

What does a health research embedded New Zealand health system look like?

Responses from NZHR's stakeholder survey as at 10/11/21

New Zealanders for Health Research is developing a “compelling case” for embedding health research into the reformed health system, and describing what that will look like. It will be based on NZHR's [submission](#) to the Health Transition Unit (HTU), will include a specifically Te Ao Māori lens, and be informed by the results of our stakeholder survey.

The survey remains open at <https://www.surveymonkey.com/r/NZHR2021> for anybody else who wishes to contribute, with many thanks to the eleven who have already done so - very much appreciated and a rich source of additional important perspectives.

About half of the respondents identified themselves as health and medical researchers, with the remainder comprising a mix of patient/consumer representatives, health research funders/investors and a policy advisor.

The survey asked stakeholders to rate the importance of twelve randomly presented elements of NZHR's HTU submission, all of which were thought to be either very important or somewhat important by a majority of responses. Presented in rated order of importance these elements are:

1. clinical research specialists such as research fellows and nurse researchers are routinely members of clinical teams to ensure services are provided in accordance with best contemporary evidence
2. people find it easy to participate in a clinical trial of a new therapy/intervention if they have a condition it might be able to treat
3. health care providers have the administrative and staffing capacity to enable them to operate as clinical trial sites for third party funded research projects
4. clinical training agencies are mandated to ensure that their processes require emerging and current clinicians to practice according to best evidence based standards of care
5. clinicians routinely engage with, and are expected and incentivised, to participate in health and clinical research which is being undertaken in the health care settings in which they work
6. there are research and evidence based clinical standards and/or guidelines for health service delivery which health service providers should be contractually required to adhere to
7. entities that profit from lifestyle choices which, based on the results of health research, are demonstrably associated with poor health outcomes are regulated to mitigate and minimise the health risks associated with their products and services

8. the health system has a dedicated unit which ensures that, and monitors the extent to which, health research is at the heart of policy making and service commissioning decisions
9. accountability for dedicated government investment in health research (eg for the Health Research Council, health related national science challenges, recently announced new funding for infectious disease research) is located within the health system itself (rather than MBIE etc)
10. health care organisations are contractually funded and mandated to undertake and require clinician participation in health and medical research in their facilities
11. clinical training agencies are mandated to ensure that their processes require emerging and current clinicians to undertake research at a level which could translate into criteria for professional development and/or CME points
12. there are tailored national, community and family/whanau level evidenced based advertising, marketing and advocacy/support campaigns to encourage healthy and discourage unhealthy lifestyles

Respondents' verbatim comments in response to being asked to identify the top three things that would be different if health research was embedded as an essential component of New Zealand's reformed health and disability system included:

- Firstly, without research into population health, its gaps and needs, the whole exercise will fail. Particularly the role of clinician researchers on the and in the system and whatever reforms they introduce will need implementation - without implementation scientists among others who will do the work? And finally, what will evaluation evidence look like if its not built in as the metrics from the get go? And a fourth would be consumers - how are consumers and patients views being incorporated in the co design?
- Reduced burden on future health care costs 2. Improved quality of life for Kiwi's living with a medical condition 3. Increased awareness of the importance of research alongside care (prevention and cure)
- Iterative, evidence-based improvements to health services and the standard of care; 2) increased attraction and retention of expert clinical and research staff due to job satisfaction and opportunities; 3) greater access to scientific innovations which improve care, including new diagnostic tools, medicinal products, and devices.
- By itself the embedding of health research into the health system would change little I fear, and some current research issues even risk getting worse (see point 3 below). A number of more foundational aspects of health research would need to be addressed at the same time to create meaningful change. Having said that, it may be easier to address these as part of a major reform than within the current system. Three important issues are: 1) Everyone conducting research must be a competent researcher with a thorough understanding of scientific methodology. This shouldn't even need stating but currently a significant number of both academic scientists and clinician researchers are lacking this competence

and understanding to an alarming degree. Addressing this requires significant investment in education as well as in mentoring young (clinician) researchers. 2) Expert patients must be involved in all aspects of research, including in deciding what gets funded, how trials are designed and what outcome measures are used. Currently patients either simply function as guinea pigs or, if their input is sought, this is done on a superficial level and amounts to little more than the research version of green-washing. Addressing this requires a completely new pathway to first identify suitable expert patients, i.e. patients with personal lived experience, connections to the wider patient community as well as at least a good basic understanding of the scientific method, and to then enable them to provide meaningful input as they may have financial barriers as well as practical ones due to their condition. 3) Oversight, accountability and transparency must be improved and are essential to reduce research waste. Encouraging more clinicians to undertake research - a good thing in principle - carries the risk of more clinicians attempting to prove their pet theories by running underpowered trials of the research version of GIGO: garbage in - garbage run through garbage methodology - garbage out. So-called evidence-based medicine - another good thing in principle - is already far too often based on just such poor "research". The replication crisis didn't come out of nowhere. Nor did the term eminence-based medicine.

- Robust monitoring and evaluation of current health practice - to inform effective and economic better practice. Research that addresses key health issues insitu for New Zealanders conducted by NZ researchers. Supporting capacity building and capability of Maori health researchers.
- Research that relates to New Zealand in particular helps us to be more efficient and effective in the way we prevent diagnose and treat conditions such as Coeliac Disease.
- consistency, improved equity, balance
- Improved linkage between clinicians at all levels (not just medical doctors) and researchers. 2. Faster implementation of research into practice. 3. Allow for the development of a research culture embedded within the health system rather than tacked onto the edges.
- More up to date health care. 2. Stronger evidence-based health care. 3. Greater economic returns to NZ through intellectual property development.
- 1 We would be more proactive in our prioritisation of issues which may impact us in the future, so for areas like dementia, we would be placing more emphasis on proven ways to make changes early to delay, defer, or avoid dementia onset
2. we would educate people better, using facts
3. we would better prepare our staffing
- Improved engagement of clinicians in medical research More clinical trials More research focused on New Zealand patients

In response to being asked to list any additional important features of a New Zealand health system distinguished by health research as an embedded and essential component respondents said:

- Investment in research aligned to the projected future burden of disease from a group of conditions (heart, cancer, neurology etc)
- The funding for health research is backed by a "pathway to impact" process whereby the system commits to implement any product or service which is demonstrated to be efficacious and cost-effective - rather than endless pilot studies which are never translated into practice.
- I'd like to repeat the necessity of embedding expert patients - as active participants at all levels - into any health research, no matter where that research itself is embedded. There must be a mechanism that ensures clinician researchers don't concentrate just on the common diseases in prestigious fields such as cancer or Alzheimer's while rare and/or controversial conditions miss out. Again. There must be cooperation between clinician researchers. This applies to cross-disciplinary cooperation across seniority to avoid silo- and eminence-based thinking. It also applies to cooperation between different locations to ensure large enough patient cohorts to achieve good statistical power. Fewer but much better trials should be the goal.
- Research enables evidence based best practice across all components of healthcare. It is really important the theory informs practice but equally important that practice informs theory - research needs to be an integral component of healthcare
- community/whole of system commitment
- collaborative working across research and clinical institutions. An emphasis on patient and public participation in research agenda setting.
- There is a career structure for professional health researchers
- Communities need to be able to see themselves in research and evidence not be represented by studies done in Europe and other countries with different lifestyles, peoples and environments.