

New Zealand needs a Practice Based Research Network

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ABSTRACT

Practice Based Research Networks (PBRNs) are groups of general practices collaborating to produce research. Contemporary New Zealand health information technology systems are ideal for electronic data extraction for PBRN research. Stakeholders have a valuable, but typically underutilised, part to play in research. Development of an e-participation platform will facilitate stakeholder engagement. New Zealand is in a unique position to create an innovative, low cost, stakeholder-engaged PBRN. This type of PBRN would offer unparalleled research opportunities, and would strengthen New Zealand's general practice research capacity. The more research information we have based on our New Zealand population, the more appropriate care we can provide. Establishing a stakeholder-engaged PBRN in New Zealand will promote and support transformational change within our health system.

In June 2015 I had the privilege of attending the annual Practice Based Research Network (PBRN) Conference held in Bethesda, near Washington D.C. The conference is hosted by the North American Primary Care Research Group and the United States (US) Agency for Healthcare Research and Quality. In this article I draw on the knowledge I gained at that conference and discuss its translation to New Zealand.

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PBRNs consist of general practices 'working together to answer community-based health care questions and translate research findings into practice'.¹ General practice research has been based on review of routinely collected data since inception of the discipline.² The widespread use of electronic medical records (EMRs), coding systems, and the ability to digitally extract anonymised data provides modern PBRNs with unparalleled research opportunities.²

PBRNs in New Zealand

PBRNs are not a novel concept in New Zealand. The earliest network was established in 1986 under the auspices of the Royal New Zealand College of General Practitioners, funded by the Medical Research Council (now the Health Research Council) and the Department of Health (now the Ministry of Health). This PBRN

randomly selected general practitioners to form 'an ongoing, integrated, information network'.³ By 1990 it had foundered, possibly due to successive government ideological and primary health care policy changes that ultimately resulted in the withdrawal of financial support for this network.

The Computer Research Network of the Royal New Zealand College of General Practitioners was a highly productive research unit run from the University of Otago's Department of General Practice from 1989 through the 1990s. The Computer Research Network involved 450 doctors from 181 general practices caring for 810 000 patients throughout New Zealand.⁴ Ultimately, this research unit also foundered through lack of financial support, possibly due to economic deregulation, the introduction of a competitive market model for universities, and issues with management.

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PBRNs in North America

The first research networks in North America were established 30 years ago: today there are 174 PBRNs in the US and Canada.¹ PBRNs are typically based in research institutions or university departments that provide academic direction, administrative support, and substantial funding. Residual funding comes from individual project grants. Without institutional backing, it is difficult for networks to survive.

Despite the institutional financial backing of the North American PBRNs, their research output seems disproportionately low when they use EMRs, (analogous to our Practice Management Software) for research. There appear to be two main reasons for this. First, the PBRNs have to work across numerous different types of patient management software. Second, most doctors in the US still use their EMRs almost exclusively for billing.⁵ The clinical features of an EMR, e.g. recall and audit tools, are seldom utilised because these tools are reported to be unwieldy and difficult to access. Practice facilitators are required if EMRs are to be used for PBRN research, as few people within general practices are able to extract the required data.

New Zealand has several major advantages in our ability to extract and use electronic data from medical records for research.

1. **EMRs are used uniformly by New Zealand general practitioners (GPs).** Practice remuneration is directly linked with accurately recorded information. Uniformity of EMR use makes inter-practice comparisons of electronic records feasible.
2. **Data extraction is straightforward.** Today ~90% of New Zealand GPs use one patient management system (MedTech32). This uniformity reduces time and complexity for data extraction programmes.
3. **Data extraction is integral to New Zealand EMRs.** New Zealand IT systems have been developed in the context of GPs, via Primary Health Organisations and District Health Boards, being required to provide information to the Ministry of Health under the Health Act 1956.⁶ To fulfil their obligations, data

extraction has been integral to our patient management systems since the 1990s. NZ led the world in developing the capacity for data retrieval.⁷

4. **New Zealand GPs were early adopters of EMRs.** In 1989 17% of general practices used computers for at least some administration tasks. By 1994 this proportion had increased to over 80%.⁴ In 2003, 99.8% of New Zealand general practices had at least one computer: 90% were using patient management software in some capacity, and over 70% were considered 'paperless' and used EMRs alone.⁸ Around the same time only 17% of primary care physicians in the US, and 12% in Canada, were using EMRs.⁸
5. **New Zealand GPs were early adopters of research using EMRs.** New Zealand not only led the world in the use of electronic records, we were also quick off the mark to use these records for research. In 2003 an international comparison NZ ranked first for primary care research publications per capita.⁹
6. **New Zealand GPs routinely conduct research using their EMR.** New Zealand GPs have some simple research requirements as part of GP training, continuing professional development requirements, and CORNERSTONE® accreditation. While the audit requirements and quality improvement cycles are fairly basic, this is far beyond what our North American colleagues seem able to do.

There is some room for improvement in New Zealand GPs' EMRs that would facilitate research efforts. Comprehensive, consistent coding of consultations, as well as linking medications to long-term conditions greatly simplifies electronic record review.

A NZ PBRN: the technology is here, the time is right

I am currently working on the Health Research Council funded Safety, Harm and Risk reduction Project (SHARP). This project digitally extracts anonymised patient records from consenting randomly selected NZ general practices. The records are compiled into a secure web portal

and then reviewed by the eight GP researchers in the study team, who live in different locations from the far north to the far south of New Zealand. This technique is readily replicable and is an ideal research model for a low-cost PBRN.

A New Zealand PBRN would provide a research contact point for patients, GPs, academics, and institutions. It could facilitate collaborative research ideas, as well as strengthen New Zealand's GP research capacity and encourage more GPs to participate in research.

Stakeholder participation

Stakeholder engagement was the theme of the 2015 PBRN conference in Bethesda. Medical research in New Zealand is typically initiated by academics or is industry driven. However, a research focus confined to professional, academic or commercial interests is unlikely to meet the health needs of New Zealanders.¹⁰

Patients have a unique perspective and a valuable contribution to make. Stakeholders are not limited to patients, however, and also include clinicians, academics, funders, special interest groups, and the wider community. Stakeholder engagement aims to empower participants to influence the direction of research. Stakeholders can be involved throughout the research process by establishing research agendas, research planning, methodological debate, and contributing to specific projects.¹¹ Stakeholder-led research epitomises the New Zealand National Health IT Plan Update 2013/14 concept of consumer empowerment and self-care.¹²

Stakeholder involvement in research is still in its infancy internationally. There is no evidence to recommend a particular method of stakeholder engagement or participation.¹³ Traditional methods of stakeholder engagement facilitate relationship-building and trust, but have limitations, particularly the time and cost of engagement.¹⁴ e-Participation is a well established tool for political stakeholder engagement, and is readily transferrable to a health research setting, for facilitating participant collaboration throughout the research process. E-Participation may overcome some traditional barriers to engagement,

e.g. access barriers for mobility-limited¹⁵ and rural stakeholders.¹³ Further research is needed to clarify whether New Zealand stakeholders find e-participation acceptable and usable for health research collaboration.

Potential future: Better research, better health

New Zealand has the IT experience, systems and capacity to set up an innovative, low cost, stakeholder-engaged PBRN. The same data extraction tools developed for the SHARP study could be used to collate anonymised data from PBRN participating practices. With appropriate academic support, stakeholders could develop research questions via e-participation. Researchers would then examine the anonymised data to answer specific research questions. This stakeholder-engaged PBRN format offers unique patient-centred research opportunities, and would strengthen New Zealand's general practice research capacity.

The more research information we have based on our New Zealand population, the more appropriate care we can provide. Establishing a stakeholder-engaged PBRN in New Zealand could promote and support transformational change within our health system.

If you are interested in becoming a founding member of the New Zealand Practice Based Research Network, please email Dr Sharon Leitch at sharon.leitch@otago.ac.nz.

References

1. Agency for Healthcare Research and Quality. Practice-Based Research Networks [Accessed 21 September 2015]. Available from: <https://pbrn.ahrq.gov/>.
2. de Lusignan S, van Weel C. The use of routinely collected computer data for research in primary care: opportunities and challenges. *Fam Pract*. 2006;23(2):253–63. doi:10.1093/fampra/ctm106
3. Kijakovic M, Seddon T, Reinken J, McLeod D. The rise and fall of a general practice information network. *N Z Fam Physician*. 1992;73–6
4. Dovey SM, Tilyard M. The computer research network of the Royal New Zealand College of General Practitioners: an approach to general practice research in New Zealand. *Br J Gen Pract*. 1996;46(413):749–52
5. Hsiao C-J, Hing E, Ashman J. Trends in electronic health record system use among office-based physicians, United

- States, 2007–2012: US Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics; 2014.
6. Ministry of Health. Health Act 1956. 65: Ministry of Health; 1956.
 7. Stevens R. Medical Record Databases. Just What you Need?: Office of the Privacy Commissioner; 1998 [Accessed 27 September 2015]. Available from: <https://www.privacy.org.nz/news-and-publications/speeches-and-presentations/medical-record-databases-just-what-you-need/>
 8. Didham R, Martin I, Wood R, Harrison K. Information technology systems in general practice medicine in New Zealand. *N Z Med J*. 2004;117(1198):U977.
 9. Ovhed I, Royen PV, Håkansson A. What is the future of primary care research? Probably fairly bright, if we may believe the historical development. *Scand J Prim Health Care*. 2005;23(4):248–53. doi:10.1080/02813430500316692
 10. Herbison P, Hay-Smith J, Paterson H. et al. Research priorities in urinary incontinence: results from citizens' juries. *BJOG*. 2009;116(5):713–8. doi:10.1111/j.1471-0528.2008.02093.x
 11. Entwistle VA, Renfrew MJ, Yearley S. et al. Lay perspectives: advantages for health research. *BMJ*. 1998;316(7129):463–6. doi:10.1136/bmj.316.7129.463
 12. Ministry of Health. National Health IT Plan Update 2013/14. Wellington: Ministry of Health; 2013.
 13. Domecq JP, Prutsky G, Elraiyah T. et al. Patient engagement in research: a systematic review. *BMC Health Serv Res*. 2014;14(1):89. doi:10.1186/1472-6963-14-89
 14. Lavalley DC, Wicks P, Alfonso Cristancho R, Mullins CD. Stakeholder engagement in patient-centered outcomes research: high-touch or high-tech? *Expert Rev Pharmacoecon Outcomes Res*. 2014;14(3):335–44. doi:10.1586/14737167.2014.901890
 15. Shprecher D, Noyes K, Biglan K, et al. Willingness of Parkinson's disease patients to participate in research using internet-based technology. *Telemed e-Health*. 2012;18(9):684–7.

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