Discussion Paper

National primary health care practice-based research networks 14 February 2022



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Background

There are currently approximately 20 Practice Based Research Networks (PBRNs) in Australia with varying sizes. Most PBRNs are based in general practice and administered through academic institutions. PBRNs vary in constituents from groups of individual primary care clinicians, practices and researchers working together, to collaborations between organisations such as Primary Health Networks and academic institutions. All PBRNs engage clinicians in research to identify and answer relevant community-based health care questions and translate research findings into practice. Some are engaged in the conduct of large-scale multi-site studies.

The Australian Medical Research and Innovation Strategy's 2020-2022 Medical Research and Innovation Priorities recognises the importance of PBRNs and specifically calls for a concerted effort towards conducting geographically relevant and scalable primary health care (PHC) research through PBRNs. PBRNs require both research and infrastructure funding to sustain necessary engagement between researchers and practitioners/community. However, there is a lack of centralised or government funding to support the infrastructure of PBRNs.

The Australasian Association for Academic Primary Care advocates for an effective and sustainable national network of PBRNs that is led by a collaboration between academic institutions, individual PBRNs, PHC professional organisations and members of the PHC research community. This paper presents notable examples of international models of national PBRNs or national networks of PBRNs for the purpose of informing the Australian Health Department, government funding bodes, the PHC research community and the consumer community in devising strategies to build a strong Australian national PBRN. A well-planned and sustainably funded national PBRN will contribute to impactful trials and cohort studies on issues that matter to advancing Australian PHC and national health policies to improve the health and wellbeing of Australians. A short summary of the types of funding models is also presented to aid the consideration of approaches to support a national network.

NOTABLE EXAMPLES OF INTERNATIONAL MODELS OF NATIONAL NETWORKS OF PBRNs

- NHS Research Scotland (NRS) Primary Care Network (Scotland) Established in 2002 as a framework to coordinate national research activity in primary care, this network is funded by the Chief Science Officer (CSO) of the National Health Scheme (NHS) board to facilitate high quality, funded, research studies, both academic and commercial, which are relevant to primary care. It consists of a central management team and strategy board that includes (and reports to) the CSO. Regional PBRN nodes are managed by universities and hospitals, and report to local NHS board and the national network. Each regional node is responsible for specific management of the national infrastructure. Specific research topics have a single contact person.
- NIHR Clinical Research Network (CRN) (UK) A CRN Coordinating Centre provides national leadership and coordination to 15 local clinical research networks and 30 specialties who coordinate and support the delivery of high-quality research both by geography and therapy area. The CRN funds the additional staff, facilities, equipment and support services required for research in these networks. It also provides a vast range of national and local resources and activities (eg. specialist training, patient and public involvement opportunities and engagement initiatives, and communications expertise) to support health and care organisations, staff, patients and service users to be research active.

- <u>The National Dental PBRN</u> (USA) This is a consortium of participating practices and dental organizations committed to dental research. The national network has an administrative body that sits under and receives funding from the National Institute of Dental and Craniofacial Research (NIDCR), part of the US National Institutes of Health (NIH).
- <u>Pediatric Research in Office Settings (PROS)</u> (USA) Founded in 1986, PROS is the American Academy of Pediatrics' (AAP) PBRN. The Academy invested in a national network through establishing a taskforce that identified and connected key researchers and existing local PBRNs to Academy "PBRN chapter coordinators" [volunteers]. AAP national office manages the PBRN day to day organisation. Key staff includes a PBRN director and two 2 Academy directors, and the PBRN steering committee includes Academy board representatives. The PBRN Steering committee then liaises with chapters and principle investigators (PIs) who then coordinate practice-based research.
- AHRQ Primary Care PBRNs (USA) This is a network of networks funded by the Agency for Health Research and Quality (AHRQ) in recognition of this work and its ability to improve the health of all Americans, and the potential of these networks to engage clinicians in quality improvement activities. AHRQ provides funding for local sized PBRNs, coordinates annual conference for the PBRNs and PBRN-related webinars, and serves as a repository for PBRN research.
- <u>CHEERS (Creating Healthcare Excellence through Education and Research)</u> (USA) This clinical research network, funded by the NIH, is created by the Duke Department of Head and Neck Surgery & Communication Sciences and the Duke Clinical Research Institute. It centres around alliances between academic institutions and community practitioners, bringing high-quality, large-scale, multi-centre clinical research opportunities in all disorders within otolaryngology to providers across the country. It is led by university professors with minimal dedicated organisational staff.
- HelseOmsorg21 (HO21) (Health Care 21) (Norway) Established in 2013 by the Ministry of Health and Care Services), the goal of HO21 is to contribute to 3 objectives: good public health, groundbreaking research, and business development and national economic development. The HO21 Council was appointed in 2015 to facilitate collaborations between key stakeholders. Part of its strategy is to build health care research networks outside of hospitals. Plan is to develop local research networks and have those feed into a national research network council.

NOTABLE EXAMPLES OF AUSTRALIAN MODELS OF LARGE-SCALE NETWORKS

There is currently no national PBRN or national networks of PBRNs in Australia. Below are examples of Australian networks funded for specific purposes. PARTNER, a national rural network that will build on existing PBRNs in five states will be launched in March 2022.

- <u>Australian Sentinel Practices Research Network (ASPREN)</u> Established in 1991 by the
 Royal Australian College of General Practitioners, this is a network of sentinel general practitioners
 and nurse practitioners who report de-identified information on Influenza like illness and other
 conditions seen in general practice. ASPREN is currently funded by the Commonwealth Department
 of Health and directed through the Discipline of General Practice at The University of Adelaide.
 ASPREN is not a PBRN. Data is used for infectious disease surveillance and general practice research.</u>
- ASPirin in Reducing Events in the Elderly (ASPREE) and ASPREE-XT (ASPREE –
 <u>eXTension</u>) ASPREE, funded primarily from the US and Australian governments (eg. NIH,
 NHMRC), is a randomised, blinded, placebo-controlled clinical trial of low-dose aspirin in healthy
 older adults conducted in general practices in several Australian states. ASPREE-XT, funded by NIH,
 is an ongoing, follow-up observational study to investigate long-lasting effects of low-dose aspirin on
 disease, such as cancer. Both ASPREE and ASPREE-XT are clinical trials, not PBRNs.

- National Prescribing Service (NPS) MedicineInsight MedicineInsight is managed by NPS
 MedicineWise with funding from the Commonwealth Department of Health to support post-market
 surveillance of medicines. The key function of this primary care quality improvement program is as
 data custodian to extract of de-identified data from GP medical records and implement governance
 processes to enable researchers to access the data to answer specific research questions.
- PARTNER Rural Primary Care Trials Network Funded recently by MRFF Rural, Regional and Remote Clinical Trial Enabling Infrastructure Program, this national rural primary care trials network will be launched in March 2022 and will build on existing PBRNs in five states to create infrastructure to support clinical trials in rural general practice. A national and five state coordinators are funded for local practice engagement and education, an electronic trial recruitment tool which integrates with the GP electronic medical record, and a data extraction tool to collect outcome data. A national Steering Group is being established to oversee its governance and establish methods of engagement with external researchers who wish to access the network. PARTNER is a collaboration between five academic institutions and has been funded for five years. It represents a potentially scalable model for an Australian PBRN.

TYPES OF NATIONAL PBRN FUNDING MODELS

As identified in the examples above and in an extensive literature review from Monash University, several funding models exist to support the functioning of a national network of PBRNs. Different types of funding are required to ensure appropriate infrastructure at the national level, and research capacity at individual PBRN and cross network level.

- Dedicated funding for building and maintaining PBRN infrastructure combined with long-term funding commitment to build research capacity and fund primary care research studies that use the PBRN research infrastructure (Genel et al. 2003; Cole et al. 2014).
- Dedicated and ongoing funding from national agencies, national professional organisations or health organisations, and international governing bodies (e.g., the National Cancer Institute (NCI), the Agency of Healthcare and Research Quality (AHRQ) and the Centers for Disease Control and Prevention) (Lanier et al. 2008).
- Development of business cases for research and quality improvement activities (Dania et al. 2021). This funding supports local activities that contribute to a functional national network of PBRNs, but does not support the infrastructure required to connect and support a national network of PBRNs.
- Voluntary financial or service contributions from members. This method is known to be unsustainable, largely relying on the passion of individuals and relationships between individual researchers and clinicians.
- Funds to pay for data extraction and acquisition costs. This funding supports project work that contributes to a functioning PBRN, though does not support the ongoing infrastructure costs required to connect and support a national network of PBRNs.
- Funding for a part-time research person to support local practice engagement (Hoffman et al. 2015).

CONCLUSION

Overall, funding for existing national PBRN networks is most often supported by substantial long-term funding from national government for infrastructure, including local PBRN coordinators, and governance of national PBRNs. In addition, support from organisational bodies and funding towards specific research and quality improvement activities are critical for growing capacity of the national and local PBRNs and disseminate findings through the national PBRN network.

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