, because of their condition, “in the middle of the health equation” and asks for a future that embraces a nationwide collaborative and strategic plan on behalf of all New Zealanders suffering from LAM . |

A set of eight principles is proposed to guide the New Zealand health system. These principles are listed on page 9 of I. Future Direction and page 31 of II. Roadmap of Actions.

3 Do you think that these are the right principles for the New Zealand health system? Will these be helpful to guide us to implement the Strategy?

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| --- |
| The principles are correct, however, the NZ LAM Trust and other rare disease advocacy groups must be seen as an accepted and recognised voice on behalf of the approximate 8% of New Zealanders who suffer from rare conditions. The NZ LAM Trust and The National Organisation for Rare Disorders ( NZORD), on behalf of thousands of New Zealanders suffering from rare diseases, ask and expect to be included in the “Shared Services Framework”. The first and most important part of this sharing and inclusion is the establishment, by the NZ Government, of a New Zealand Rare Diseases Strategy. Our country has lagged so far behind many other countries in the establishment of such a Strategy; this Consultation Document and this submission asks that “The New Direction” spoken of by Dr Margaret Wilsher in the short on line film background, listens to and acts on this request as a vital part of the “road map of actions”. |

### Five strategic themes

4 Do these five themes provide the right focus for action? Do the sections ‘What great might look like in 10 years’ provide enough clarity and stretch to guide us?

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| The five theme as outlined in “Future Directions” are commendable and worthy, however this submission reminds the “theme writers” that this is more than an academic exercise re the next ten years. The writer of this submission sincerely hopes that carefully chosen focus groups, with experience, knowledge, empathy and communication skills, and backed by adequate resources, will result in “Future Directions” that we will be proud of, in a much shorter time than ten years.“Changing the Mindset”, putting the patient in the “Middle of the Health Equation” , so that “All New Zealanders live well, stay well and get well” is of utmost importance.However, this submitter asks that the 'Roadmap of Actions' accepts that not all New Zealanders are the same nor have the same problems; their health issues require a specific “road map of actions”. Rare Disease patients are, in many cases, not 'people powered', they may not be able to help 'change the mindset', they may not have the ability or the facilities to work adequately in the middle of the 'health equation'. |

### Roadmap of Actions

5 Are these the most important action areas to guide change in each strategic theme? Are there other actions that would be better at helping us reach our desired future?

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| The most important action to guide change is to establish focussed “Listening Groups” – individuals whose abilities include listening skills and communication skills to help enable the desired future changes to be put in place. |

### Turning strategy into action

6 What sort of approaches do you think will best support the ongoing development of the Roadmap of Actions? Do you have ideas for tracking and reporting of progress?

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| Following on from 5 above, tracking and reporting focus groups must meet 6 monthly for the next 5 years, to process and ensure that the ‘roadmap’ is on track. |

### Any other matters

7 Are there any other comments you want to make as part of your submission?

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| The approach re ongoing development as described in 6 above must involve competent empathetic people and must involve patient advocates where appropriate. Ie, Advocates for patients with rare disorders |

NOTES TO BE READ ALONGSIDE THE ENCLOSED SUBMISSION'S CONSULTATION QUESTIONS:

1: Challenges and Opportunities

The Strategic Framework Update must take this long overdue opportunity to address and include all New Zealanders living with a rare disease and must accept,embody and provide an equitable share of funding and resources for this group.

\*\*The internationally accepted incidence of a person diagnosed and suffering with a rare condition is fewer than one person per two thousand in the population ( 1 per 2000); There are between 7000 and 8000 known rare diseases representing approximately 8% of the New Zealand population.

The New Zealand LAM Trust advocates on behalf of 26 diagnosed women with the rare and invariably fatal lung disease Lymphangioleiomyomatosis ( known as LAM).

Please refer to [www.lam.org.nz](http://www.lam.org.nz/)

2: The Future We Want:

The New Zealand LAM Trust, on behalf of women suffering from LAM asks for a future that embraces a “changing mindset”; this means that at all levels of our health system, the Strategy must signal a new direction, where “putting the patient in the middle of the health equation”, means exactly that.

Part of this changing mindset must include all New Zealanders who suffer from rare conditions and who are not always able to advocate for themselves; the NZ LAM Trust is particularly aware of the constancy of some LAM patients “not being”, because of their condition, “in the middle of the health equation” and asks for a future that embraces a nationwide collaborative and strategic plan on behalf of all New Zealanders suffering from LAM.

3: Principles and Implementation

The NZ LAM Trust and The National Organisation for Rare Disorders ( NZORD), on behalf of thousands of New Zealanders suffering from rare diseases, ask and expect to be included in the “Shared Services Framework”.

The first and most important part of this sharing and inclusion is the establishment, by the NZ Government, of a New Zealand Rare Diseases Strategy. Our country has lagged so far behind many other countries in the establishment of such a Strategy; this Consultation Document and this submission asks that “The New Direction” spoken of by Dr Margaret Wilsher in the short on line film background, listens to and acts on this request as a vital part of the “road map of actions”.

4: Future Directions

The writer of this submission sincerely hopes that carefully chosen focus groups, with experience, knowledge, empathy and communication skills, and backed by adequate resources, will result in “Future Directions” that we will be proud of, in a much shorter time than ten years. “Changing the Mindset”, putting the patient in the “Middle of the Health Equation” , so that “All New Zealanders live well, stay well and get well” is of utmost importance. However, this submitter asks that the 'Roadmap of Actions' accepts that not all New Zealanders are the same nor have the same problems; their health issues require a specific “road map of actions”. Rare Disease patients are, in many cases, not 'people powered', they may not be able to help 'change the mindset', they may not have the ability or the facilities to work adequately in the middle of the 'health equation'.

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| **82** | Submitter name | Abigail Milne |
| Submitter organisation | The Werry Centre |

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| --- | --- |
| This submission was completed by: *(name)* | The Werry Centre |
| Address: *(street/box number)* | University of Auckland, 261 Morrin Road |
|  *(town/city)* | St Johns, Auckland |
| Email: | s.dashfield@auckland.ac.nz |
| Organisation (if applicable): | The Werry Centre |
| Position (if applicable): | General Manager |

Are you submitting this *(tick one box only in this section)*:

[ ]  as an individual or individuals (not on behalf of an organisation)

X on behalf of a group or organisation(s)

[ ]  I do not give permission for my personal details to be released.

(The above information will be taken into consideration if your submission is requested under the Official Information Act 1982.)

Please indicate which sector(s) your submission represents
*(you may tick more than one box in this section)*:

[ ]  Māori [ ]  Regulatory authority

[ ]  Pacific [ ]  Consumer

[ ]  Asian [ ]  District health board

X Education/training [ ]  Local government

[ ]  Service provider [ ]  Government

X Non-governmental organisation [ ]  Pharmacy professional association

[ ]  Primary health organisation [ ]  Other professional association

[ ]  Professional association

X Academic/research [ ]  Other *(please specify)*:

### Challenges and opportunities

The Strategy reflects a range of challenges and opportunities that are relevant to New Zealand’s health system. Some of these are outlined in I. Future Direction on pages 5–7.

1. Are there any additional or different challenges or opportunities that should be part of the background for the Strategy?

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| The challenges and opportunities section of the strategy makes particular reference to the affordability challenges associated with the aging population, long term conditions and the impacts of obesity. While it is highly relevant to focus on these issues, the Government must also be mindful of the need to increase investment into early childhood, which as shown by Peter Gluckman and others, offers the most valuable opportunity for long term gains for society. Around 10 percent of the world’s children suffer from mental health problems (mainly anxiety, depression and conduct disorder). Moreover, New Zealand has a high rate of adolescent morbidity (and the highest rate of teenage suicide) compared with other OECD nations. The majority of these children become unhappy adults. Adult mental illness reduces GDP by at least 5% through reduced productivity or inability to work, increased crime and health care costs[[12]](#footnote-12). Actions to reduce mental illness among children would produce major benefits to New Zealand society. The draft roadmap on P29 is not adequately reflective of this. We are also slightly confused by the specific mention of a pathway for children with Foetal Alcohol Spectrum Disorders (FASD) in the roadmap on P29.We agree with the statement on P6 that some of NZ population groups receive unequal benefits from the health and disability system. Currently mental health services to children and adolescents remain underfunded compared to adults (per head of population). It would be good to see this addressed with a greater focus on ensuring an optimal start to life (better infant mental health, less abuse, etc.) and on reducing suicide. |

### The future we want

The statement on page 8 of I. Future Direction seeks to capture the future we want for our health system:

So that **all** New Zealanders **live well, stay well, get well**, we will be **people-powered**, providing services **closer to home**, designed for **value and high performance**, and working as **one team** in a **smart system**.

2. Does the statement capture what you want from New Zealand’s health system? What would you change or suggest instead?

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| The statement broadly captures what the New Zealand health system should be doing. |

A set of eight principles is proposed to guide the New Zealand health system. These principles are listed on page 9 of I. Future Direction and page 31 of II. Roadmap of Actions.

3 Do you think that these are the right principles for the New Zealand health system? Will these be helpful to guide us to implement the Strategy?

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| The 8 guiding principles are helpful and sufficiently general to be inclusive of health and system issues facing all New Zealanders. |

### Five strategic themes

The Strategy proposes five strategic themes to focus action – people-powered, closer to home, value and high performance, one team and smart system (I. Future Direction, from page 10).

4 Do these five themes provide the right focus for action? Do the sections ‘What great might look like in 10 years’ provide enough clarity and stretch to guide us?

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| The five themes provide a useful focus for change. 1. People powered - it is great to see mention of improved health literacy on P11. In order to have truly collaborative care, clients and families need access to high quality and up to date information. Increasing opportunities for clinicians, clients and families to have common access to such information via reputable websites (e.g. for children, sites such as Kidshealth, Plunket and the Werry centre) that are joined at a higher level as "Ministry validated or preferred sources" would allow this to happen in a sustainable way. Technology is both a new solution and a problem. It is great to see e-therapies such as SPARX highlighted as potential new parts of the health system. It is also great to hear about the possibility of a common health IT system on P15 and a national electronic health record on P46. At present, a good chunk of clinician time is spent negotiating multiple IT systems and replicating information because these systems spoon, rather than talk with each other. Being able to share records with clients will also be beneficial for collaborative goal setting and management. 2. Closer to home - it is good to see mention of early investment in the health and well-being of children, parents and whānau as the foundation for life long health - and that such an approach will require coordination across agencies. It would be useful to add supporting parents with mental illness and/or addiction and their children in this section and also to the summary of tasks geared toward a great start for children, families and whānau on P38. 5. Smart System - It is good to aim for quality at a systems level. It is also important to maintain quality of individual professional practice. Though individual specialities must constantly adapt to work together within a common system, changes at the systems level should be carefully planned in collaboration with these professions to ensure their success. The various medical colleges, nursing councils and others should be actively consulted and invited to participate in these processes. Also, maintaining current gains in investment approaches (e.g. via Pharmac) is important. It will be important to ensure that these are preserved in the face of international agreements such as the TPPA |

### Roadmap of Actions

II. Roadmap of Actions has 20 areas for action over the next five years.

5 Are these the most important action areas to guide change in each strategic theme? Are there other actions that would be better at helping us reach our desired future?

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| It's great that common physical health issues such as diabetes, cancer, obesity and heart disease are mentioned in the strategy document. The same cannot be said for mental health problems. The wording in Action 5 on P37 would benefit from greater balance - mental health conditions (which contribute to a significant proportion of long term conditions) include depression, anxiety disorders, psychosis and the significant consequence of suicide. A commitment to funding evidence based therapies would be useful on P39. This is currently done via Pharmac for medication, but there is no similar process for therapies. |

### Turning strategy into action

6 What sort of approaches do you think will best support the ongoing development of the Roadmap of Actions? Do you have ideas for tracking and reporting of progress?

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| It is good to measure outcomes, but remember that outcomes for the sector will probably differ from outcomes for the individual. It is necessary to balance what is good for the sector as a whole with what is good for individual clients, families and also clinicians. In the case of the former, service user experience measures (as mentioned on P40) will help us to know if health services are working for individuals. In the case of the latter, productivity is not what drives people to work in health - it's caring for others. If jobs are altered to reduce clinician satisfaction, services are unlikely to improve.Outcomes for Mental Health should aim to line up with outcomes for other sectors as they are mutually dependent, whether this is done in one step or stages. Sector outcomes that are at cross- purposes with those from different sectors are likely to lead to poorer intra-sector and cross-sector results.  |

### Any other matters

7 Are there any other comments you want to make as part of your submission?

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| Adequate capacity and continuity of ministry staff will also be necessary for the plans for today to come to fruition. Timely release of higher level plans will allow better alignment of workforce development and sector activities with government priorities. |

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| **83** | Submitter name | Kay Sloan |
| Submitter organisation |  |

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| --- | --- |
| This submission was completed by: *(name)* | Kay Sloan  |
| Address: *(street/box number)* | [redacted] |
|  *(town/city)* | [redacted] |
| Email: | [redacted] |
| Organisation (if applicable): | [redacted] |
| Position (if applicable): | [redacted] |

Are you submitting this *(tick one box only in this section)*:

[x]  as an individual or individuals (not on behalf of an organisation)

If you are an individual or individuals, the Ministry of Health will remove your personal details from your submission, and your name(s) will not be listed in the published summary of submissions, if you check the following box:

[ ]  I do not give permission for my personal details to be released.

(The above information will be taken into consideration if your submission is requested under the Official Information Act 1982.)

Please indicate which sector(s) your submission represents
*(you may tick more than one box in this section)*:

[ ]  Māori [ ]  Regulatory authority

[ ]  Pacific [ ]  Consumer

[ ]  Asian [ ]  District health board

[ ]  Education/training [ ]  Local government

[ ]  Service provider [ ]  Government

[ ]  Non-governmental organisation [ ]  Pharmacy professional association

[ ]  Primary health organisation [ ]  Other professional association

[ ]  Professional association

[ ]  Academic/research [ ]  Other *(please specify)*:

### Challenges and opportunities

1. Are there any additional or different challenges or opportunities that should be part of the background for the Strategy?

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| --- |
| Opportunities to review and free up the access to prescription medication. On one hand we want to allow people to better self manage and improve their health literacy for their health conditions and on the other hand are very restrictive on access to prescription medication.Solutions to free up some prescription medication to become over the counter pharmacy only and to review access to repeat prescribing for known diagnosed long term conditions.  |

### The future we want

The statement on page 8 of I. Future Direction seeks to capture the future we want for our health system:

So that **all** New Zealanders **live well, stay well, get well**, we will be **people-powered**, providing services **closer to home**, designed for **value and high performance**, and working as **one team** in a **smart system**.

2. Does the statement capture what you want from New Zealand’s health system? What would you change or suggest instead?

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|      Like the one team smart system as a goal for future direction  |

A set of eight principles is proposed to guide the New Zealand health system. These principles are listed on page 9 of I. Future Direction and page 31 of II. Roadmap of Actions.

3 Do you think that these are the right principles for the New Zealand health system? Will these be helpful to guide us to implement the Strategy?

|  |
| --- |
|      Good principles  |

### Five strategic themes

The Strategy proposes five strategic themes to focus action – people-powered, closer to home, value and high performance, one team and smart system (I. Future Direction, from page 10).

4 Do these five themes provide the right focus for action? Do the sections ‘What great might look like in 10 years’ provide enough clarity and stretch to guide us?

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|      Yes  |

### Roadmap of Actions

II. Roadmap of Actions has 20 areas for action over the next five years.

5 Are these the most important action areas to guide change in each strategic theme? Are there other actions that would be better at helping us reach our desired future?

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| As mentioned above the review to allow better access to prescription medication will support improved access, closer to home, and raising the level of health management to the people.  |

### Turning strategy into action

6 What sort of approaches do you think will best support the ongoing development of the Roadmap of Actions? Do you have ideas for tracking and reporting of progress?

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|      For the one team consideration to less DHB’s .  |

### Any other matters

7 Are there any other comments you want to make as part of your submission?

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| Good to review the Strategy.  |

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| **84** | Submitter name | [redacted] |
| Submitter organisation |  |

Update of the New Zealand Health Strategy

All New Zealanders live well, stay well, get well

Consultation draft

Submission form

**From Samantha Dalwood, Disability Advisor, Waitemata District Health Board**

### Challenges and opportunities

The Strategy reflects a range of challenges and opportunities that are relevant to New Zealand’s health system. Some of these are outlined in I. Future Direction on pages 5–7.

1. Are there any additional or different challenges or opportunities that should be part of the background for the Strategy?

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| * Technology is important enabler and is rightfully included in the document. However, it is important to note that while technology will make a difference for many people, there will always been a need for face-to-face relationships, particularly for people with learning disabilities.
* The challenge of delivering equitable outcomes across population groups is mentioned once in this section and yet does not translate well to key opportunities or to the roadmap of actions. Consideration of ‘all New Zealanders’ does not address this well as it is not explicit enough.
* There is a lack of data about disabled people in New Zealand. Sounds information needs to be available to ensure good decision making is made.
* I would like to see specific mention of disabled people as a population group. The health inequities of disabled people, particularly people with learning disabilities, are well researched and reduction of these should be reflected in the Health Strategy -

The Ministry of Health. 2011. *Health Indicators for New Zealanders with Intellectual Disability*.  <https://www.health.govt.nz/system/files/documents/publications/health-indicators-nzders-intellectual-disability.pdf> The Overall results section states that **“***For all indicators examined in this report, people with intellectual disability were more disadvantaged, in terms of their health and life expectancy, compared to people without intellectual disability. The group with intellectual disability experienced higher rates of specific health conditions, and they also used health services more (apart from preventive screening services). These results are consistent with those from similar overseas studies”*This is supported by the Ministry of Health. 2013. *Innovative Methods of Providing Health Services for People with Intellectual Disability: A review of the literature*.<https://www.health.govt.nz/system/files/documents/publications/innovative-methods-providing-health-services-for-people-with-intellectual-disability-dec13-v2.pdf> states “Recent reviews and studies show that people with intellectual disability often have worse health status than the general population. Their life expectancy is lower, and they are 2.5 times more likely to have health problems, including epilepsy, heart conditions, diabetes and morbid obesity.People with intellectual disability have higher rates of hospitalisation than the general population and similar rates of utilisation of primary care. However, the evidence suggests that they do not receive health services frequently enough, and that the quality of health services they do receive is often inadequate. In New Zealand, people with intellectual disability are four times more likely than people without intellectual disability to enter hospital with an avoidable condition. They also have lower screening rates than people without intellectual disability.”The Health Equity Assessment Tool specifically refers to people with disabilities as a group to be considered when looking at health inequity.<http://www.pha.org.nz/documents/health-equity-assessment-tool-guide1.pdf> “Inequalities to be considered include:•  ethnic•  gender•  socioeconomic•  geographical |

### The future we want

The statement on page 8 of I. Future Direction seeks to capture the future we want for our health system:

So that **all** New Zealanders **live well, stay well, get well**, we will be **people-powered**, providing services **closer to home**, designed for **value and high performance**, and working as **one team** in a **smart system**.

2. Does the statement capture what you want from New Zealand’s health system? What would you change or suggest instead?

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| There is a risk with the term “All New Zealanders” that it dilutes the issues of health inequity. I believe that it should be more explicit as to the population groups that we mean by this. I would like to see disabled people included as a group that are affected by health inequity and look at how this inequity can be addressed. |

A set of eight principles is proposed to guide the New Zealand health system. These principles are listed on page 9 of I. Future Direction and page 31 of II. Roadmap of Actions.

3 Do you think that these are the right principles for the New Zealand health system? Will these be helpful to guide us to implement the Strategy?

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| * These are good high level principles, but I want to reiterate that I believe that disabled people should be included as a specific equity group, particularly in principles 1, 2, 5 & 8
 |

### Five strategic themes

The Strategy proposes five strategic themes to focus action – people-powered, closer to home, value and high performance, one team and smart system (I. Future Direction, from page 10).

4 Do these five themes provide the right focus for action? Do the sections ‘What great might look like in 10 years’ provide enough clarity and stretch to guide us?

|  |
| --- |
| The five themes are acceptable.* **People-powered** addresses co-design, individual responsibility for health and health literacy, which are all important elements to consider. I would like to see disabled people included specifically in the area of co-design, particularly people with cognitive impairment. The term **People-powered** does risk sounding like ‘consultant speak’ rather than something like ‘Community-led’, which sounds more real.
* **Value and High Performance** There is opportunity here to include equity as a key health and wider system performance measure and to refocus funding to achieve this. Responsive services (culturally responsive and responsive to patient experience and to people with disabilities) could be a key performance measure in itself.
* **One Team** health navigators (a workforce that is not-well-defined) are becoming ‘the answer’ in many parts of the system. How we train, resource and utilise this new workforce, who are working with some of the most vulnerable and complex patients, still needs much more consideration. **Smart System** is again a technology heavy section. Technological solutions are an important element of focus, but must work together with the people side of health. Feedback from the disability sector is clear that, while technology is an answer, it is not THE answer to accessing quality healthcare and reducing health inequalities for disabled people.
 |

### Roadmap of Actions

II. Roadmap of Actions has 20 areas for action over the next five years.

5 Are these the most important action areas to guide change in each strategic theme? Are there other actions that would be better at helping us reach our desired future?

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| --- |
| **Commentary on some of the specific actions:**Action 1: Inform and involve peopleTechnology is important, but should be used with other face-to-face communication as well. It can be alienating for some population groups, ie. Rural populations with no broadband access.Action 2: People-led designPatient-led design is great, but would like to see more than three examples being showcased.Action 3: Shift servicesThis section appears to lack definition and concrete activity.Action 4: WorkforceStaff need to be trained to work with disabled people, particularly people with learning disabilities, in a more inclusive way. Action 6: A great startFor families who have a baby or young child with a disability, there need to be better support at the time of diagnosis. There is not a joined up system and it is hard for families to know what support is available and how to access support. There is no clear pathway for families and they are often given lots of information with little support to navigate the system. Action 12: Quality and Safetya. This action refers to rest homes and we note that this should be residential care. Quality in residential care is important area but the Roadmap action does not have enough clarity on this point. The Putting People First review findings need to be implemented to protect disabled people.Action 16: Build system leadership, talent and workforceWorkforce development needs to include a focus on empowering providers of care and the population (as noted above) and to enable inclusive approaches to addressing inequalities (including the range of disabilities). Health literacy, in its broadest sense (organisational literacy and patient literacy) is a useful mechanism to facilitate this development and the DHBs have health literacy approaches in progress to begin this work.Action 18: Strengthen national analytical capability People are increasingly able to interact with the health system online – this requires online functionalities to provide information to users in their preferred language with funding earmarked for ongoing support. English should not be the only language option available to individuals who wish to access information about the health system online. |

### Turning strategy into action

6 What sort of approaches do you think will best support the ongoing development of the Roadmap of Actions? Do you have ideas for tracking and reporting of progress?

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| From the Waitemata DHB submission – “There is a growing call for equity focussed health reporting. An approach that mandates equity focussed reporting will best support an ongoing focus on achieving health equity. Currently, service providers can reach health targets for ‘all New Zealanders’ while failing to reach the same target for Māori or other priority populations. For example a breast screening provider may ensure that 80.9% of New Zealand Europeans access a service, but only 61.5% of Māori, resulting in a total population result that nearly reaches the 70% target. There are a number of ways to require, provide and enable equity focussed reporting across the sector and we recommend leadership and investment in this area.” I would like to add that this is relevant to disabled people, particularly people with learning disabilities, who are less likely to engage in screening programmes that the mainstream population. The need for accurate data on disabled people is relevant to all tracking and reporting on outcomes. |

### Any other matters

7 Are there any other comments you want to make as part of your submission?

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|  Just to reiterate that the inequitable health outcomes of disabled people, particularly people with learning disabilities, should be part of work to address health inequities in the population. |

1. Clinical Advisor for Digital Innovation, Waitematā District Health Board, Auckland [↑](#footnote-ref-1)
2. Perioperative Physician, Auckland District Health Board, Auckland [↑](#footnote-ref-2)
3. At <http://www.health.govt.nz/about-ministry/what-we-do/new-zealand-health-strategy-update> [↑](#footnote-ref-3)
4. Reddy JI, Cooke PJ, van Schalkwyk JM, Hannam JA, Fitzharris P, Mitchell SJ. *Anaphylaxis is more common with rocuronium and succinylcholine than with atracurium.* Anesthesiology. 2015 Jan;122(1):39-45. [↑](#footnote-ref-4)
5. See for example this series in The Lancet. <http://www.thelancet.com/series/alcohol-and-global-health> [↑](#footnote-ref-5)
6. There’s an evolutionary component here—unsuccessful advertisers simply go out of business. [↑](#footnote-ref-6)
7. This assertion will be disputed by the Salt Institute, EuSalt and their acolytes, just as happened with the Tobacco Institute fifty years ago. [↑](#footnote-ref-7)
8. See <http://www.stats.govt.nz/browse_for_stats/snapshots-of-nz/nz-social-indicators/Home/Health/hazardous-drinking.aspx> [↑](#footnote-ref-8)
9. See [Cochrane Review 2008, CD000165](http://www.ncbi.nlm.nih.gov/pubmed/18425860). Many hours of counselling may work slightly better. [↑](#footnote-ref-9)
10. Deming WE. [Out of the crisis](https://mitpress.mit.edu/books/out-crisis). [↑](#footnote-ref-10)
11. There is no “security in obscurity”. [↑](#footnote-ref-11)
12. Report of the WISH Mental Health and Wellbeing in Children Forum 2015, Healthy Young Minds. Transforming the Mental Health of Children. [↑](#footnote-ref-12)