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# Developing a national primary care research network: a qualitative study of stakeholder views

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### ABSTRACT

Introduction. Primary care research is critical to address Aotearoa New Zealand's (NZ) health sector challenges. These include health inequities, workforce issues and the need for evaluation of health system changes. Internationally, primary care data are routinely collected and used to understand these issues by primary care research and surveillance networks (PCRN). NZ currently has no such infrastructure. Aim. To explore health sector stakeholders' views on the utility of, and critical elements needed for, a national PCRN in NZ. Methods. Twenty semi-structured interviews and a focus group were conducted with key stakeholders, representing different perspectives within the health sector, including Hauora Māori providers. Data were analysed thematically. Results. Six themes were identified that included both challenges within current primary care research and ideas for a future network. The themes were: disconnection between research, practice and policy; desire for better infrastructure; improving health equity for Maori and other groups who experience inequity; responding to the research needs of communities; reciprocity between research and practice; and the need for data to allow evidence-informed decision-making. Improving health equity for Māori was identified as a critical function for a national PCRN. Discussion. Stakeholders identified challenges in conducting primary care research and translating research into practice and policy in NZ. Stakeholders from across the health sector supported a national PCRN and identified what its function should be and how it could operate. These views were used to develop a set of recommendations to guide the development of a national PCRN.

**Keywords:** New Zealand, practice-based research network, PBRN, PCRN, primary care, primary care research network, qualitative research, stakeholder views.

# Introduction

The Aotearoa New Zealand (NZ) health system is undergoing a significant restructure as of 1 July 2022.<sup>1</sup> For these changes to achieve equitable health for all New Zealanders, there needs to be an adequate understanding of population health needs at both a national and local level. Due to the critical role of general practitioners and other primary healthcare providers as the first point-of-care for patients, primary care research should be integral for supporting innovation and monitoring population health.<sup>2</sup> Moreover, primary care research can provide valuable insight into health inequities, workforce issues, and health system delivery.<sup>3,4</sup> In many other countries, such data are routinely collected through established primary care research and surveillance networks (PCRNs).<sup>5,6</sup> Surveillance networks rely largely on passive collection of routinely collected data to monitor specific health conditions;<sup>7</sup> research networks are used to conduct specific research projects including intervention studies, randomised control trials, or other non-routine-data projects.<sup>3</sup> Research and surveillance networks collect some level of routine data, but can also conduct more specified projects.<sup>5</sup> These networks provide a view into the function of primary care as a critical component of population health, as well as enhanced understanding of disease epidemiology and exploration of potential community-based interventions.<sup>7,8</sup> Although the exact structure of such networks varies depending on the country

### WHAT GAP THIS FILLS

What is already known: Internationally, primary care/ practice-based research networks play a critical role in primary care research and can be used to monitor and evaluate healthcare delivery, interventions, and population health needs. Currently, we have no such network in New Zealand. What this study adds: This study describes the views of stakeholders from different levels of the health system on what a national primary care research network should look like in New Zealand, and how it should function.

and the healthcare system in question,<sup>9</sup> these networks all provide data on patient interactions in primary care that can be used for health monitoring and specific health research.<sup>10</sup>

Several regional PCRNs have existed in NZ in the past, but have dissolved due to funding constraints.<sup>2</sup> The Institute for Environmental Science and Research (ESR) oversees a national primary care surveillance system for monitoring certain illnesses, such as influenza-like illness, contracted through a private sentinel practice network for primary care monitoring.<sup>11</sup> In addition to providing data to the ESR, this network provides data to participating general practices and some health organisations, but not in an easily visible connected way.<sup>12</sup> There are also some emerging regional research collaboratives;<sup>13</sup> however, there is no infrastructure for connecting these networks in order to investigate questions of national importance.

The recent Health and Disability System Review specifies the need for NZ to prioritise a national primary care dataset to provide an upward flow of information to inform research, policy and service development.<sup>1</sup> An accessible national research network could achieve these goals. The aim of the present study was to explore the views of health sector stakeholders on the utility of, and critical elements needed for, a national PCRN.

# **Methods**

### Design, study setting and sampling

Semi-structured interviews were conducted between April and October 2021 with participants from across the health system. Purposive sampling was used to select a nationally distributed group of participants, including those in rural and urban settings, and from Hauora Māori and mainstream healthcare services. Interview invitations were sent to contacts from the following categories: practising clinicians, clinical or managerial leaders from the Royal New Zealand College of General Practitioners (RNZCGP) and Primary Health Organisations (PHO), and primary care researchers and government officials from the Ministry of Health (MoH), the Health and Disability Review Transition Unit (TU), and the Health Research Council (HRC). Several participants were members of more than one category (eg practising clinician and holding a PHO leadership position).

In addition, a focus group was held at the annual RNZCGP Conference (GP21), which included participants from pharmacy, academic departments of general practice/primary health care, rural health providers, and front-line general practitioners.

### **Data collection**

An interview topic guide was developed from a literature review of PCRNs and reviewed by all the authors. Questions focussed on Infrastructure and Governance, Equity, Practitioner Involvement, Research Support, Data Management and Funding (Supplementary File S1). Semi-structured interviews were conducted via video call by AP. Additional questions were asked of Māori stakeholders about an independent, but linked, Māori research network versus an integrated structure, as well as how data sovereignty might be considered. Interviews were recorded and transcribed using Zoom auto-transcription; at the completion of the interview, AP took notes, listened to the recording, and checked the accuracy of the transcript. The interviewer generated a summary of each interview.

The focus group was a conference workshop; attendees broke into small groups with each group allocated one topic from the interview guide to discuss, before presenting back to the larger group. One member of the research team took notes for each small group, and another member transcribed a summary of the larger group discussion.

### Data analysis

A framework-guided rapid thematic analysis against the topic guide was conducted by AP, CA and TS.<sup>14</sup> A standard template was developed (by AP, CA, TS), which was used to categorise data from interview summaries according to each topic in the interview. Focus group notes were categorised similarly. Interview recordings, summaries and templates were reviewed by at least two team members. CA, AP and TS met twice to review interview summaries and identify and ensure agreement on recurrent themes. Further discussions to refine themes and develop recommendations were undertaken with all the authors. The consolidated criteria for reporting qualitative research (COREQ<sup>15</sup>) were used to inform reporting of the study findings (Supplementary File S2).

Ethics approval was obtained from the University of Otago Human Ethics Committee (D21/138).

### Results

### **Participants**

Interviewed participants included five practising clinicians and practice managers, seven representatives from the

Location	n
North Island	
Rural	3
Urban	11
South Island	
Rural	2
Urban	4
Sex	
Male	12
Female	8
Ethnicity	
NZ European/European	13
Māori	5
Pacific	L
Other	I

Table I.Participant demographics.

RNZCGP and PHOs, five government officials from the MoH, TU and HRC, and three public health physicians, primary care academic general practitioners and general practitioners in training. There were 22 participants in the focus group from pharmacy, academic departments of general practice/ primary health care, rural health providers, and frontline general practitioners (Table 1).

# Themes

We identified six themes that included both challenges within current primary care research and ideas for a future network. The themes were: disconnection, desire for better infrastructure, improving health equity for Māori and other groups who experience inequity, responding to the needs of communities, reciprocity between research and practice, and the need for data to allow evidence-informed decision-making.

For the additional views around structure from Māori stakeholders, views were evenly split; however, stakeholders emphasised that whether separate or combined, the non-Māori network still needed to meet Te Tiriti obligations. Expert advice was identified as critical when considering Māori Data sovereignty.

# Disconnection

Disconnection was a recurrent theme, both in how participants described the current state of primary care data, and in how they described the relationship between research and clinical practice. Primary care data exist in several disconnected datasets, with little cohesive information available for research or for evidence-informed policy decision-making. The lack of a co-ordinated approach to primary care data leads to lost opportunities for research. The system is awash with data, but in primary care that data is sequestered within PHOs... good quality data is not visible to the Ministry... (P1)

Research was viewed as disconnected from the problems faced by working clinicians, and those in practice had limited time and opportunity to engage with research.

...the people down doing the work who can see what is going on don't have the opportunity and the time to think about it and do it and be curious – curiosity time should be valued! (P2)

# Desire for better infrastructure

Participants indicated a desire for improved primary care research infrastructure. Some participants felt that although a minimum data set is needed, this function should be overseen by the health system, while the network focussed on recruiting practices for specific projects. Others favoured an independent research network that also managed a national primary care data set.

I believe there should be a primary care data warehouse, but that that should sit with the Māori Health Authority and Health NZ, that of course researchers can access... the government should have that so that it can monitor the impacts of what it's purchasing. (P3)

Participants from the MoH indicated that work on embedding research and data collection into the system via a national health data platform was underway; however, it was unclear when this would be operational, and to what extent it would be available for independent research.

All participants indicated that a network should be government funded, because primary care health research should be embedded within the system, and a research network would be beneficial to the sector. Suggested funders included the MoH; the Ministry of Business, Innovation and Employment; Health NZ and the Māori Health Authority; or via the Health Research Council.

It's sad that we don't already have this, because it should be part of our health system, we should be self-auditing what we do and how it works. That should come from Health. And whether that's permanent funding by Health Research Council, or the Ministry of Health or Health NZ. It should come through that government agency. I believe it will if we are able to get this off the ground and it will be so important for our country. (P4)

# Improving health equity for Māori and groups who experience inequity

Participants wanted Māori partnership at every level of the network and representation across minority groups. Moreover, improving equity in health research and the health system generally was identified by most participants as a critical component of a national primary care research network.

Have Māori governance and leadership from the start – they will ask the critical questions of the intentions and be helpful in describing how to make manifest equity goals. (P6)

Primary job of a network should be to address equity, if not addressing equity then it will increase inequity. (P14)

Participants noted the importance of meeting Te Tiriti obligations:

It's about weaving in Te Tiriti – and if you weave in Te Tiriti then you've got equity principles. (P5)

Māori stakeholders also noted that, although research identifying known inequities may sometimes still be required, it is time to move towards solution-focussed projects and strategies to improve equity.

There are still areas where we don't have a good description of health inequities... it's probably because they aren't the big-ticket item like long-term conditions, they're smaller in scope, they're probably under-focused on or underaddressed- so there is probably still some descriptive work to do... Then interventions, because you get to a point where you want to see if you can actually make things different. (P3)

### **Responding to community needs**

Participants discussed how academic research sometimes benefits the researcher more than the participants in the study. Instead, national research infrastructure needed the flexibility to respond to local and regional community needs. Research projects should benefit their communities, and take a holistic view of primary care, including the intersection between primary care and the wider determinants of health, and building community capacity.

There's sometimes a disconnect between what the researchers want and what the communities need... And sometimes you know historically, it's been quite an extractive process where the, the researchers only get what they want and again... There's nothing that goes back into their community. (P9)

The goal in my mind, is to build the resilience in the communities to be self-managing and self-determining and that they take responsibility for their health. Not just for their own personal, individual, but for the communities and for almost like an ownership of the health services. They're the health promoters, they're the ones putting out the messages, they're the ones encouraging and supporting friends, family, whānau, to access what's available. (P13)

### **Reciprocity between research and practice**

Currently, those working in the primary health sector have limited opportunities, and for some, limited desire to engage with research, exacerbated by heavy workloads and lack of understanding.

The problem...is a lot of clinicians are actually just burnt out. And so as, doctors are getting older, or some of the young ones are coming through, they start to become a bit cynical [towards research]. (P12)

Research priorities should be relevant and based on values important to working clinicians. Network governance should include members from multiple layers of the sector and provide opportunities for research-interested practitioners to be involved. However, a research network should put minimal burden on clinicians. Instead, it should add value for participating practitioners by answering important questions, providing personal or career development opportunities, or access to university resources.

To encourage people they need to be able to see that it adds value so any entity needs to be purposeful... That it can progress their own careers and benefit them personally as well so whether that is CME points, or name in a paper or whatever else it is – then that's good. (P2)

### Data for informed decision-making

Another strong theme was the need for better primary care data and research to inform policy and decision-making at a national level.

Need to also be mindful of the fact that we are living in this dynamic space, where we need to be smart, politically, about what would really help our politicians, Ministry, decision makers - how can primary care assist them, in their decision making? (P4)

However, participants were also hesitant about allowing the MoH or other higher-level health sector organisations unfettered access to primary care data. There was tension between participants acknowledging that data should inform policy decision-making (and currently does not), and concern that without input from frontline clinicians and academics to provide context, these organisations could misinterpret the data.

Careful though around government access – the concern is that the data will be taken out of context and utilised for deficit-based purposes, pulling down or diminishing primary care if there isn't a primary care lens on that data. (P8) The closer I get to government the less confident I am about their ability to manage data, especially the Ministry of Health, I would trust Stats NZ with data because..., data management is their job and they care a lot about it. (P7)

Privacy and security of patient data were key concerns for participants, with several citing the recent information technology hack at Waikato District Health Board (DHB) as being evidence of the need for stringent security. Māori data sovereignty being handled appropriately from the outset was also considered critical when providing data at a national level.

There are concerns around hacking and security, so people are much more aware of the risks for health data, and it's important to act as kaitiaki and make sure the research network have very very strong data security. (P5)

# Māori stakeholder views around structure, and Māori data sovereignty

Māori stakeholders were evenly split about whether a research network should be a separate Māori Primary Care Research Network, or within an integrated network with a Māori health research stream, to best meet the needs of Māori. A separate network was favoured by some:

Sometimes when you are integrated within the system, your voice can be overshadowed by others who are within that space because inequity exists everywhere, every domain and we all need to ensure that equity is achieved for all but we also have specific obligations, under Te Tiriti, so having something separate where we feel safer, with one another. (P9)

Others suggested an integrated network would be better. In either case, participants highlighted that the general network would still need to meet Te Tiriti obligations and be equity focussed:

So the main body needs to be unapologetically pro-equity with strong Māori leadership, but with an additional specifically Māori focussed network for Hauora Māori providers to do additional targeted research. (P10)

Another provider indicated that iwi or Hauora Māori will establish their own network if desired.

if we as [name of Iwi] decide we want to do that [set up a separate research network], we'll just set up our own thing. (P11)

When asked about how stakeholders would like to see Māori data sovereignty concerns addressed, participants highlighted the need to consult with people with people knowledge in this area, and to do so from the early stages of the project.

If this gets legs then involving Te Mana Raraunga the Māori data sovereignty group, or other organisations who have expert knowledge on this. (P10)

# Discussion

There are many descriptions in the international literature of how PCRNs have been developed in different contexts.<sup>6-9,16-18</sup> However, to our knowledge, this is the first formal study to investigate the views from health sector stakeholders on what they believe a national PCRN should look like *before* one has been established.

In this study of health sector stakeholders, participants expressed dissatisfaction with the current challenges in the field of primary care research. Participants identified that primary care data were disconnected, making it challenging to conduct research to inform evidence-informed decisions for practice and policy. Furthermore, academic research was considered disconnected from primary care practice. Frontline primary care providers had limited opportunities to engage in research, and may not see the relevance or benefit of primary care research for their practice. Instead, participants expressed a desire for improved infrastructure, and reciprocity between researchers and practitioners. Participants expressed broad support for improving NZ's primary care research infrastructure with a national PCRN. Participants highlighted the need to provide research evidence that could inform policy and decision-making at a national level. Participants all felt that the government should provide all or part of the funding for this kind of national research infrastructure. There was, however, ambivalence towards the idea of the MoH having access to primary care data in the absence of primary care researchers or clinicians to provide context to that data.

The need to bridge the gap between practice and research, and the potential for PCRNs to answer clinically relevant questions, has also been highlighted as a key driver for PCRN formation in countries such as the US<sup>3,10</sup> and England,<sup>5</sup> where PCRN infrastructure is now wellestablished. Similarly, a recent scoping review of the literature on PCRN formation also identified that a key element for PCRNs is a reciprocal, mutually beneficial, relationship between academics (and/or academic institutions) and participating clinicians.<sup>19</sup> The desire for research to enable evidence-informed decision-making and quality improvement of health service provision reflects another motivating factor identified in the literature for PCRN formation.<sup>19,20</sup> Our participants saw government agencies as the core funders of a national PCRN. International examples of PCRNs vary widely in where their funding is drawn from.<sup>5,7,16,17</sup>

### Box I. Recommendations for the establishment of a National Primary Care Research Network

Recommendations

- I. New Zealand needs a National Primary Care Research Network.
- 2. The purpose of the network should be to improve health outcomes and health equity.
- 3. The network should have Māori partnership at every level.
- 4. The governance of the network should include Te Tiriti partners, frontline clinicians, researchers, service planners and consumers.
- 5. The network and research priorities must be relevant for primary care and the communities they serve, as well as reflecting regional and national health priorities.
- 6. The network should be flexible and take a broad view of primary care.
- 7. The network should have different levels of engagement for working clinicians, including providing opportunities for capacity-building for research-interested clinicians.
- 8. Data must be securely managed, and Māori data sovereignty addressed.
- 9. Opportunities for Māori-led and Kaupapa Māori research within the network must be available.
- 10. The network should be centrally funded.

Nonetheless, academic institutions generally provide some level of funding support (though this may only be in the form of academic salaries), and government health agencies do provide some or all of the infrastructure funding for national-level networks.<sup>19</sup>

Stakeholders highlighted specific elements needed for a national PCRN unique to the NZ context. Primarily, participants discussed the need for co-design with Māori, and to have improving health equity as a central focus. In addition the need for Māori data sovereignty to be handled appropriately was highlighted by stakeholders, as was the importance of having community representation within the network structure. Moreover, additional thinking was needed on the question of how to partner Hauora Māori providers with a national research infrastructure, and whether having separate linked networks, or one network with dedicated research streams, would be preferable.

A strength of the study was the purposive sampling used to ensure that participants were chosen from both the North and South Islands, and rural and urban health sector environments. Specific care was taken to include views from Māori health sector stakeholders. A further strength was the expertise of the authors; the members comprised senior academic primary care clinicians from across all the academic primary care departments in the country, and a representative from the RNZCGP, and were able to act as an academic expert advisory group.

Limitations were that only one Pacific provider was included, and that all the working healthcare providers interviewed were either general practitioners or practice managers in general practices. One participant from the practice manager category had a nursing background; however, the nursing voice remains limited in this study. Although the representation at the focus group was slightly broader (including a clinical pharmacist, medical students, and a rural hospital doctor among others), this study did not highlight the views of practitioners from other areas of primary care. The focus group self-selected on the basis of conference advertising, and thus may have been more likely to hold favourable views towards a PCRN. Furthermore, although many of the participants worked part- or fulltime in general practice, care should be taken in extrapolating the views of these participants to represent all working GPs.

Calls for a revived national NZ PCRN have been made before.<sup>2</sup> The recent Health and Disability System Review Report,<sup>1</sup> which forms the basis of the current health system reform, identifies the need for a national primary care data set. The NZ health system is currently in a state of flux, and during this transition while changes are being designed and implemented, is the ideal time to embed primary care research and data infrastructure within the new system. Our study demonstrates that the desire for improved research infrastructure exists within the health system, not just at the academic level. We have summarised stakeholders' views on the purpose of this infrastructure and how it should function as a set of recommendations for the development of a national PCRN (Box 1).

# Conclusion

This research provides evidence of the existing challenges in the primary care research space and the areas where change is needed. Stakeholders from different levels of the health sector expressed support for a national PCRN and provided guidance on how such a network should function. The recommendations developed from these views should be used to guide the establishment of a national PCRN.

# Supplementary material

Supplementary material is available online.

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**Data availability.** The data that were used in this study cannot be publicly shared. Informed consent, in line with the approving ethics committee, only allows for the use of de-identified extracts within research reporting and writing, in order to maintain the privacy of participants.

Conflicts of interest. Tim Stokes is an Editor of the Journal of Primary Health Care, but was blinded from the peer-review process for this paper.

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