

Appendix E World café findings

As part of the project a World Café-style workshop was held (via teleconference due to COVID-19), providing important insights from a wide range of stakeholders on what the ideal clinical trials infrastructure for Aotearoa New Zealand looks like, and what should come from this unique opportunity in the health sector. The findings from this World Café workshop, alongside previously gathered current-state material, were used to refine and develop options for the Delphi survey presented to key stakeholders.

Purpose and effectiveness of World Café workshop

A World Café workshop is a facilitator-led discussion, usually conducted in person for the purpose of socialisation of ideas, consensus building, and gauging key stakeholder interests and opinions. The aim of the workshop is to create an environment that fosters and develops conversation and allows group members to build on previous discussions to eventually reach some detailed conclusions or consensus. The facilitator plays a key, active role in pushing attendees to socialise and develop ideas. Essentially, attendees are placed into groups and given strict timelines to discuss and build some sort of consensus on the topics provided. Once the time is up, the groups move around tables to discuss other topics until all groups have been to all tables.

The workshop started with an introduction and a karakia to welcome everyone and set the scene of the day. A presentation was also given on the current state findings from our survey, interviews, registry data analysis, and international best practice literature review for further context. The day was then broken down into three broad activities:

1. A 25-minute discussion in four larger groups of the value of research in healthcare. As with any significant investment, it is important to understand the value of the outcomes (both quantitatively and qualitatively) to justify the decision and provide investment motivation. Attendees of the workshop were asked to discuss the value of research for health outcomes, for healthcare systems, for Māori and Pacific specifically, and for a resilient healthcare workforce.
2. Eight rounds of discussion in smaller groups, where attendees had 12-15 minutes to discuss each of the workstream topics that are components of the overall project workstreams. The topics for discussion were collaboration, consumer engagement, data systems and technology, equity, data governance and use, prioritisation, knowledge translation and implementation, workforce capability, and clinical trials infrastructure and activity.
3. A 30-minute discussion about clinical trials infrastructure, designed to build on the discussions had throughout the day. Attendees were asked to reflect on what had been discussed and developed in previous sessions to then provide an idea of what future clinical trials infrastructure may look like, and what options this project may recommend to the Ministry of Health when considering health infrastructure investment. There were three main categories for consideration:
 - What does the minimum-viable product look like (i.e. what is absolutely essential in any investment decision, given limited resources)?

- What does the gold standard clinical trials infrastructure look like (i.e. if resources were not constrained)?
- What does an optimal solution look like (i.e. somewhere in between that covers all necessities but has some extras too)?

What was produced is a rich set of information to be used in conjunction with current-state findings to inform the Delphi survey, presenting options to key stakeholders for further refinement and detail.

Why is research so important in healthcare?

As heard throughout the current state analysis, research does not generally garner the support or backing it requires in a healthcare context. Research in healthcare is often seen as a 'pie in the sky', or nice-to-have activity, especially in the public health sector where resources are consistently constrained. Part of any successful development of options must address the need for research to be embedded into healthcare and to be accepted as an important and necessary function of both care and systems. There is a range of literature that aims to explore the benefit of healthcare research (and clinical research and trials more specifically) quantitatively, however wider considerations are also required.

Below explores the key themes of attendee responses across the four domains of value discussed:

- Workforce resilience
- Health outcomes
- Healthcare systems
- Māori and Pacific.

Healthcare workforce resilience relies upon research

International evidence indicates that healthcare institutions engaging in research attract quality staff and deliver better outcomes. Clinical research is a rewarding part of being a medical professional. It demonstrates to patients that knowledge and care are advancing. Clinical trials drive innovation and improve patient care, now and into the future. Without the workforce, we cannot run clinical trials. Within the government, research needs to be a priority. Health New Zealand needs to support and grow the workforce. Key Performance Indicators (KPIs) are needed around growing and supporting the clinical trial workforce.

New Zealanders want to know that our health care system is innovative. The country needs to be at the forefront to drive change rather than being a late follower. Clinical trials allow patients to take new medicines and be part of the latest technologies and techniques for clinical care. Without them, patients may wait years before new practices get adopted.

We need to fund researchers continuously to create better outcomes. The lack of paid time to conduct clinical trial research is the biggest issue the workforce faces. The periodic nature of clinical trials creates workforce instability. Currently, there is a limited trained workforce in New Zealand. While many professionals might be interested in participating in health research, they don't have the time or support to undertake research. Becoming a PI requires a lengthy period of supervised training and

support with post-fellowship opportunities. With a national infrastructure, people could connect and work more efficiently.

New Zealand- specific problems exist that require investigation, including health care interventions to improve the health of Māori and Pacific populations. We urgently need to address the lack of Māori and Pacific researchers. We cannot solely rely on international clinical trial data to bring that advancement. We need to keep and grow this knowledge within New Zealand. It is vital that we attract and retain talent.

If I look at myself, all the research that I am involved in is in my own time. There's no time built into my week to deal with being the PI for the multiple trials that I am trying to run. So, if I do that work during the day, that means I come home and do my clinical admin work at home. In terms of resilience, that gets pretty tiring after a while, especially if you are looking after the wards and getting slammed there. The research jobs that are meant to be critical, like signing off adverse event forms get shelved...at a point you get to this level of being burnt out and starting [to think] 'I need to pull out of these things'. That's not part of your job, that's gonna be the first thing to go. That's why NZ will lose key researchers just because it's not built into our job.

Research contributes to better health outcomes

Clinical trials provide access to drugs, devices, and treatments that are otherwise not available on the market. Clinical trials remain a source of treatment and hope relied upon by many New Zealanders. Infrastructure that enables research will make trials more accessible and even out inequities. Sufficient infrastructure will mean that people typically neglected by healthcare will have better health outcomes (i.e. Māori, Pacific, people living rurally).

Clinical trials contribute to standard of care in many areas of health care. A high level of standard of care means Aotearoa New Zealand would be better placed to receive further treatments and trials as well. It would enable clinical trials to become more routine in terms of administration and process. There is huge cost saving potential and Aotearoa New Zealand would become a well-oiled machine with standardised services etc.

New Zealand is hamstrung around innovation – if we are unable to test important interventions with clinical trials in Aotearoa New Zealand, there will be no innovation. Infrastructure is necessary for capitalising on Aotearoa New Zealand's ability and strength to innovate – huge innovation values currently foregone.

Health providers involved in research have better outcomes than those who do not (even if the patients don't necessarily become better off because of trials). Exposure to change and questioning current practice (status quo) is extremely important. Aotearoa New Zealand needs to be able to test things within our country-specific context to see that it works for New Zealanders – cost saving in the long-run.

Healthcare systems rely upon research to be effective and efficient

During this value proposition exercise at the World Café forum, attendees were asked to express why there is value in research for healthcare systems and how they function. Below summarises the main findings.

Continuity of service and level of care are dependent on research (and clinical trials). If the status quo is not being regularly tested and updated to best practice, there may be potential benefits foregone – particularly for patients and consumers who are getting less than optimal, or potentially even damaging, care.

Unless you have funding [for research], one can't have continuity.

There is currently variation in the care and support clinicians are administering to patients and consumers. This variation is potentially harmful, inefficient, and diminishes the continuity of service. Research helps to inform best practice and standardise procedure and interventions.

Variation in current support around the country.

Greater quality of research, and reassurance in processes used in research.

Overall, research increases the general level of care.

To bring up a general level of care.

Research is also critical to extend care and support to domains of healthcare previously unsupported (i.e. novel diseases, treatments new to Aotearoa, etc.). Research allows for development of infrastructure to embed this care and support and make previously unsupported domains of healthcare supported.

Areas that are impossible to get support right now but are important.

Research also attracts interest from health professionals and strengthens not only the quality of care, but also the quality, depth, and breadth of the workforce as an integral part of the healthcare system in Aotearoa.

Competing edge with other countries to be able to attract the health professionals.

Health research infrastructure plays a key role in achieving better outcomes for Māori and Pacific

The question of how health research impacts Māori and Pacific was answered with a slightly different slant, focusing on what a clinical trials infrastructure would enable. Effectively, a system that is designed to have research embedded within healthcare will support Māori and Pacific peoples' participation and achieve equity in outcomes for both patients and researchers.

Creating a learning healthcare infrastructure with a sound cultural foundation (culturally safe and competent) will ultimately place value on Māori and Pacific research and promote equitable outcomes

and opportunities. This includes designing an ethics process that includes cultural frameworks and ensure a specialised ethics committee can provide support for Māori and Pacific research methods.

It will also provide a more comprehensive, coordinated approach that is aligned with the Māori Health Authority and other organisations, reducing duplication and allowing for leveraging of existing relationships to promote greater Māori and Pacific capacity and capability. This is a unique opportunity to build on current strategic momentum and use the Wai2575 principles to build infrastructure that has Māori at the forefront of objectives.

New clinical trials infrastructure may also include ring-fenced funding streams for Māori and Pacific workforce development to increase support (e.g. scholarships for Māori and Pacific research students) for underrepresented groups to study for key occupations (e.g. health economics) and encouraging career development for the likes of nurses. Ensuring funding and its criteria are set in ways that support engagement of Māori participants and stakeholders (e.g. funding/time to meet) is also important; hard funding is better than soft as Māori are likely to leave if 1–3-year contracts.

This in turn may increase the number of Māori and Pacific researchers and increase the interest in physician scientists as a career choice and will help to decrease the burden on the small number of cultural experts. Health is competing with other sectors for the researchers (e.g. environment,) therefore it needs to be made easier to do research in the health sector.

The value of health research and subsequent investment in clinical trials infrastructure is also realised in improving reach of communication to communities and working with communities, ensuring Tangata whenua input and more of a cultural lens across everything to learn and grow from each other. The approach is more of a collective view for meaningful involvement. Focus should also be on improving the cultural capability of the existing workforce, introducing a 'competency passport' for working with Māori, whānau etc.

Discussion of topics

The below summarises the discussion among each of the eight topic areas, covering three main points:

- What are the issues?
- What are some potential remedies?
- What might the enabling infrastructure look like?

Collaboration

What are the issues?

Many are unaware of what opportunities and trials are out there, making it harder to reach out to people with similar interests.

Apart from publicly available information it is really hard to find other research summaries from NGOs and other groups.

Even if aware, people find it hard to collaborate because of a lack of confidence and/or experience with clinical trials.

There are lots of people who don't have confidence/experience.

The lack of confidence and/or experience is also present for Indigenous researchers and likely acts as a strong barrier to involvement in clinical trials.

Indigenous – only two engaged in the trials, and I am one of them. Clinicians have no idea how to engage in clinical trials. Have very little expertise in how to undertake a trial – a major disjuncture.

The way current funding and HRC grants work promotes competition for a small pot of funds (i.e. disincentivising collaboration).

Competitive funding arrangements.

What are some potential remedies?

Firstly, there needs to be greater visibility of the clinical trials happening in Aotearoa New Zealand. Being able to see what is going on likely lowers the barriers to collaboration and involvement for researchers.

Really need to have a clear understanding what the clinical landscape is.

There must be some form of channel to facilitate collaboration between those who do not have confidence and/or experience with clinical trials and those that do (e.g. mentorship programme).

Needs collaboration with people who do have confidence/knowledge.

Networks of researchers may make it easier for those without confidence and/or experience to be involved and collaborate.

Need a network of researchers.

Part of this requires a leadership structure that encompasses the wide range of perspectives and priorities different groups have and promotes the involvement of those less experienced and pushes for members to collaborate.

Collaboration needs leadership; needs understanding of perspectives, managing priorities, cooperative spirit, mutual respect. Listening and taking responsibility are important skills.

We realized very quickly in the UK that we could have fantastic capacity, but it takes 365 [days] to get approved – so need to build up the capacity in clinical trial governance – need to get a hold on it and run faster.

You need leadership, indigenous network, the person who leads this already has a 2.0 FTE job, want to bring people together, what methods work well – about like indigenous trials initiative – a black tick, where there are methodological or methodologists, who can work the right way and are endorsed – that is a two-to-three-year window.

Collaboration must also work outside of just researcher-to-researcher relationships. This means there needs to be early collaboration opportunities for others too, such as consumers, nurses, pharmacists, participating sites etc. so that everyone is well engaged. Greater engagement with all stakeholders will ensure more meaningful research.

Requires having end-users involved in research from the beginning.

Needs all the participants to be engaged, have it as a priority – that needs prior engagement process, it won't just happen in places that don't do research all the time.

The "what" is an important issue. The one really strong piece of ammunition is the Māori and non-Māori consumer to lead this. There is a strategy around changing the culture. What is the model.

Leverage what is there – you must bring in consumers and trainers.

Have to start with outreach and engagement and understanding priorities, and what might be a shared plan to go forward.

Part of this greater engagement with all stakeholders relies on funding for involvement of groups typically not funded. Many stakeholders currently make great sacrifices to be involved in research which likely acts as a barrier to involvement.

Funding end-users to be involved in the research. Funding has special challenges for people who already have a day job – that doesn't fit the usual funding models.

You have to support the individual sites to have recovery of costs. To support the sites. Not just clinical trial staff, it is also about putting staff in to support trial initiation. Need the fundamental investment in the platforms, will always have clinical trials to recruit, or staff. That is a real problem.

Articulates our problem in Canada as well – we need to invest in the infrastructure, but we need people to bridge that first and foremost.

There is an active framework [for Indigenous research], and not enough [currently] to do it, so have to invest.

A change in funding structure that rewards collaboration may improve the level of collaboration and engagement.

incentivise for collaboration [within funding].

A focus on pragmatic trials (as well as novel studies) may also increase collaboration and provide an entry point for researchers wanting to partake in clinical trials.

How to build some relevant for a health system for the future – e.g. medical devices, wearable, etc. Pragmatic trials. Medical device trials. Not just pharmaceutical trials.

There may be a unique opportunity for clinical trials – touched on pragmatic trials – integrate health system trial infrastructure.

What might success-enabling infrastructure look like?

Some form of national visibility of trials and priorities that are embedded in healthcare may make it easier to collaborate. This top-down approach could be fed to lower-level researchers through key opinion leaders.

National infrastructure good to avoid personal agendas, get a say for smaller groups, repository of skills.

You get key opinion leaders in the hospitals and then go to management – it is the way to do it to recruit and retain, there are different tactics to take.

This may take the form of a repository or open registry that tracks and reports frequently on the clinical trials activity in Aotearoa New Zealand.

What is the best mechanism try to understand who is doing what? Is it possible to have a repository or open registry as it is a research good. E.g. avoid duplication, raise awareness to facilitate collaboration, for academics, researchers, consumers and people-led.

It could also be done through localised clinical trial management systems that would show and record the research happening within a certain proximity and allow for stakeholders to interact with the centre.

About concrete objectives – we would embed a clinical trial management system in all centres – did not have the power to mandate, but now with a plan with clear objectives and a budget. Start with the building blocks that you have or need.

Need methodological centres (not many, don't replicate to run in more units, need areas where there is critical mass of therapeutic knowledge.

Utilise current platforms e.g. Edge trial at University of Auckland platform for people to add their research.

Development of a strategy/plan that outlines the health objectives and goals of research may help to increase visibility of activity and collaboration. This would require a detailed roadmap so that it is presented in palatable, achievable steps.

Still need the long-term vision, as well as the short-term plan. People will buy into the vision but need to break it down into achievable steps. Need to put down what those steps are – what the road plan is – could be in the discussion phase in many more months. Need the plan and how to achieve the vision. Need to start narrowing down on what you can do.

If we could have that plan for two years and five years. That is both deliverable and needed and we will be successful.

Consumer engagement

What are the problems?

Overall, consumers are not being engaged well or valued throughout the clinical trial process.

Culture is critical, how do we normalise research into consumers' expectations of high-quality clinical care?

Culture is important: need to expect that consumers will always be involved. Expectations from e.g. high-prestige journals helps normalise this, national leadership would also help.

Culture to value consumers.

Culture is really important – you need to make sure consumer input is genuinely valued and that they know this. (perhaps especially for underserved/minority groups?)

From a consumer rep perspective, there needs to be a culture change where consumers feel valued, heard, and included. Lay descriptions are essential to understanding.

There is cloudiness about who the 'consumer' is in a clinical trial which may confound involvement and leave a lot of people in the dark even when they are directly affected by, or engaged with, clinical trials.

We need a clarity of who consumer is – not always the user but should be part of the system regardless.

Carers as the consumer, particularly in Pacific communities.

Challenge is all the different things consumer can mean – what is consumer is? Public face of consumers – lobbyists and activists.

This cloudiness can lead to misrepresentation of all consumer groups and their interests when being engaged by researchers.

Consider the make-up of the consumer groups, is it representative? Is there equity within the group?

There are power imbalances between researchers and consumers (patients, whānau, carers, etc.) and stigmas that can make it difficult for consumers' voices to be heard, or for consumers to speak up.

Power imbalance that can exist in meetings between professional researchers and healthcare consumers needs to be addressed.

Sometimes consumers will be reluctant to share lived experience because of stigma/shame associated with symptoms of condition; so, managing stigma is tremendously important.

Researchers may also not know where to find consumers, or how to engage with them appropriately and effectively.

The challenge is where do we go to find consumers.

What are the remedies?

There must be provision of clear, palatable, easy-to-understand information about the nature of clinical trials and treatments, the importance of clinical trials as a means of improving health outcomes, and the current trials landscape so consumers are able to see how they fit into it.

Make the research visible – for those not directly involved in it.

Highlight how research has driven/directed/influences changes in the care they/their whānau are receiving.

Media involvement/careful communication to the public.

Diversity in nature/style/medium of the communication.

Good connections needed with patient groups/representatives to ensure information flow – needs education and promotion.

Information flow – what the opportunities are. Hard for potential patients to know what the opportunities are.

Patient education and exposure to clinical trials through regular and well-advertised institutional science fairs and easy access websites like clinicaltrials.gov.

The consumers may need training to ensure they have an understanding of research.

Lay descriptions are essential to understanding.

Funding and resource to share information with consumers – specific attention for resourcing.

Provide training and support to equalise the knowledge/interaction skills.

Patients need to be exposed to health research from the outset. Even if patient is not going to be in the trial. Within waiting rooms, posters, etc. Look to the UK to see how health research is marketed towards consumers.

Promote health research as a public service/public good. Similar to donating blood. Public engagement needs to be driven at many levels, including national.

Look at how technologies can be used to widen scope for enrolment of participants. (Telehealth) Crossing geographical boundaries. Other ways of collecting data remotely.

Training and guidance for researchers to be able to communicate effectively, comfortably, and safely with consumers.

Educate our clinicians/investigators as to patient 'consumer' need and requirement for involvement.

Engagement expectations, e.g. whole community or someone with different lens/expertise.

Must bring in researchers so they can understand how consumer work and how they engage.

Talk at a level that people can understand and be empowered.

Better understanding of the consumers' sacrifices to be involved with clinical trials. This may mean funding their time or having more explicit and guaranteed incentives.

How do we recognise consumers and value their time and what they may be sacrificing to participate, i.e. paid work?

To engage consumers – there is a need for funding and resource for research.

Some explicit, mandated requirement or mechanism for greater consumer representation in strategy, funding, and priority setting, as well as trial design and focus.

Consumer representation and involvement in strategy/prioritisation setting.

Consumer involvement in e.g. funding review.

Ensure that representation is not just token representation – need the actual genuine consumer voice (not the “tame” voice!) – make sure that it is not a tick box exercise.

“Co-design” methodologies: used more in digital health technologies – it takes longer and takes more people, but you get better results both in higher quality and also in more effective translation at the end of the research. Needs to be done from the start.

Consumer voice is needed to find out what consumers actually want – not just what doctors think they want. Telehealth as an example: effort of in-person visits might be better [co-design is a way to help with this].

Patient voice is important in respect of local decisions as to which studies may be prioritised.

Engagement with consumers prior to submitting proposal for funding.

Broadening involvement – non-expert have specialties that can add value.

Consumer role – participant of the research and influencer of the research – dual role.

Really important to have input from consumer groups that have connection with patient groups - also to ensure appropriate connection into wider patient group network: aim of transparency and community communication.

Ownership sense with research gained for healthcare consumers by bringing in their voice e.g. of VUW mental health research group.

Genuine seat at the table for consumers – able to contribute fully to meetings/discourse (i.e. not limited to responses only).

Open, transparent, and well-connected – balance and credibility for the consumers sitting at the table.

Talking to people about what outcomes are valued to support study outcomes, meaningful engagement – depends on nature of research/study.

Part of this might be about conducting research on how to properly engage with consumers in ways that are meaningful, appropriate, and convenient.

Wider population-based research on how to get engagement – community leadership, GP's etc.

Almost absorbing the “customer is always right” mentality into healthcare consumers experience - and research as another important service to provide the “customer” – make it inviting and supportive.

What might the enabling infrastructure look like?

Some form of a consumer council or centralised group that can act on behalf of consumers and defend their interests, as well as help consumers to integrate into all phases of clinical trials (from design through to dissemination).

A consumer council – central group then by locality/topic interest.

Value of having an overarching group with networks into communities.

National consumer group – know what is going on with research and clinical trials, they have knowledge and expertise and a passion for this type of work.

Website that has good visibility over range of trials happening in Aotearoa NZ, and the option for consumers to search for relevant studies, plus useful resources.

Possibility for consumer facing website/resource that allow consumers search for studies relevant to them.

Data systems and technology

What are the issues?

Firstly, there are currently multiple data systems, platforms, and technologies in place that are not linked or connected. This means not only inefficiencies and lack of interoperability, but also lost opportunities when data is gathered for one purpose and cannot be reused for another. This variation is compounded when looking across regions and DHBs with considerable differences in the supporting data infrastructure available to researchers.

There are also inconsistencies between the systems used in Aotearoa New Zealand and overseas. International studies require the use of their own platforms which are generally not like those used here. As a result, training is required to be able to use each platform.

International trials also create issues around privacy and access to data sets, and specifically data sovereignty issues with Māori data. International trials usually require the data to be stored overseas, which can forfeit Māori control over their own data. Privacy and data access issues are also present at a national level, especially when considering how data is stored currently (often in spreadsheets on unsecured laptops).

The quality of data in Aotearoa New Zealand is variable because of inconsistencies in approaches to capturing, managing, storing, and manipulating data. Part of this is likely due to a lack of national access to systems and support, although this issue is likely higher-level and more significant. When people can access national resources such as registries, it is hard to get a hold of the data required and is generally resource intensive.

What can be done to address the issues and what would this look like?

Firstly, a technology and governance strategy should be developed around the gathering of data and how it can be used and integrated. This would then create consistency nationally so that all regions have access to the same level of data infrastructure at two levels: technology and expertise.

Secondly, there needs to be a change to the mandate of technology at a systems level (e.g. REDCap) to ensure systems are available across the country so everyone has access to similar capability as well as a standardised form of procedure that can be taught and streamlined. Above this there should be infrastructure that sits across the regions that can be used to connect and share trial data and settings to promote richer findings.

Thirdly, there needs to be more expertise. For example, a pooled resource of statisticians, database managers, etc. available as needed would enable better trials and provide necessary capacity and guidance for researchers.

Equity

What are the issues?

Equity issues identified at the World Café reflected what we heard in the interviews and survey. Below is a high-level summary of issues identified.

- Current funding does not allow for relationship building and co-design of trials (i.e. funding only available after trial approval).
- We currently invest only in pākehā research methodologies.
- The Māori and Pacific researcher workforce is small and very stretched.
- Māori and Pacific and other populations are not always involved in decision-making
- There is not research career pathway including for Māori and Pacific students
- International trials pose problems for informed consent and control of ethnicity data.
- Information is not always understandable or translated.
- Highly exclusive criteria for participation impacts those with co-morbidities
- Ethnicity data doesn't enable correct ethnicity identification for clinical trials
- Top-down prioritisation doesn't always hit the mark for what communities want and need.
- Expertise is not valued or recognised.

What can be done to address the issues and what this would look like?

The importance of a top-down leadership approach was identified as being a critical starting point. Māori and Pacific must be represented at the governance and leadership level to ensure Vision Mātauranga is embedded in the system and that the value of Kaupapa Māori and Pacific research methodologies is understood and promoted.

A Treaty-based science structure needs to be at the foundation of any new infrastructure. The first important step is to develop a clear high-level vision that embeds Vision Mātauranga and describes what participation looks like at all levels from governance down through the whole system.

Following this is the need to describe the processes required for achieving the vision.

Important aspects that will be key to success are:

- getting the tone and language right
- balancing an overarching prioritisation view with the priorities driven by Māori, Pacific and other high need communities (e.g. migrants and rural communities).

- Enabling a more distributed and inclusive research structure throughout the health sector.

Relationship building with and input from communities and iwi across multiple levels will encourage community advocacy and a holistic approach when determining what is important and how best to engage and enable participation. Layers at which to build relationship include:

- Governance
- Policy: Māori Health Authority and Health New Zealand
- Institutions/networks
- Researcher

Attendees agreed that to improve equity the research structure needs to be less centred around tertiary and secondary care. There needs to be incentives for general practices to become involved in research, particularly to enable participation from rural areas. This will require a funding system that is set up to allow all health care providers to do research, the UK system is an example of how this can work.

In addition, research that is co-designed, driven by Kaupapa Māori and Pacific methodologies and uses understandable language will promote inclusion and participation for all and enable more equitable outcomes. This will require inclusion of Māori and Pacific and other less represented groups early in the development process.

A centralised clinical trial participant recruitment system was considered as an option to support more equitable recruitment as there would be more visibility. Another aspect to enable participation from less represented groups is to ensure that entry criteria are more inclusive. Currently criteria are often highly selective meaning that populations with more co-morbidities are excluded.

Improving NHI ethnicity data and including iwi data as well as extending NHIs to realm countries was raised as a way of enabling correct ethnicity identification in clinical trials and participation from people moving between New Zealand and realm countries.

The funding system needs to adequately support the importance of relationship building, co-design of research with communities (including with whānau) to achieve more equitable participation and reciprocity of findings back to the community.

There was a suggestion to fund people from a diverse range of settings rather than research projects. This will help to overcome the current issues with soft funding that inhibits relationship building and inclusion from the outset of research.

Many attendees agreed that there needs to be more support and resources available to support the very small and stretched current Māori and Pacific researcher workforce.

A centralised support and resource mechanism was suggested to act as a central knowledge pool. This could include the establishment of cultural coordinator roles and the idea of researchers working in cohorts rather than as individuals therefore sharing the load more evenly.

Increased use of technology such as telehealth and teletrials could be used more frequently to both support workforce and increase participation in rural areas.

A number of attendees noted that enabling and promoting research as a career options needed to start in schools and follow through to university across multiple fields. The following were suggested as ways to encourage Māori and Pacific students to undertake a research-focused pathway.

- Increase the number of schoolteachers with the capability to teach science in Te Reo.
- Included more research in training across all fields (e.g. medicine, nursing, allied health) to make it visible and model the use of Māori and Pacific research methods and frameworks to students at school and university levels. If people see themselves in research that will encourage participation.
- Listen to Māori and Pacific students to find out what will help to bring them to undertake a career in research.
- Make research a career option rather than an add on.
- Universities to include an aspirational objective in their five-year plan to build research particularly for Māori and Pacific students.

Formally recognise role of education by Māori and partner with Māori research groups to develop the workforce.

The International Federation of Pharmaceutical Manufacturers & Associations, of which Medicines New Zealand is a member, is currently embarking on an equity initiative for clinical trials. This may mean there is an appetite for considering equity issues internationally.

New Zealand could use this appetite as an opportunity to create a national level (to give mana to create change) cultural researcher/coordinator role to work at an international to begin to educate international industry sponsors about New Zealand's Māori and Pacific populations needs including the need to retain local control of ethnicity data for international trials and other aspects of equitable trial opportunities.

Data governance and use

What are the issues?

The primary issue raised concerns the culturally appropriate use, sharing, and storage of data, particularly from Māori patients.

Tension between sponsor/pharma driven trials and NZ governance of data/data sovereignty.

National collaboration/infrastructure may affect consent: data goes out of local control?
Some data really is international data: international trials, some registries – needs consent, but also needs participants to be allowed to consent to offshore data use.

[Sovereignty] issues of sending NZ data offshore.

People (researchers and patients) are unaware of where to find guidance for governance and culturally appropriate use and storage of data.

People want to do the right thing, but don't always know where to go. Gaps between ethics and local governance. HDEC doesn't review out-of-scope, but not everyone has

access to a local institutional ethics committee. Governance is often seen as a barrier rather than an enabler. Nationally is there a solution to bridge this gap?

Does there need to more public education around clinical trials. Data is like a donation (like donating blood).

Long term governance and storage of data, dissolved team, funding ended – who will be around to curate that data at the end?

Issues are also arising as artificial intelligence (AI) and its use with health data becomes more common.

There's some education [around AI use in data] but needs to be more generally available/focused.

Machine learning/AI. The needs strong clinical governance, which is not yet well developed.

There appears to be a lack of consistent approaches to how to govern the use and storage of data.

Privacy. Do researchers use a consistent approach, is this transparent (which will improve participant/consumer confidence), and what is the role of governance in privacy aspects?

A lack of willingness to share data can cause inefficiencies in research.

Need to ensure data is available so knowledge can be extracted from it – don't want to have to repeat research when data already exists.

Some researchers are resistant to data sharing.

There are misconceptions around data ownership and sovereignty and the nature of the exchange of data when taking part in a clinical trial.

Data is a gift (taonga) rather than a commodity that participants sell to the investigators, re: data 'ownership'.

Intersection of data sovereignty and equity is important: artificial intelligence tends to be used in ways that worsen discrimination.

How can these be addressed?

Many suggested there needs to be new easy-to-follow governance guidance to inform some standards for patients and researchers on culturally appropriate use, sharing, and storage of data throughout the trial process. This would include data security.

It would be helpful, using both the clinical governance (with a focus on Māori data sovereignty) and IT governance 'lenses' but this may need to be balanced against regional/iwi autonomy and accessibility to (clinical) data. There is a need for a transparent, consistent approach to governance.

Ethics committees need to make sure clear data information is included in the research project and applications e.g. data management, data storage, data usage plans.

In PIS everyone needs to include data information clauses for participants.

National governance set of standards what do we need to enable users to abide/use the data.

National conversation as a community of what is acceptable use of data.

Need a general/community conversation around what level of data sharing is appropriate, and what accountabilities should be implemented if individuals breach rules.

Governance - 'rules' need to be practical and implementable.

Principles of data governance would be a useful good step - need to look at best practice overseas to then see how it can fit in Aotearoa.

Principles of data for patients e.g. Code of Rights. Set of statements framed positively.

How is information relayed to consumer - need a structure and approach that is communicated to participants.

Documents should be in plain English and understandable.

The guidance needs to be actionable and hold some sort of power to ensure researchers are accountable for their actions when using, sharing, and storing data.

Combining provision of infrastructure with embedding of governance requirements.

Need enforcement of plans – lots of people have plans, but how do we make sure these are actually implemented (cf. the US dbGaP setup for genetic studies)?

This may mean that the guidance is accompanied by legislation to ensure it has power in forcing compliance and creating accountability.

Place for legislation to ensure data is protected? Auditing, sponsors responsibility as part of M&E of project, NHA maybe the sponsor?

Funding may be required to ensure that any guidance reflects best practice and it can be met effectively by those using, sharing, or storing data.

Funding supporting best practice.

Proper funding to enable compliance with these standards.

Consistency of data usage, sharing, and storage practices across primary, secondary, and tertiary care is required to fully capture the benefits of sharing data (and the subsequent value of being able to re-use data).

Need a co-ordinated (top-down) approach so everyone is using the same approaches.

Advocating for REDCap or another standardised secure system.

All health providers utilising same health information platform.

Training and education opportunities were suggested to make sure patients and researchers are competent and educated around the culturally safe use, sharing, and storage of data.

NZ specific training module on how to comply and be competent in this field (like GCP).

The nature of data exchange during clinical trials needs to be reframed. This may also feed into the education of researchers and patients.

Reframing. Participating in trials is not giving up something, with no involvement of participant into the future.

Need to take into account Te Tiriti and understanding what data is and who owns data. Māori can provide us with insight into governance and the data is donated to us as researchers as a gift and is one of the most important things our Māori colleagues can help us with.

There needs to be standards set for data sovereignty and the use, sharing, and storage of Māori data specifically. Iwi would be most appropriate parties to lead the creation of these standards.

Iwi leadership forum will set standards for all of New Zealand.

At clinical trials level need more investment in data sovereignty issues. Sponsor-driven trials 'require' participants to sign away their rights to their data. Increasing focus on tissue and data not leaving NZ (UoA/UoO), and governorship of that data/tissue.

National guidance about how to honour Māori data sovereignty - a practical guide. Documents should be in plain English and understandable.

Centralisation of data storage was suggested to ensure appropriate access and maximisation of value drawn from data (and re-use of data). This idea, however, may have its drawbacks when considering how to manage risks and data breaches. Further discussion about how to control this risk would be necessary.

Trial registries in line with ICJME requirements are strongly encouraging data sharing e.g. as part of registration researchers are required to state upfront what the data sharing conditions for their study will be.

Treasure of knowledge, should all the data go to Health NZ? Do we need a national data repository specifically for clinical trials? How do we interface routinely gathered data and clinical trial data?

Central repository - issue if breached, how do you manage security?

- Risk benefit trade off
- Store identifiable/unidentifiable data separately
- Potential standardised hub
- Individual PI does not own the data

- Separating out the infrastructure from collecting data to storing data
- Same architecture being used nationally

Knowledge translation and implementation

What are the issues?

The ability to translate research findings into practice is heavily contingent on the underlying research culture, particularly in organisations that do not see research as a core part of their service delivery.

Often there will be physicians in therapeutic areas that butt heads with [DHB] managers who have little interest in doing anything novel. Will cost more, will take away from other resources.

Times when the different workforces cannot get off the shop floor to go and be with that person. Until we address underlying research culture, the priority must be that we are equipped to get people to be able to get away from BAU. Capacity, capability, time recognition.

There is a distinct lack of a translational research funding pool, structure, or methodology in Aotearoa that makes it near impossible to systematically translate research findings into clinical care.

We do not have a translational research funding pool, structure or even agreed methodology...

The lack of a systematic translation approach can be seen clearly when regional DHBs use different types of interventions. This is likely because they do not know otherwise and have a poor perception of best practice. Variation in intervention usage ultimately has consequences for patients' outcomes when they are not being provided the best treatment available.

Different DHBs using different interventions etc. – translation is not equal across regions.

Best practice is not disseminated well to healthcare workers or patients, which limits implementability of findings and slows down the translation process.

People need safety of local peer evaluation and evidence for effective implementation. Lots of time goes by before are willing and comfortable to be able to put it into practice (2-3 years sometimes). Finding positive studies, yet people still not wanting to take the information on.

If clinicians are finding it hard to convey knowledge, it flows down; others find it hard to interpret. If we cannot do it between people working in health, never going to get it to consumers in a way that is useful to them.

The Health Research Council do currently require some reflection on how research will be translated in research proposal requirements, however this may not be sufficient to enact translation.

HRC does require reflections about the translational potential for something currently.

You need to have your eye on how it is going to be implemented, how it will be disseminated, and [how] people will be made aware.

Specific funding for translational science is a missing link that prevents research findings from being easily translated into practice.

Not just about trialists, the missing function being important, recognised, and being funded.

Translation grants are necessary drivers for translation. Otherwise, it will not be done ad-hoc.

Can do trial, get great improvements, but cannot continue afterward [for translation].

What can be done to address the issues?

Multiple attendees suggested the need for a dedicated funding stream (i.e. fenced off) for knowledge translation to ensure it is not forgotten about, a rarely performed activity, or traded-off against other trial components in budget bids.

Government funded grants that are well-established and fit for purpose... Clinical and impact focused. Re-focus people to be involved in translation of findings. Strong purpose for translation. Different strands of funding streams where you can better meet criteria.

Separation of funding for clinical trials from other [health] research. Poorest research is generally in underpowered studies and where there are the smallest pots of money. Makes them even less translatable and implementable.

The Australian Department of Health translational funding system was raised as a strong reference point of what successfully props up translation research and implementation of findings.

Need to look at Australian Department of Health commissioning rapid applied clinical research and translation. Funding of \$60m per round. Research co-designed between communities, hospitals, researchers, etc. Interventional in nature, broad applicability, and can be rapidly implemented as the findings emerged. Action research at clinical trials level. Underpinned by good translational methodology. Don't have any approach to that at the moment in New Zealand. Need co-design and co-creation in New Zealand. Often in indigenous communities, deliver powerful results that are embedded. Fits into both research and health funding streams - not one single one. Principles worth looking at.

Others said existing funding streams and contract arrangements must incorporate new contingencies or clauses that allow for funding allocations for translation once a trial has been successful.

Some funding mechanism to extend funding once deliverable met and show the change - support to implement it and put into practice nationally. Should be condition of funding that translation is part of play. Some sort of framework and methodology to take things forward, even if just contextualised in NZ jurisdictions. From there, can take further. Something the funding bodies are not currently thinking about.

Potential to translate must be part of the funding agreement - why do it otherwise? Should be ascertained and agreed to at the outset.

Policy changes and mandated requirements could improve the uptake of translational research and implantation of findings into care.

Design research that is implementable to start with. Have to co-design that is important to the end user in the first place.

Some sort of key performance indicators required to support innovation and translation. Huge opportunities lost through conservatism and thinking it is outside of your prerogative.

Can we refresh/reinvigorate the NZ health research strategy? This needs implementing in the new health system structures.

Maybe not make it as voluntary as it was last time - mandating and requiring the standards to be met as part of commissioning and purchasing requirements. Currently some sort of random trickle-down to implement published international research findings, no systematic approach.

Informing clinicians about what they should be doing but need some power behind it to implement (cannot just give recommendations).

Specific, well-defined workforce and career development opportunities, plus permanent roles in translational research and implementation of findings into care are required. It was also noted this needs to be at a local, low level (preferably at point of care).

Must be people that can implement change – PDSA cycle, where are the bodies on the floor to make those changes?

Implementing in practice is something you do locally. Yes, agree nationally in terms of priorities etc. but you do it locally.

An attendee gave an example of a successful, dedicated role for implementation of findings into care, with rich career development potential.

Career opportunities, not just in medicine. In other workforce areas too. Where you provide opportunities for training – some of that in clinical translation. Before COVID we had a colleague come to NZ to do training in translation models. Partially funded by [UK] equivalent of a DHB. Their job was to take the research and be the hands and minds to work to implement some of that which was necessary. For that individual, was a career opportunity. Got training, advancement, working at the top of their scope. Recognising career structures and opportunities for staff.

There needs to be workforce (that are not necessarily the investigators of the research) to be able to disseminate ideas, findings, and best practice among researchers and patients.

Trialists are not necessarily the ones who should be selling the ideas to people and disseminating. Need scientific communicators to market it to people. Otherwise, people are resistant to change. Understanding of psychology of change management and the way to get things into layman's terms.

Publishing things in journals and guidelines is not what drives practice change. 1-on-1 interactions with clinicians at the bedside to discuss with them the emerging evidence and understanding their point of view is important. To change practice, need to not just tell, but listen as well.

What would enabling infrastructure look like?

Attendees generally agreed there should be a body/network/model within the public health system tasked with enabling knowledge translation and implementation of findings in Aotearoa. It should take what has worked well in different contexts and adapt it to our national environment. The body/network/model needs enough power to be able to mandate knowledge translation and implementation and force compliance in research.

Critical function of the new health authority. [Current changes] position us well to do so.

Need a link to government through policy and purchasing practice.

Any clinical guidelines group would have to be big - need a lot of expertise. Would want a sub-committee group to review data and build on guidelines. Would need buy-in from primary, secondary, and tertiary care, and respect for the decisions and guidelines put in place. A guideline group itself that doesn't have enough expertise or linkage might just be rejected by those on the ground.

Some compared the potential body/network/model to an 'umbrella network', built to leverage existing local, regional, and national networks in different areas of healthcare. It could act as a connecting node to provide translational and implementation support and guidance. It would also allow for interconnectedness between local, regional, and national networks.

Talked about national networks etc. that already exist – wonder if it is a little more about embedding those a bit more deliberately into our health service so that it is necessarily more integrated with IT.

Could leverage existing networks in a more deliberate manner.

Connect regional networks to become more of a national network. For some, there are existing national networks. Small country; need to make the most of that.

In Canterbury, luck with health pathways with community and hospital. Moving to national health service is that it would be a model across the country. Rigorous, but the way we go forward. Nomination of specialists to lead processes and then feed back into networks. Should be national, will be challenges but sure we can do it.

The National Institute for Health and Care Excellence (NICE) in the UK was referenced as a good concept, but the system in its current state would not be suitable for Aotearoa's healthcare environment.

Posit some version of a NICE organisation in NZ (secondary research function, potentially an option) – depends on ensuring there is adequate engagement with relevant communities in designing the research and picked up at the end of the process.

Need to be careful that what is being translated into health care has been peer-reviewed by the wider field. The processes around knowledge translation must be robust. Benefits must be realised without the risks. Might need an intermediate step between implementation and translation – trial to see how things work in practical terms. Have to be careful not to add research onto research.

We need some sort of NICE application to be able to put things into practice – generating the practice. Would help us to identify gaps.

Difference between NZ and UK – in UK have NICE and even broader have NHS. Directors from NICE gather evidence, EDIC giving indication to the way we should be doing things. Synthesis of evidence and evidence-led care. Don't have that, far more ad-hoc between DHBs etc.

Would have to balance with PHARMAC somehow. Cannot take NICE exactly; need to take learnings and have a separate body.

Wonder if it needs to be connected within the health system, rather than NICE-type separate health system. NZ NICE would be a big thing to do. More about the function of NICE and fitting it into our HNZ system, rather than an organisation like NICE.

NICE doing great job but interested to know how it influences the way health systems develop in terms of structure, purchasing, policy. Might be a missing link.

NICE effectively:

- Provide evidence-based guidance and accessible advice for health, public health, and social care practitioners.
- Develop quality standards and performance metrics for those providing and commissioning health, public health, and social care services.
- Provide a range of information services for commissioners, practitioners, and managers across health and social care.

The former New Zealand Guidelines Group (NZGG) was also referenced throughout discussion. NZGG did not come without its own problems, however.

The guidelines group was poorly funded and not involved on the ground.

Guidelines group run out of BPAC. Fallen away somewhat – poorly funded.

Attendees suggested that any form of successful translation system requires great buy-in from IT departments and clinicians as well. Consistent data formats and systems, as well as interoperable platforms (i.e. easily accessible and interconnected between primary, secondary, and tertiary care settings) would enable translation of research much easier by lowering the barriers to information sharing and treatment integration in to day-to-day organisational operation.

Getting buy-in from IT is important from a primary care setting. E.g. PMS services – if there is something trying to embed in GP, becomes easy to do and part of BAU so it isn't hard to access particular advice, tools, etc. If you find that it is a good process that needs to be embedded, then needs to be easily implemented. Takes investment and power. Need IT suppliers to make this possible. Also, data systems etc. to be consistent.

Embedding those a bit more deliberately into our health service so that it is necessarily more integrated with IT.

The role of the body/network/model would potentially capture all the issues (and remedies) above, with functions such as:

- The power to write and influence policy regarding translation requirements and key performance indicators for translation of research and findings into practice.
- Provision of virtual and hard resource to guide and facilitate translation and implementation of research into care.
- Explicit roles for translation facilitators that work with researchers and practitioners to match needs and convert research findings into practice.
- Potentially have some mandate for funding to ensure translation is not traded-off against other trial aspects, forgotten about, or poorly done.

Prioritisation

What are the issues?

- Prioritisation is needed both within and across fields of research
- Combining prioritisation with trial development can help in producing good research proposals and protocols that have community support.
- Rural research needs large-scale national participation, and that needs some sort of prioritisation of 'little voices' -- prioritisation needs to go broader than DHBs.
- Health delivery research may need localised prioritisation.
- Need to balance prioritisation of research with impact against blue skies research: don't want to squeeze out innovation
- Very important that prioritisation processes are transparent
- Australian collaborations are often driven by Australian priorities where NZ will join or include a patient population.
- Benefits - prioritisation gives direction
 - Mitigates current situation with prioritisation guided by default by (overseas) industry
 - Enhances a NZ voice (clarity in larger groups)
 - Efficiency
 - Room for quality improvement activities

What can be done to address them, and what does it look like?

- Does the new single health agency have a role as commissioner of research?
- Build upon the role of networks prioritising within their individual fields (though they need some resource for this)
- Involve consumers more systematically in prioritisation, ensuring that they can provide an informed voice.
- Involve front line clinicians and participants at a local level. Prioritisation among end users helps with translation. If not reasonably aligned to researchers'/clinicians' interests, prioritisation may not work.

Clinical trials infrastructure and activity

What can be done to address the issues and what this would look like?

Central coordination of trial activity allows prioritisation of research, and the ability to conduct larger and better designed trials that deliver impactful more meaningful outcomes. This picture contrasts with the current state with a number of smaller fragmented trials that don't always deliver meaningful results.

Networks will need as standard practice to include all key stakeholders including connections with patient groups. Patients can be advocates for research to bring it to the attention of politicians and policy makers. Funding is needed for under-resourced networks. There is an opportunity to build new therapy/technology specific networks with knowledge sharing at a central contact point.

The workforce is a key element of infrastructure and networks. Steps we can take include:

Establishing research nurse positions. Not funded to undertake research.

Having research added into job descriptions - grandparenting clause in contracts. Research then seen as an important element of career path.

Research activity and quality set as a KPI for health institutions - to address the tension between care delivery and research; monitor and measure.

Developing a culture of independent evaluation of healthcare systems as an important aspect of research to drive clinical care improvement

There is a need to embed research at a high level in the health system, with research leadership from the top level. This is needed to ensure that in the new Health NZ and Māori Health Authority there is a culture of inquisitiveness and shared aim for quality improvement in care. This means that research is a key part of a national clinical structure. Improvement is needed in research governance, and in implementing national standards where there are resource constraints. HealthNZ may provide a more unified approach.

As well as leadership, there is a need for a cultural shift within the clinical community, so that research is embraced as part of a patient clinical journey. The provision of ring-fenced, dedicated time would ensure consistent capacity for research. Adequate staffing is therefore key.

Private and Public sector collaboration enables research through increased capacity and capability in delivery of research protocols for all stakeholders, resulting in a win, win.

Education could provide more incentive to explore a research career path. This will need working with colleges and professional bodies, as well as academic institutions.

What sort of national infrastructure will best support conduct of best practice clinical trials across the country?

We should aim for resources in terms of best practice that we can all agree on: eg. a repository of documents, one place where people can go for advice on ethics, biostatistical work and advice on research design. This will require infrastructure – a knowledge repository of information and access to expertise that you may not otherwise be able to access locally or within your work group. This infrastructure has physical and human properties, with core central activities and dispersed site activities. IT platforms in primary care could support recruitment.

Having options and opportunities for people within the service will be key - this will only work if the new structure sees research as a key part of what we do in the health service, and that this flows into opportunities for career advancement. Sustainable (non-project specific) support for clinical academics to become established (senior clinical research fellows) would provide a better career path than a series of precarious short-term positions.

Infrastructure will have to have connection to consumers: communication and meaningful engagement with the consumer is key.

The governance of such an entity is important. It will have to be accessible and connected to all. There will need to be a representative governance structure that connects with a wide range of stakeholders.

Discussion of infrastructure options

This section serves as a summary of the discussions surrounding the infrastructure options, where attendees were asked to consider minimum viable product, best-case, and optimal scenarios.

Many suggested the infrastructure should sit within the remit of Health New Zealand and the Māori Health Authority that are currently being formed to ensure Te Tiriti is fully embodied in how the infrastructure is utilised to reduce inequities in clinical trials.

Situated within health service – refer people and ask them to be part of trials. Data also integrated into the health service. Integrity of electronic health record; global system with linkages of data types.

Health New Zealand and Māori Health Authority remit perhaps; embedding and procurement aspects.

Māori led, crown funded, operational.

Look at Māori Health Authority – drop down into partnership domains.

Strong views on Maototanga Titanga views.

Health NZ include research funding.

Māori Health Authority as a commissioning agency.

Re-embed that it is part of research provision – operations as business as usual.

Commissioning approach – needs to be commissioned same as providers, Te Tiriti and equity focused.

Purpose driven by Te Tiriti.

Recognition of practice within Māori Health Authority.

Embedded across the health system at all levels.

Many also suggested that the infrastructure should look like a hub and spoke, which suggests some form of centralised resource that can be accessed from anywhere that leverages existing connections and networks. It may mean some sort of hub for guidance, support, etc. and then extension of that to local and regional node points.

Connection to rural urban centres – tap into health providers to engage with communities.

Somewhere between centres of excellence and network model (trial coordinating centre?) – needs to sit to support existing centres, and then also uplift the ones that are currently left out. Organisation bridging and linking groups and activities. Hub-and-spoke type design.

Strong linkage with local providers.

Funding researchers not projects – funding coordinators at remote/rural sites to aid inclusion.

Moderated system to collate ideas, encourage collaboration, network – researchers, communities. Virtual networks.

Increase provincial/rural/remote community engagement – tele-trial technology, funded researchers based in those sites, access to researcher education.

Promoting health research to consumers/embedding research in clinical settings.

Support for researchers to attend to patients (paperwork, ethics, trial support).

Further, the focus must be on the provision of localised resources, or resources that are easily accessible in rural and otherwise not well-connected locations. This is particularly important for technical expertise such as statistics, health economics, and data management.

DHB resource - dedicated at the institution and where you recruit patients.

Local level support in developing ideas and facilitating support throughout trial - protocol writing, conduct, engagement, etc. Resource to get the trial up and running and moving forward.

Moderated forum where people can talk about ideas and grow them. Somewhere to go to get expertise, direction where to find.

Local resource to create local, regional, and then national expertise. Need people to be able to access.

Access to resources that are scarce in particular locations (pools of resources – stats/questionnaire design/database design).

Research design services.

Investment in and connection to rural localities etc. (virtual networks and people on ground).

Some suggested the development of a long-term strategy or statement to ensure research and clinical trials are a mandated key part of health care.

Need to understand barriers to attract workforce – long term strategy.

Clear statement of research being an integral part of health care.

A national governance group may help to organise this strategy and ensure accountability and successful follow-through of research objectives.

National trials leadership governance group.

National sponsorship body.

National CT leadership governance group.

One system that all have access to but governance of IT infrastructure for research is important and better use of existing data sets eg NMDS.

One of the most apparent needs is for guidance that is rigorously tested, reviewed, updated, and disseminated in an appropriate, efficient, and effective way. This may come in the form of something that takes lessons/positives from the National Institute for Health and Care Excellence.

National standards for data governance.

Clarity around data sovereignty/governance – integrated into the design of IT systems.

Integrated data sharing requirements.

Data management system – minimum standards, training, access to nationally collected clinical data.

Guidelines (writing) versus translation into practice (meaningful engagement).

Awareness of the advantages/disadvantages of NICE – focus on the advantages of the structure/system and how we can leverage them not using the term “NICE” like.

“federating” systems that throw threads to a higher layer rather than a big structure dropping threads down?

Best practice guidelines and Standards of Service Provision were helpful for patients as well as clinicians. These are to be replaced by QPIs within the health system, removing useful tools for information transfer.

National standards for data standards and minimum standards for systems used.

There must be some mechanism for training pathways created for clinical researchers or people wanting to get into clinical trials.

Training pathway for clinical researchers. Need to consider where it sits.

Needs training, education, and support roles of good quality to be able to get researchers to conduct successful research. Work with tertiary providers etc.

Training system that teaches people how to do research.

Ongoing/updated research – national modules including data sovereignty, ethical considerations, current issues keep evolving.

Levels of education – if going to do a research project, needs to be supported, but not necessarily aim to be a full-time researcher.

Assistance from 'beginner/training wheels' to successful/independent research.

Education, training, and career pathways (vocational pathway) in research (including consumer involvement in research teams and lead research); assistance through the spectrum of experience.

Networks for learning and capacity.

There must be career pathways for existing clinical researchers to be involved in clinical trials.

Career pathways for academics and clinicians (research staff etc.).

Provide continuity of employment and career development within clinical research. Developing and keeping expertise engaged in CTs. Managing workforce across research groups – floating resources that could be shared. Sense of collaboration – national approach that *isn't* competing for funding etc.

Active protection – Māori researcher – grow workforce.

Career development opportunities/training pathway for people working in health research.

vocational training – like in the vocational medical training programme/Post-grad certification/online self-certification.

Research could be a vocational pathway. Not just an add-on to another vocation.

A standardised trial management system may be important to ensure interoperability, promote network benefits, and allow for support resources to be universal and well applied. This may take the form of a product already on the market such as REDCap, EDGE, or could be bespoke and take lessons learned from existing platforms.

Trial management system – a piece of software for management of clinical trials available to everyone e.g. EDGE clinical trial management system and organisations of trials. not redcap that is a data collection.

Ready access for REDCap (or databases generally), with support to go along with it.

Trials management system available to everyone – would work for trials and other forms of research.

There must be some sort of mandated requirement for research (i.e. KPIs to ensure accountability for research activity, or lack of).

Research as a KPI in the new system – accountability, cannot be non-essential.

Providing a link/advocating for research within different areas of action to ensure the environment is good for conducting research in NZ. Agency with responsibility for ensuring the strengths and successes of current research activity – empowered and can advocate appropriately when legislation, budget, privacy changes etc. are made.

Platform to publicise trials that consumers may wish to participate in.

Mechanisms for sharing research findings – centralised, embedded in research plan, consumer involvement.

A consumer council and greater consumer interface into trials to allow more autonomy over the research conducted, as well as a better relationship between researchers and patients to lower barriers.

Consumer council.

Ability to interact directly with consumers too, interface for discussion.

Resource for community engagement (time, money).

The patient/consumer: ensuring they have reliable/accessible information to facilitate translation from a 'bottom-up' perspective.

Some way to accommodate and facilitate interorganisational relationships within the health sector, private/commercial organisations, and with iwi.

Relationship building with other entities – PHARMAC SOC for example.

Linkages to, and collaboration around, translation; capacity to influence this. One of the career pathways that clinicians take. Network to have connections with private sector, tech incubator programmes etc. to invest into putting research into practice.

Facilitation of relationships and matching – getting researchers to be able to engage with other networks, communities, labs, technical support, iwi, etc. Register of knowledge and expertise.

Connections to Māori/iwi/whanau; patient groups/representatives/patients – lived experience.

Many suggested new funding streams specifically for clinical trials and all that they encompass. This would likely run parallel to existing health and research funding.

Include own funding.

Ring fenced funding.

Do away with annual competitive grant applications/funding.

Funding/rewarding collaboration versus competition.

Funding model that rewards collaborations and inclusiveness (not competition).

Funding to support core [data] operations.

Increased access to data and shareability. This could take the form of some central registry or repository, but also is necessarily wider and relates to shared platforms and standards of use and reporting to make data easily accessible and usable.

Data – access.

NMDS/NHI data exists – leverage this appropriately, expansion of systematic data collection, e.g. QOL, Wellbeing.

NZ providers of databases for trials exist, they could be leveraged to provide this skill set nationally.

Mechanisms for sharing research findings.