A SNAPSHOT OF AUSTRALIAN PRACTICE BASED RESEARCH NETWORKS IN PRIMARY CARE
Acknowledgements

The findings from this study are based on survey and interview findings. Some participants opted to be acknowledged in this report; the table below lists them. We would like to thank all those who participated.

<table>
<thead>
<tr>
<th>Name</th>
<th>Affiliation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rachel Canaway</td>
<td>The University of Melbourne</td>
</tr>
<tr>
<td>Meaghan Quinn</td>
<td>eviDent Foundation</td>
</tr>
<tr>
<td>Constance Dimity Pond</td>
<td>University of Newcastle</td>
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<tr>
<td>Michelle Guppy</td>
<td>University of New England</td>
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<tr>
<td>Nigel Stocks</td>
<td>University of Adelaide</td>
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<tr>
<td>Richard Reed</td>
<td>Flinders University</td>
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<tr>
<td>Jennifer Reath</td>
<td>Western Sydney University</td>
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<tr>
<td>Siaw-Teng Liaw</td>
<td>UNSW Sydney</td>
</tr>
<tr>
<td>Kristi Milley</td>
<td>Primary Care Collaborative Cancer Clinical Trials Group</td>
</tr>
<tr>
<td>Paul Glasziou</td>
<td>Bond University</td>
</tr>
<tr>
<td>Mark Nelson</td>
<td>University of Tasmania</td>
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<td>Katharine Wallis</td>
<td>The University of Queensland</td>
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<tr>
<td>Clare Heal</td>
<td>James Cook University</td>
</tr>
<tr>
<td>Alyssa Horgan</td>
<td>University of Wollongong</td>
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<tr>
<td>Katelyn Barnes</td>
<td>ACT Health and ANU Medical School</td>
</tr>
<tr>
<td>Jan Radford</td>
<td>University of Tasmania</td>
</tr>
<tr>
<td>Liz Sturgiss</td>
<td>Monash University</td>
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</table>

Funding

This work was funded by a Medical Research Future Fund grant to the Melbourne Academic Centre for Health (MACH) Advanced Health Research Translation Centre.
1. Executive Summary

Primary care scaffolds the broader Australian health care system. Digitisation of health records and increasing availability of data extraction methods and database linkage now provide the opportunity to produce a strong primary care evidence base to inform health practice and policy.

Practice-based research networks (PBRNs) are a vital element in expanding Australia’s research capacity and output to contribute to this evidence base. As organisational structures which promote relationships between academic researchers and primary care practices, they can facilitate research which is relevant to the local needs of primary care practitioners, as well as provide a structure through which new health practices and policies can be implemented and monitored.

While broadly having similar motivation – to lead or support research in primary care - the 18 PBRNs which were identified and included in the current report showed diverse levels of development, focus, membership structure and governance which is detailed in this report. Representatives from these PBRNs were able to see the benefits of a national PBRN or overarching linkage between PBRNs to provide national data, but were mindful of the need to ‘protect’ their members from external researchers whose demands might serve to either alienate members from involvement in their local PBRN or who may overlook the specific needs of members related to their specific patient caseload.

A national network could assist in overcoming the obstacles which face the development and maintenance of PBRNs. There is a need for an overarching strategy and guidance or governance to be devised to facilitate national involvement in projects. All PBRNs in this study highlighted as their major challenges a lack of funding, and the limited capacity of staff to assist in facilitating research.

It has been previously suggested that a national network might extend the reach of local PBRNs whilst reducing their individual workloads. However, progress will require sensitive consideration and appropriate acknowledgement of those who have worked hard to maintain PBRNs at a local level over the last decade.
2. Background

Practice Based Research Networks (PBRNs) are sustained collaborations between practitioners and academicians dedicated to developing relevant research questions, working together on study design and conduct, and translating new knowledge into practice (Pearce et al, 2004).

PBRNs provide the setting and organisational infrastructure to address research questions of relevance to those who are interested in the work of primary care and can ‘change the culture of biomedical science by shifting the focus of research from technology in the hospital to patients and diseases in the community’ (Van Weel, 2002). This results in bi-directional translational research opportunities by providing evidence to both enhance clinical practice and to support policy which underpins good health practices. In some countries, PBRNs interact to create national networks.

PBRNs in the USA

The concept of a national sentinel practice network was first proposed in 1979 meeting at a meeting of the North America Primary Care Research Group (NAPCRG) (Green and Hickner, 2006). At the time, Canada, the UK and Australia had individual morbidity databases, but only the Netherlands Institute of General Practice had a network of sentinel practices, established in 1965.

From the 1970s onwards, and initially driven by the voluntary efforts of family practitioners who elicited funding from private foundations, professional societies and government (Green and Hickner, 2006) PBRNs in the USA were being established. In the late 1990s the Agency for Health Care Research and Quality (AHRQ) was designated by the US Congress to be the principal source of funding for primary care (Lanier 2005), resulting in substantial growth from a reported 28 in 1994 (Niebauer and Nutting, 1994) to 133 in 2015 (as of May 2015). In addition to the 133 US PBRNs, the AHRQ also had registered 41 Affiliate and International PBRNs. AHRQ funds the PBRN Resource Centre at the University of Indiana (www. http://pbrn.ahrq.gov/about, [accessed 15th February 2021]). Over the last two decades, the USA has offered a range of funding specific to PBRNs ranging from Practice-Based Research Network Planning Grants in 2000, to PBRNs Translating Research Into Practice (TRIP) Awards in 2004-2005.

In September 2012, AHRQ funded 5-year grants to establish eight Centers for Primary Care Practice-Based Research and Learning (P30 Center Grants). While each centre has a different aim and focus, they all share the goal to improve patient outcomes by bringing together multiple PBRNs to stimulate innovation in improving the organization and delivery of primary care, to conduct and translate research (see Table 1).
<table>
<thead>
<tr>
<th>Table 1: USA Centres for Primary Care Practice-Based Research and Learning (P30 Center Grants) [accessed from <a href="https://pbrn.ahrq.gov/pbrn-profiles/p30-centers">https://pbrn.ahrq.gov/pbrn-profiles/p30-centers</a>, 15 Feb 2021]</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CoCoNet2: Coordinated Coalition of Primary Care Research Networks</strong></td>
</tr>
<tr>
<td><strong>COIN: Collaborative Ohio Inquiry Network</strong></td>
</tr>
<tr>
<td><strong>C-PRL: National Center for Pediatric Practice Based Research and Learning</strong></td>
</tr>
<tr>
<td><strong>Meta-LARC: Meta-network Learning and Research Center</strong></td>
</tr>
<tr>
<td><strong>MOSAIC: Meaningful Outcomes and Science to Advance Innovations Center of Excellence</strong></td>
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<tr>
<td><strong>N²: Building a Network of Safety Net PBRNs</strong></td>
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<tr>
<td><strong>PPRNet: Primary (Care) Practice Research Network</strong></td>
</tr>
<tr>
<td><strong>PRIME Net: Primary Care MultiEthnic Network Center in Practice-Based Research and Learning</strong></td>
</tr>
</tbody>
</table>
PBRNs in the UK

While the establishment of the Birmingham Research Unit of the Royal College of General Practitioners in 1967 marked the start of PBRNs in the UK, rapid development did not commence until the 1990s. In 1993 the Northern Primary Care Research Network (NoReN) and the Wessex Research network (WReN) received funding from the National Health Service, and from 1998 the National Health Service (NHS) made funding available for PBRNs. This resulted in rapid growth of bottom-up networks. Subsequent formation and funding of regional primary care research networks linked to local universities led to conduct of, or participation in, large clinical trials.

The National Institutes of Health Research (NIHR) Clinical Research Network (CRN) is the clinical research arm of the NIHR. The CRN is comprised of 15 Local Clinical Research Networks and 30 Specialties who coordinate and support research delivery both by geography and therapy area. National leadership and coordination is provided through the CRN Coordinating Centre, which supported more than 6,000 studies and recruited over 732,000 participants in 2019/2020. The CRN ‘meets costs of additional staff, facilities, equipment and support services so that research is not subsidised with funding that has been provided for health and care treatments and service. The CRN also provides a vast range of national and local resources and activities designed to support health and care organisations, staff, patients and service users to be research active. These include specialist training, information systems to manage and report research, patient and public involvement opportunities and engagement initiatives, and communications expertise’.

The Clinical Research Network receives funding which it allocates to the local Networks to provide, among other things, Study Support Services which can provide comprehensive information about local patient pathways and study feasibility for external researchers.

PBRNs in Canada

The Canadian Primary Care Sentinel Surveillance Network (CPCSSN) has brought together 12 PBRNs under a common governance structure for research, disease surveillance and quality improvement. CPCSSN collects de-identified health information from Electronic Medical Records (EMRs) and securely stores them. It is able to provide approved researchers with anonymized data sets for analysis.

Federations of PBRNs

Federations of PBRNs have been in existence since the late 1990s (Van Weel, Smith & Beasley, 2000). In 2001, the World Organization of Family Doctors (WONCA) sponsored the development of the International Federation of Primary Care Research Networks (IFPCRN). The membership of the IFPCRN includes functioning networks, as well as individuals who are interested in starting networks or in network research. Currently 153 licenced PBRN clinicians are listed as part of this network, which is housed on the USA’s Agency for Health Care Research and Quality (AHRQ) website (https://pbrn.ahrq.gov/pbrn-registry/international-federation-primary-care-research-networks, accessed 15th February, 2021).
**PBRNs in Australia**

Australia’s PBRN establishment has lagged behind that of UK and USA. This has had an impact on our ability to collect data from the many primary care settings across our continent, which in turn limits the impact of primary care research on health outcomes and policy change.

In Australia, some PBRNs commenced development with funding from the Research Capacity Building Initiative (RCBI) of the Department of Health and Ageing’s Primary Health Care Research Education and Development (PHCREd) Program. University departments of rural health and general practice were funded to build the research capacity of primary health care practitioners through education, training and development opportunities. Some departments chose to use this funding to seed the development of small local PBRNs (Soos et al 2010).

Discontinuation of PHCREd funding in 2011 left many PBRNs struggling for existence. In 2013 the Australian Association for Academic Primary Care (AAAPC) in partnership with the Department of General Practice at the University of Melbourne, was funded by the Australian Primary Health Care Research Institute (APHCRI) to establish a national support service for existing Australian PBRNs (Temple-Smith et al 2015). Subsequently 23 networks were identified, but whether they have continued to be operational since 2013 is unclear. The MACH have now funded the Department of General Practice, University of Melbourne to undertake the current research to provide a snapshot of current primary care based PBRNs and their operational capacity. In recent years, other primary care-based research networks have also been established for non-GP clinicians such as chiropractors, oral health practitioners, and complementary medicine practitioners, however the details of their research capacity are unknown.

PBRNs are the equivalent to a clinical laboratory in the primary care setting, and to undertake large scale population-based interventions in primary care, it is essential to have practices representing the breadth of practices in Australia. The aim of the study was therefore to determine the research capacity of PBRNs which exist in Australia in the primary care setting.

Mapping the characteristics of existing PBRNs and their operational capacity will show their current capacity to contribute to an Australia-wide PBRN. This mapping exercise and qualitative inquiry are needed so that the current ‘state of play’ can be understood. Currently information about PBRNs is not available collectively, and so whether PBRNs or combinations of PBRNs have the capacity to deliver large scale interventions is unknown. Once the snapshot is complete, information will be at hand to inform strategic planning, policy and research towards capacity building around primary care research. including trials, data collection and use.
3. Study design and methods

3.1. Aims
The research described in this report aimed to determine the research capacity of PBRNs which exist in Australia in the primary care setting.

3.2. Research questions
- Which PBRNs exist in the primary care setting in Australia?
- What are each PBRN’s aims, organisational structure, membership, governance, operational activities, communication, and types of research projects undertaken?
- What education and training is offered by each PBRN?
- What linkages does each PBRN have with other organisations?
- What sustains each PBRN?
- What are each PBRN’s current challenges, successes and achievements?

3.3. Investigators
The study was carried out by staff in the Department of General Practice, The University of Melbourne
- Prof Meredith Temple-Smith BSc, MPH, DHSc.
- Ms Kitty Novy RN.
- Associate Prof Jo-Anne Manski-Nankervis BSc(Hons), MBBS(Hons), CHIA, PhD, FRACGP.
- Dr Phyllis Lau, BPharm(Hons), PhD.
- Prof Lena Sanci, MBBS, PhD, FRACGP.

3.4. Data collection: survey and interviews
Ethics approval was obtained from the University of Melbourne for two methods of data collection.

A survey, delivered via Qualtrix, contained questions about the PBRN’s aims, organisational structure, membership, governance, operational activities, communication, and types of research projects undertaken (see Appendix 1). The Plain Language Statement appeared at the start of the survey. Completion of the survey was taken as consent. At the end of the survey, participants could nominate their interest in participating in an interview.

Interviews were undertaken with PBRN co-ordinators (or their nominated PBRN representative) to elicit details which were more difficult or time-consuming to answer in a survey. The semi-structured interview guide (see Appendix 2) focused on education and
training offered by the PBRN, linkages with other organisations, sustainability of the PBRN, current challenges, and successes and achievements. Interviews were audio-recorded and transcribed.

Much of the information in both the survey and the interview is likely to be public knowledge to network members but may not be in a format readily accessible to others.

3.5 Recruitment
Generally, PBRNs have an administrator, who may or may not be an academic, and an academic lead, either of whom could appropriately answer questions about the operations and functional capacity of the PBRN.

Invitations to participate in the study were sent to:
1. University Heads of Departments of General Practice or Primary Care
2. Fourteen members of the Australasian Association for Academic Primary Care who had previously expressed interest in involvement in any future PBRN development work
3. Other key stakeholders or bodies working in primary care identified by snowballing or internet searches.

It included potential participants in all states and territories and those with an interest in different aspects of primary care, including oral health and complementary medicine. Not all of those who were contacted chose to participate, and while efforts were made to cast the net widely and follow up on possible leads, we may have not identified all Australian primary care based PBRNs. We thus acknowledge that this snapshot report has some limitations.

Appendix 3 shows participants’ involvement in the survey and interview. All survey participants had access to the Plain Language Statement at the start of the survey; those nominating to participate in an interview were emailed plain language statements and consent forms as well as the interview guide. Phone/zoom interviews were undertaken by KN between September and November 2020. Interview participants were given the opportunity to review their transcript.

3.6 Data analysis
The survey responses were exported from Qualtrics into an Excel spreadsheet and the data checked for completeness.

Three surveys were removed from the final analysis, as in some cases more than one person from the same PBRN had completed the survey. One representative from each PBRN was sufficient for the purposes of the survey, and so where two respondents had completed the survey on behalf of the same PBRN, the survey which was kept was one with the greater level of detailed content and accuracy, as ascertained subsequently from the interview. Analysis of the interviews was undertaken subsequent to analysis of the survey data. The interviews provided descriptive excerpts to illustrate issues raised by survey responders and
they also introduced additional themes which were incorporated into the results described in the results below.

4.0 Results

Twenty-one surveys were completed by 21 participants, representing 18 PBRNs. Interviews were completed with 14 participants, representing 13 PBRNs. Table 1 shows the number of PBRNs by state or territory. Table 2 describes geographical boundaries, and the dates on which PBRN each was established.

Responses were received from PBRNs in the following states and territory:

Table 1. State or territory of participating PBRNs, N=18

<table>
<thead>
<tr>
<th>PBRN</th>
<th>ACT</th>
<th>NSW</th>
<th>NT</th>
<th>QLD</th>
<th>SA</th>
<th>TAS</th>
<th>VIC</th>
<th>WA</th>
<th>National</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>5</td>
<td>0</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>5</td>
<td>18</td>
</tr>
</tbody>
</table>

Six additional PBRNs were identified through snowballing, but did not participate in the survey or interview. There were no PBRNs identified in Western Australia or Northern Territory.

<table>
<thead>
<tr>
<th>NETWORK/ HOST ORGANISATION</th>
<th>GEOGRAPHICAL BOUNDARIES</th>
<th>DATE ESTABLISHED</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASPREE- XT</td>
<td>National</td>
<td>2002</td>
</tr>
<tr>
<td>Monash University</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The University of Adelaide</td>
<td></td>
<td></td>
</tr>
<tr>
<td>eviDent Foundation</td>
<td>Currently limited to Victoria but a national organisation</td>
<td>2009 by the CRC for Oral Health and Australian Dental Association and then the eviDent Foundation, established as a company in 2011.</td>
</tr>
<tr>
<td>GOLDNet</td>
<td>Mostly Gold Coast region, but not strictly confined to that.</td>
<td>2019</td>
</tr>
<tr>
<td>Bond University</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Griffith University</td>
<td></td>
<td></td>
</tr>
<tr>
<td>General Practice Teaching and Research Network</td>
<td>The current boundaries are South Australia and the Northern Territory</td>
<td>2008</td>
</tr>
<tr>
<td>Flinders University</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Illawarra and Southern Practice Research Network (ISPRN)</td>
<td>Australia wide, however our membership seems to predominantly be within NSW.</td>
<td>2011</td>
</tr>
<tr>
<td>University of Wollongong</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MonReN</td>
<td>South-east Melbourne</td>
<td>2010</td>
</tr>
<tr>
<td>Monash University</td>
<td></td>
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</table>
A brief description of the 18 PBRNs, showing their and professions in the membership, type of co-ordination and their capability for electronic data extraction are given in Table 3 below.

<table>
<thead>
<tr>
<th>Network of Research General Practice (NRGP)</th>
<th>University of Newcastle</th>
<th>Fairly consistent with the local PHN</th>
<th>2008-2009</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>New England GP Research Network</strong></td>
<td>University of New England</td>
<td>New England Region of NSW-includes the towns of Tamworth, Manila, Gunnedah, Armidale, Guyra, Uralla, Inverell, Glen Innes, Tenterfield.</td>
<td>Recomenced 2020 after 3 years in abeyance</td>
</tr>
<tr>
<td><strong>Northern Tasmania General Practice-Based Research Network</strong></td>
<td>University of Tasmania</td>
<td>Northern Tasmania</td>
<td>2015</td>
</tr>
<tr>
<td><strong>North Queensland Practice Based Research Network</strong></td>
<td>James Cook University</td>
<td>Mackay, Townsville and Cairns</td>
<td>2004</td>
</tr>
<tr>
<td><strong>PracNet</strong></td>
<td>ACT Health and ANU Medical School</td>
<td>All of the ACT and nearby South-east NSW areas; the footprint of the ANU Medical School</td>
<td>1999</td>
</tr>
<tr>
<td><strong>Primary Care Collaborative Cancer Clinical Trials Group (PC4)</strong></td>
<td>University of Melbourne</td>
<td>National</td>
<td>2009</td>
</tr>
<tr>
<td><strong>UNSW electronic Practice Based Research Network</strong></td>
<td>UNSW Sydney</td>
<td>South West Sydney</td>
<td>2010</td>
</tr>
<tr>
<td><strong>UQGP Research</strong></td>
<td>The University of Queensland</td>
<td>Greater Brisbane at present</td>
<td>2020</td>
</tr>
<tr>
<td><strong>Victorian Practice Based Research Network (VicReN)</strong></td>
<td>The University of Melbourne</td>
<td>Australia</td>
<td>2008</td>
</tr>
<tr>
<td><strong>WATCH and INFLATE Clinical Trials Networks</strong></td>
<td>Western Sydney University</td>
<td>Australia wide</td>
<td>2013</td>
</tr>
<tr>
<td><strong>Western Sydney University GP Teaching Network</strong></td>
<td>Western Sydney University</td>
<td>Greater Western Sydney including Nepean Blue Mountains, Western and South Western Sydney regions. Also includes GPs from our Rural Clinical Schools in Central Western NSW and the Northern Rivers of NSW</td>
<td>2010</td>
</tr>
<tr>
<td>Network/ host organisation</td>
<td>Date established</td>
<td>Total number of members/practices Number of active members/practices involved in research in 2019</td>
<td>Members’ professions</td>
</tr>
<tr>
<td>----------------------------</td>
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</tr>
<tr>
<td>ASPREE- XT.</td>
<td>2002</td>
<td>Total: 2500 members 2019: 1500 active members as evidenced by co-investigator status</td>
<td>GPs GP academics Non-GP academics</td>
</tr>
<tr>
<td>Monash University</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Australian Sentinel Practices REsearch Network (ASPREN)</td>
<td>1991</td>
<td>Total: 350 members 2019: approximately 350 active members but it varies throughout the year</td>
<td>GPS in Clinical Practice Nurses</td>
</tr>
<tr>
<td>The University of Adelaide</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>eviDent Foundation</td>
<td>2009</td>
<td>Total: 127 members 2019: 48 active practices and 82 active active individual members involved In addition, 15 practices and 40 staff who were not members participated in research</td>
<td>Oral Health professionals GP academics Pharmacists Psychologists</td>
</tr>
<tr>
<td>General Practice Teaching and Research Network Flinders University</td>
<td>2008</td>
<td>Total: 55 general practices for teaching, and 20 for research. 2019: 100 GPs, approx. 25 practice nurses, and approx. 20 practice managers</td>
<td>GPs in clinical practice GP academics Non-GP academics Nurses Practice Managers</td>
</tr>
<tr>
<td>Bond University</td>
<td>2019</td>
<td>Total: 36 GPs or practices directly signed up as members 2019: about 20 members involved</td>
<td>GPs in Clinical Practice GP academics Non-GP academics Nurses Practice Managers Allied Health - nutritionist</td>
</tr>
<tr>
<td>GOLDNet</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Network Name</td>
<td>Year</td>
<td>Total Members</td>
<td>Practices</td>
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</tr>
<tr>
<td>Illawarra and Southern Practice Research Network (ISPRN) University of Wollongong</td>
<td>2011</td>
<td>Total: 94 members in 64 practices or organisations</td>
<td>2019: 9 practices and 11 individual members</td>
</tr>
<tr>
<td>MonReN Monash University</td>
<td></td>
<td>Total: Approx 1000 teaching and research practices</td>
<td>2019: Approx 100 active practices but unsure how many were PBRN members</td>
</tr>
<tr>
<td>Network of Research General Practice (NRGP) University of Newcastle</td>
<td></td>
<td>Total: Approx 18 practices with 70-80 GPs</td>
<td>2019: 18 practices and 20 individual members</td>
</tr>
<tr>
<td>New England GP Research Network University of New England</td>
<td>1999</td>
<td>Total: Currently re-recruiting and re-establishing the network after a 3-year hiatus.</td>
<td>2019: Member involvement-unsure.</td>
</tr>
<tr>
<td>Northern Tasmania General Practice-based research network University of Tasmania</td>
<td>2010</td>
<td>Total: The PBRN is mostly based on the general practices who offer clinical placements to our medical students.</td>
<td>2019: 23 practices with 100-200 individual members</td>
</tr>
<tr>
<td>Network</td>
<td>Timeframe</td>
<td>Type</td>
<td>Members</td>
</tr>
<tr>
<td>----------------------------------------------</td>
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<tr>
<td>North Queensland Practice Based Research Network&lt;br&gt;James Cook University</td>
<td>2011</td>
<td>Total: Approx 10 practices&lt;br&gt;2019: 10 practices; 30 individual members</td>
<td>GP academics&lt;br&gt;GPS in clinical practice&lt;br&gt;Pharmacists&lt;br&gt;Nurses</td>
</tr>
<tr>
<td>Primary Care Collaborative Cancer Clinical Trials Group (PC4)&lt;br&gt;University of Melbourne</td>
<td>2009</td>
<td>Total: 771 members&lt;br&gt;2019: 30 Practices and around 30 individual members.</td>
<td>GPs in clinical practice&lt;br&gt;GP academics&lt;br&gt;Non- GP academics&lt;br&gt;Nurses&lt;br&gt;Pharmacists&lt;br&gt;Psychologists&lt;br&gt;Physiotherapists&lt;br&gt;Complementary Integrative Medicine providers</td>
</tr>
<tr>
<td>PracNet&lt;br&gt;ACT Health and ANU Medical School practice-based research network</td>
<td>2015</td>
<td>Total: 30- 34 practices with 243 members&lt;br&gt;2019: 34 individual practices active plus 100 GP clinicians</td>
<td>GPs in clinical practice&lt;br&gt;GP Academics&lt;br&gt;Non-GP academics&lt;br&gt;Nurses&lt;br&gt;Practice Mangers</td>
</tr>
<tr>
<td>UNSW electronic Practice Based Research Network: ePBRN&lt;br&gt;UNSW Sydney</td>
<td>2010</td>
<td>Total: 17 practices&lt;br&gt;2019: The ePBRN participates as a whole through the data collected. But about half of the practices were involved in research that may or may not use the data collected through the ePBRN</td>
<td>GPs in clinical practice&lt;br&gt;GP academics&lt;br&gt;Non-GP academics&lt;br&gt;Nurses&lt;br&gt;Practice Managers South Western District Health Services&lt;br&gt;Cancer Services&lt;br&gt;Medical Services&lt;br&gt;Emergency Services</td>
</tr>
<tr>
<td>Network Name</td>
<td>Institution</td>
<td>Total Members</td>
<td>GPs in Clinical Practice</td>
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<td>--------------------------</td>
</tr>
<tr>
<td>UQGP Research</td>
<td>The University of Queensland</td>
<td>Not very many, 'we are fledgling'</td>
<td>GPs in clinical practice GP academics</td>
</tr>
<tr>
<td>Victorian Practice Based Research Network (VicRen)</td>
<td>The University of Melbourne Rachel</td>
<td>Total: ePBRN has 120 practices contributing de-identified data for research (Data for Decisions Program) which is a subset of VicREN. The broader VicREN research and education network comprises 600+ general practices who are consistently involved from a broader department relationship network of around 1000 practices. VicREN also permits individual clinicians who have an interest in primary care research to join the network and there are 195 of those. 2019: 211 practices; 31 projects</td>
<td>GPs in clinical practice Non-GP academics GP academics Practice Nurses Psychologists Complementary Integrative Medicine providers Physiotherapists</td>
</tr>
<tr>
<td>WATCH and INFLATE Clinical Trials Networks</td>
<td>Western Sydney University</td>
<td>2013 Total: 6 members 2019: all Aboriginal Medical Services involved</td>
<td>Aboriginal Medical Services</td>
</tr>
<tr>
<td>Western Sydney University GP Teaching Network</td>
<td>Western Sydney University</td>
<td>Total: Approx 400 GPs</td>
<td>GPs in clinical practice GP academics</td>
</tr>
</tbody>
</table>
4.1 Host organisation

Sixteen PBRNs were hosted by a university (one co-hosted by a PHN), with one led by a government organisation and one by an independent not-for-profit organisation.

4.2 Professional groups represented within the PBRN

Almost all participant PBRNs have GPs in clinical practice and GP academics (who may also be in clinical practice) as members. Many also included nurses. Pharmacists and psychologists are included in six of the participating PBRNs, with one PBRN focusing on chiropractors and oral health practitioners respectively.

Six PBRNs included ‘other professionals’, including GP Practice Managers, nutritionists, diabetes educators, dieticians, sonographers, immunisation nurses, local community health services staff, staff in cancer services, emergency services and a non-GP medical specialist.
4.3 Main role of the PBRN

Fourteen PBRNs see their purpose as conducting research and 11 also support others to conduct research. Unsurprisingly, given that some PBRNs were established through their role in supervising medical students in general practice placements, 7 PBRNs note teaching to be another aspect of role.

4.4 Membership payment

No PBRN charges its members a membership fee.

4.5 Membership management

Members joined the PBRNs in a variety of ways. Five PBRNs utilise online registration, and 6 PBRNs stated they have other means of potential members providing an expression of interest. Both informal and formal processes are used. The majority of PBRNs use a mix of methods to find members.

Three PBRNs invite practices to be part of studies, and when they show interest, offer them membership of the PBRN. Other PBRNs rely on potential members emailing or attending meetings and expressing interest. On receiving an informal expression of interest from a potential member, PBRNs then generally mail a membership form which requests details about the practice and their research interests or alternatively a phone call may be used to collect these details.

Formal processes include the signing of a contract or memorandum of understanding with the university, or a formal appointment of the member as a co-investigator, requiring a signed agreement and submission of a CV.

4.6 Information collected about members

Information on members collected by PBRNs varies widely. Most collect some personal information, such as qualifications of members and their place of practice. The data collected by each PBRN relates to the specific purpose of the PBRN. Some PBRNs are interested in their members’ other professional memberships, and their expectations of PBRN membership.
4.7 What limits the number of projects the PBRN is involved in at any time?

PBRNs are at various stages of development and have differing capacities for research involvement. PBRNs offered a variety of reasons for limitation of the number of projects undertaken at any one time. Effectively most limitations were driven by funding and/or capacity, either of the PBRN or the member.

The funding/time of a PBRN research academic to drive or oversee projects and the PBRN co-ordinator to co-ordinate projects was commonly offered as a limitation on PBRN research. However, some PBRNs also were concerned not to place too much pressure on member practices, particularly those which take on medical students for placement. One PBRN limited practices to 2 studies at any time.

In addition, infrastructure and equipment was also named as a possible limitation.

4.8 Do you allow external researchers to access your PBRN?

There is large variation between PBRNs in relation to allowing researchers external to the PBRN or home institution access to membership. Some PBRNs advertise external projects to their members, but will not actively recruit participants for external research. Other PBRNs allow external researchers to access the PBRN if they meet certain criteria, which are either assessed formally through an EOI or a Steering Committee, or informally through the Network Co-ordinator or Director.

A range of selection criteria are used to decide whether or not to allow researchers access to the PBRN. These criteria included:

- Alignment of objectives
• Burden on practices
• Public good
• Of interest to, or suitable for, practices
• Benefits to practice, including respectful engagement
• Enabling a partnership between the researchers and the PBRN member

4.9  Do you charge fees to outside organisations to use your PBRN?

Seven PBRNs stated that they did not apply fees for researchers to use their services. Three organisations charge fees to both inside and outside organisations wishing to access PBRN membership, and one organisation charges fees only to researchers outside the organisation. Two organisations utilise a pricing policy to set their fees. These fees are charged to fund staff who may contact practices about participation on behalf of the researchers.

4.10 Accessing and extracting data from member practices

Some PBRNs collect general information about the clinical practice in which their members work. This may include data extracted directly from members’ electronic medical records, to allow statistical analysis of this data. Examples of this include data collected on total patient numbers and immunisation status of patients. To enable this data collection, PBRNs which are focussed on specific research projects generally have information about software used by members.

The capacity to access or extract data from electronic medical records is essential for the production of primary care datasets. Nine PBRNs have the capacity to access or extract data from member practices; four do not. Five did not know if they have the capacity to do this. One had achieved limited data access on a small scale for a single project, another had oversight of students conducting audits in practices in which they were placed, and others had utilised data from practices as part of specific research projects. Increased funding and staffing were seen to be essential to achieve data access or extraction on a broader scale.
4.11 INTERVIEWS

The following results were collected from the interview data.

Are your practices research ready?

Research readiness is a term often used to describe the ability of a practice or professional to undertake research.

While many PBRNs included practices and professionals who had previously undertaken research of various types, no participant offered a definition of research readiness and no mention was made of any assessment of research-readiness. However, some participants had specific ideas of research readiness, which are summarised in Appendix 4.

Education and training

While some PBRNs were unable to offer training opportunities at all, other PBRNS offered a range of different training opportunities which included:

- Yearly rural showcase day
- Yearly research development day – research training plus presentations from recently completed projects
- Certificates for practices involved in research
- Research abstracts showing results for practices to put on waiting room walls
- Problem solving meetings for all practices involved in a research project
- Webinars
- Journal club
- GP supervisor evidence-based medicine workshops

What’s working well in your PBRNs?

Some participants described the success of the PBRNs through the quality or outcome of the research which has been conducted. For example, PBRNs which provided access to general practice for medical students undertaking research often produced high quality papers or good outcomes for the students, and also provided solutions to specific problems for the local community. Other PBRNs mentioned the development in research skills of GPs who began with very modest projects. In addition, PBRN staff, PBRN members and the relationships between them were seen to be working well. A number of responses to this question are detailed in Appendix 5.

What are the challenges in your PBRN?

PBRNs all basically faced the same challenges - funding, and the capacity of academics and practices to take on research. One participant mentioned the need to present research findings in a positive light, to ensure practices don’t feel the weight of constant criticism.
It’s maintaining engagement to make it sustainable for the practice and the GPs because we all know that they feel that they’re under a lot of pressure and really research is a bit peripheral to deliver at clinical services at many respects.

Funding. Then convincing our colleagues that they need to design projects and provide compensation for the efforts that practices need to put in to the research.

Funding, sustainable support. Uni Depts often are in competition rather than seeking to collaborate. Where there are collaborations it is based on historical relationships with little opportunity for new departments to become involved.

Funding and finding the value proposition for the GPs to be involved in research because they are so busy.

Funding...we might need to become a branch of a bigger PBRN, and use their resources and website and get some of their funding....

We rely on the goodwill of lots of busy academics who come to the concept development workshops to help other researchers

We’ve been very, very careful to consider the needs and wishes of the GPs who are involved with research, and that anything that goes out is so well interpreted and worded that it can’t be misinterpreted as being critical.

Views on a national PBRN

Respondents could see the benefits of a national PBRN.

Having a national network would enable us to engage better in research opportunities...An advantage of a network of networks is the ability to quickly get data from primary care to answer questions of national importance.

It would be a great advantage....it could help with professional development of PBRN staff.

Some Departments are strong in data linkage and some in health services so if we could put that together it would work to the advantage of both research and general practice.

A primary care network of networks perhaps, that would be good.

Autonomy

Despite being able to see some benefits of a national PBRN, several participants had concerns about the impact of a national PBRN on their PBRN practices and preferred the concept of autonomy.
I don’t want to be used, and I don’t want my practices to be used...you’ve got to think, what’s in it for me personally, what’s in it for my students, for our community of GP. I do not want anyone kicking the heads of our GPs, it’s the best way to make sure I’ll never work with you again.

...you don’t necessarily know how to work with them, and if you use my name, and you don’t involve me, why would I do that?
The only disadvantage would be overloading – too many PBRNs approaching the same people... so the national PBRN needs to be as inclusive as possible

It can’t be just used to recruit for our friends in secondary care or in tertiary care or in the hospital system, we can’t be using our network to do their projects. It must be used by primary care academics and physicians.

**Control**
The concerns to protect their PBRN practices led to comments about fears of competitiveness for control of a national PBRN.

If we had funding for a national PBRN there would need to be discussion preceding the establishment looking at how all Departments could be brought in as equal partners so there wasn’t one established research department taking ownership.

The challenge will be overcoming the competitive approach which has become entrenched and which is reinforced by the limited funding opportunities, and the way these are structured.

I think we all just need to step back a bit, don’t be selfish, and think about the interest of the population we serve.

The biggest threat to a national PBRN is the league-of-gentlemen approach....you know, that this is the local for local people and visitors aren’t welcome here...you will have people saying we have spent years and years and we have 15 practices and they are our practices and you can’t approach them.

You have to have a custom organisation to help run it. Whoever gets selected to do that obviously has an advantage over everybody else in terms of access to those resources. And so there is always going to be some rivalry or some competitiveness about that.

Some participants voiced the view that practices should have the choice to decide for themselves whether they wanted to participate in a national collaboration.

Well my attitude would be that it is for the practices to decide. All practices should have an equal opportunity to be enrolled and all researchers should have an equal opportunity to exploit the network.
It won’t work if it’s a single national PBRN; a network exists on the basis of relationships. I feel it’s got to be a network of networks. I feel that the PBRNs themselves need, and by that I mean the members themselves, need to feel like they have got autonomy over what they choose to be involved in or not.

What is needed to run a national PBRN?

It was acknowledged that a range of features would be necessary to run a national PBRN.

Central presence, either geographically or virtually

Somebody has to take leadership and you can’t have a totally distributed model. You still need a core centralised office. You’ve got to have somebody to lead it and a team that can support it but who wants to work at a national level.

You could have a hub that co-ordinates across all the states and then have satellite officers or people responsible for managing their own area and then have an Executive Officer Network that co-ordinates...

You are going to have to offer money and a place at the table as an academic.

Maintaining local interests and funding

The importance of the local nature of research and local ownership was stressed.

I think that’s one thing that people have to overcome is that sense of loss of ownership...somehow we still have to maintain the local flavour for those practices and GPs who perhaps don’t want to identify with an institute or university from another state.

The MRFF in primary care – you can only be CI on one so if you wanted to contribute to an application to fund a national PBRN it would be at the expense of applying for funding for your own.

Rural has very different issues to urban and there is potential for the research priorities of urban based PBRNs to outweigh the priorities of rural networks.

(Practices) like people who they know; they like that point of contact.

What do practices need to encourage them to participate in PBRNs?

When asked what would encourage primary care practices to become involved in research many highlighted that, for primary care health practitioners in general, research is of secondary importance to clinical care.

I have to say that for most, if we could call them bag carrying GPs, research is a sideline, you know? They’re more interested in what is happening to their patients on
a day to day, week to week, month to month basis... we (are) coming in and asking them for, their collaboration and participation in projects and we can’t just assume that they will always be happy to do so. And, we do need to be able to provide adequate compensation for their time and efforts.

I don’t know how someone doing a national project would manage to entice practices into doing something that isn’t interesting for them. There would have to be funding involved. Often when I get practices to do stuff it generally works on a favour basis. You know, I’ll come and do your locum....

But I think having that sort of network layered with a network of research practices that do randomised trials would be really good ...what would happen is that all of the practices that were part of the national network would also contribute data to a Medicine Insight type program. So that it could be used for various sorts of purposes that we use Medicine Insight for at the moment. ...it would be a valuable resource for researchers ... (who) don’t need to collect this information because (they) will get it from the data extraction that occurs within those practices.

5.0 Discussion

Primary care scaffolds the broader Australian health care system, yet lacks a strong integrated evidence base. Digitisation of health records and increasing availability of data extraction methods and linkage between databases now provide the opportunity to produce a strong evidence base to inform health practice and policy.

Practice-based research networks (PBRNs) are a vital element in expanding Australia’s research capacity and output to contribute to this evidence base. As organisational structures which promote relationships between academic researchers and primary care practices, they can facilitate research which is relevant to the local needs of primary care practitioners, as well as provide a structure through which new health practices and policies can be implemented and monitored.

While little work has investigated barriers to research for other primary care practitioners, in the early 2000s barriers to GPs’ involvement in research included time constraints, feelings of being overwhelmed by administrative tasks and lack of recognition or reward (Zwar et al 2006; Rait 2002.) Current PBRNs are well-placed to resolve these concerns by providing oversight and guidance to assist in the conduct of research, and ensuring that research conducted in a clinical practice does not impact negatively on its daily activities. To date a particular strength of some PBRNs has been a strong sense of ownership within participating practices facilitated by a bottom up approach which encourages identification of research questions from clinical practice, with clear application at the local level (Hayes, Parchman, Howard, 2011).

In Australia it was noted over a decade ago that to extend beyond small scale descriptive and survey-based studies, more efficient standardised structures, processes and funding are necessary (Zwar et al, 2006). The UK and USA both have a very healthy PBRN infrastructure and dedicated funding streams. In contrast, the establishment of PBRNs in Australia has
been patchy. The Commonwealth Government’s PHCREd strategy (2000-2014) enabled the seeding of PBRNs under their Research Capacity Building Initiative (RCBI) which ceased in December 2011 (Australian Government Department of Health, 2014). The early promise shown by many PBRNs was thwarted by the absence of ongoing funding which impacted the further development and maturation of almost all PBRNs, and precluded the establishment of others. A review undertaken by the Australian Primary Care Research Network (APCReN), a short-lived national umbrella organisation for PBRNs ultimately curtailed by lack of ongoing PHCREd funding, found 23 PBRNs in existence in 2013 (Temple-Smith et al 2015). All were engaged and enthusiastic about APCReN, and what it might be able to achieve.

While broadly having similar motivation – to lead or support research in primary care - the 18 PBRNs included in the current report showed diverse levels of development, focus, membership structure and governance. They offer a range of research training and different types of events through which research translation can occur. What is clearly evident is the enthusiasm and commitment of these PBRNs despite a constant lack of funding, and very real limitations imposed by the limited staff or capacity of staff to assist in facilitating research. These have been constant challenges for PBRNs over the last two decades.

A key role for many Departments of General Practice has been organising medical student placements for their general practice rotation, an activity which allowed the building of relationships between practices and the Department. Some medical schools now have centralised university model of medical student general practice placement, which has resulted in the shrinking of many academic Departments of General Practice, thus distancing them from the practices which take their medical students. This has a flow on effect, which can hamper the establishment of strong relationships with practices which is needed to grow primary care research. Even though research is part of RACGP curriculum, there is still only a small pool of Australian general practice clinician researchers who are in great demand for health services and specific content collaborative research. Yet these are the same clinician researchers to whom we look to facilitate the development of research within primary care PBRNs. Funding is critical to support both the academics who undertake this work, and the co-ordinators who manage it.

A national network could assist in overcoming the obstacles which face the development and maintenance of PBRNs. A decade ago these obstacles were identified as sustainability, financial support, PBRN productivity, responsible conduct of research, recruitment and generalisability, and member management (McMillen, Lenze, Hawley and Osborne, 2009). Current grant schemes which might fund PBRNs are highly competitive, thereby effectively precluding the involvement of fledgling and/or previously unfunded PBRNs. Participants in this project were able to see the benefits of a national PBRN or overarching linkage between PBRNs to provide national data, but were mindful of the need to ‘protect’ their members from external researchers whose demands might serve to either alienate members from involvement in their local PBRN or who may overlook the specific needs of members related to their specific patient caseload. Whether GPs similarly perceive a need to be ‘protected’ by their local PBRNs is unknown.

It has been previously suggested that a national network might extend the reach of local PBRNs whilst reducing their individual workloads (Calmbach, Ryan, Baldwin and Knox, 2012).
PBRNs come in a variety of shapes and sizes, and there is financial benefit in reaching a critical size. Once a PBRN has been established for long enough to accurately predict their practices’ interest in research, and these practices have a trusted relationship with their PBRN, ‘guaranteeing’ recruitment of a particular number of practices to participate in research is a saleable commodity. PBRNs can suggest a budget for practice recruitment to be included on grant applications. A small proportion of this can be used for PBRN co-ordination.

In addition to or as an alternative to this process might be smaller, less developed PBRNs joining with larger or more established PBRNs. The benefits would be increased opportunities for these practices to participate in research, and more access to academic researchers. However, progress would require sensitive consideration and appropriate remuneration of those who have worked hard to maintain PBRNs at a local level over the last decade.

PBRNs are vital to expand Australia’s research capacity and output to contribute to the primary care evidence base. They also provide a structure through which new health practices and policies can be implemented and monitored. However, to benefit all PBRNs there needs to be the development of an overarching strategy plus guidance/governance to facilitate national involvement in projects. Relationship management will be key, and thus the involvement of an organization independent of any PBRN is likely to be best received.
REFERENCES


APPENDICES

APPENDIX 1: SURVEY ENTITLED “A SNAPSHOT OF AUSTRALIAN CARE PRACTICE BASED RESEARCH NETWORKS IN PRIMARY CARE” DELIVERED VIA QUALTRIX

INTRODUCTION
Welcome to the survey of Australian Primary Care Practice Based Research Networks.

Following on from a similar mapping exercise undertaken in 2013 under the auspices of the Australasian Association for Academic Primary Care (AAAPC), this survey aims to collect data on the existence and functionality of Australian primary care practice based research networks (PBRNs). The aim of this survey is to determine the existence, readiness and combined capacity of PBRNs to undertake Australia-wide research. Findings may be used by PBRNs to enhance coordination between them and thus raise the capacity of primary care-related research.

This survey covers your PBRN’s aims, organisational structure, membership, governance, operational activities, communication, and types of research projects undertaken. If this information is all available on a website, you could simply direct us to that site. We also aim to conduct an interview to collect information on education and training offered by the PBRN, linkages with other organisations, sustainability of the PBRN, current challenges, and successes and achievements. Please indicate at the end of the survey if you do not wish to be interviewed.

A summary of results will be made available to all participants. The project is being undertaken by researchers from the Department of General Practice at The University of Melbourne with advice from AAAPC, and is funded by the Melbourne Academic Centre for Health.

Please click Participant information to read the participant information and consent. By completing and submitting this survey your consent to participate is implied, so a signature is not required.

If you have any questions please contact Professor Meredith Temple-Smith at: m.temple-smith@unimelb.edu.au, or call on: 0429858248. If you would like to be named in acknowledgements of any published results as having contributed to the study, please enter your name and affiliation:
Name:
Affiliation:

In case we need to contact you or you would like a summary of the results emailed to you at the conclusion of the project, please enter your email address:

PROFILE:
What is the name of your PBRN?
What is your role in the PBRN?
In which year did your PBRN commence?

1. AIMS AND ORGANISATION STRUCTURE:
Who is your host organisation? (Tick all that apply)
What are the geographic boundaries, if any, of your PBRN?
• Primary Health Network
• Governmental organisation
• Non-governmental organisation
- University or other education provider
- GP Clinic
- Independent not-for-profit organisation
- Pharmaceutical company
- Other

How many members do you have?

What professional groups are represented in your PBRN? (Tick all that apply)
- GP academics
- Non-GP academics
- GPs in clinical practice
- Nurses
- Pharmacists
- Psychologists
- Complementary/Integrative medicine providers
- Oral health practitioners
- Chiropractors
- Physiotherapists
- Other

What are the goals, intention or mission of your PBRN?

2. ROLE OF THE PBRN:
How would you describe the main role of your PBRN? (Tick all that apply)
- Leading research work
- Supporting other researchers
- Teaching

3. YOUR MEMBERS:
What are the criteria for membership in your PBRN?

Please describe how members are invited to join.

Do members pay a membership fee?
- Yes
- No
- Do not know
- Yes
- No
- Annually
- Other

Please describe membership fee and/or the expectations of continued membership.

Is there a membership renewal process?

How often do you renew your membership?
How do you renew membership?

4. MEMBERSHIP MANAGEMENT:
What is your membership registration process? (Tick all that apply)
- Automatic
- Subscription
- Other
- Online registration
- EOI
- Other

What types of data do you collect about members? (Tick all that apply)
- Research interests
- Research experience
- Profession
- Years in practice
- Place of practice
- Other

What types of marketing do you conduct to attract membership?

5. GOVERNANCE AND STAFFING:
Do you have a Steering or Reference committee or group?
- Yes
- No

How regularly does the committee meet?
- Weekly
- Monthly
- Quarterly
- Twice per year
- Other

What positions support the functions of the PBRN? (Tick all that apply):
- Chair of the PBRN
- Network Coordinator
- Other (Please describe)

How are the support positions for your PBRN funded?

6. COMMUNICATION:
Do you have a regular form of contact with your PBRN?
- Yes
- No

How often would you communicate with them?
- Weekly
- Fortnightly
- Monthly
• Six monthly
• Annually
• As required

What is the main way you communicate with them? (e.g. newsletter, email)

7. RESEARCH PROJECTS:
In what kinds of studies has your PBRN been engaged?
If your PBRN is new what kinds of studies would your PBRN members be interested in? (Tick all that apply)
• Clinical trials
• Qualitative studies
• Observational studies
• Intervention/development/implementation studies
• Studies involving patient medical records
• Surveys
• Other
• Pharmaceutical initiated research
• Researcher-initiated research
• PBRN member-initiated research
• Student projects
• Other

Which of the following types of investigator research has your PBRN participated in?
If your PBRN is new which types would you think they would participate in? (Tick all that apply)
• Clinical trials
• Qualitative studies
• Observational studies
• Intervention/development/implementation studies
• Studies involving patient medical records
• Surveys
• Other
• Pharmaceutical initiated research
• Researcher-initiated research
• PBRN member-initiated research
• Student projects
• Other

Does your PBRN have the capacity to access or extract data from member practices?
• Yes
• No
• Do not know

8. INVOLVEMENT IN RESEARCH:
About how many PBRN practices were involved in research in 2019?
• Approximately how many practices?
• Approximately how many clinicians/staff?
About how many of your PBRN individual members (clinicians/staff) were involved in research in 2019?

Were any of the clinicians/staff and or practices participating in the 2019 research projects NOT members of your PBRN?
- Yes
- No
- Not sure

What type of research services does your PBRN provide? (Tick as many that apply)
- Assistance with ethics application
- Assistance with community (including general practice) engagement
- Recruitment of practices for researchers external to your organisation
- Recruitment of practices to researchers internal to your organisation
- Advice on research methods relevant to primary care
- Research training
- Other

What, if anything, limits the number of projects the PBRN is involved in at any time?

9. OPERATIONAL ACTIVITIES:
Do you allow researchers or other stakeholders from outside your organisation access to your PBRN for research or research services?
- Yes
- No
- Depends (Please explain)

What selection criteria do you apply to decide whether to allow researchers access to your PBRN?
- Yes
- No
- Other

Do you charge a fee for researchers wishing to use your PBRN services?
- No, we do not apply fees for researchers to use our PBRN services
- Yes, we apply fees only for researchers external to our organisation
- Yes, researchers both internal and external to our organisation are charged fees for PBRN services

Do you have a pricing policy to guide how you set the fees for your PBRN services?

10. INTERVIEW A REPRESENTATIVE OF PBRN:
Many thanks for participating.
We would also like to interview a representative of your PBRN to collect further details. If you believe someone different to you would be the most appropriate person, please write their name and contact details here. They will be sent a recruitment email with the PLS statement, consent form, and interview questions before a request for an interview time is sent.
Name of alternative PBRN representative:
Email:
Phone:
APPENDIX 2: SEMI-STRUCTURED INTERVIEW QUESTIONS

This project aims to gain deeper understanding of the capacity of PBRNs. If you agree to be interviewed, the questions asked will explore the following areas:

1. Please tell me about the history of the PBRN. How was the network established?
2. Of your members, approximately how many are involved in regular activities?
3. Ideas for Research Projects
   Where do these come from?
4. Education/Training Roles
   What sort of research training and development opportunities does your PBRN offer to people working in primary care? How do you get practices ‘research-ready’?
   How many practices in your PBRN are “research-ready”?
5. Partnerships/Linkages with other organisations
   Do you have links with other organisations such as PHNs? What role do these other organisations play in your PBRN?
6. Sustainability
   How is your PBRN funded? How are projects associated with your PBRN usually funded?
7. Current challenges & barriers
   What is the biggest challenge faced by your PBRN?
8. Successes & achievements
   What’s working well & why?
9. Collaboration
   What is your view about a national PBRN to network all the PBRNs both in general practice and other primary care disciplines?
   Do you have suggestion how this could be structured?
10. Do you have suggestions of other people in Australia who might be appropriate to be interviewed as part of this study?
### APPENDIX 3: SURVEY AND INTERVIEW PARTICIPANTS

<table>
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<tr>
<th>NETWORK/ HOST ORGANISATION</th>
<th>SURVEY COMPLETED</th>
<th>INTERVIEW COMPLETED</th>
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<td>University of Tasmania</td>
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<td>The University of Adelaide</td>
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<td>Monash University</td>
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<td>Network of Research General Practice (NRGP)</td>
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<td>University of Newcastle</td>
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<td>North Queensland Practice Based Research Network</td>
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<td>PracNet</td>
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<td>ACT Health and ANU Medical School</td>
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<td>Primary Care Collaborative Cancer Clinical Trials Group (PC4)</td>
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<td>UNSW electronic Practice Based Research Network</td>
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<td>UQGP Research</td>
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<td>WATCH and INFLATE Clinical Trials Networks</td>
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<td>Western Sydney University GP Teaching Network</td>
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APPENDIX 4: RESPONSES FROM INTERVIEWS

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<tr>
<th>ARE PRACTICES IN THIS PBRN ‘RESEARCH READY’?</th>
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<td>Starting off with a simple straightforward research project and teaching them some skills along the way...ethics involved in collection patient data, what can and can’t you do in terms of patient privacy. How you collect data in your practice, how you use your software systems to collect data, how you input data correctly.</td>
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Research readiness is that we are very closely helping the practice to do the right job.

At the very least they need good quality medical records and (to be) recording the information.

So, are they research-ready? Well they’re research-ready if you’re flexible enough. I think the onus is on the researchers rather than on the practices. From a practical point of view, you just have to deal with what is in there. The problem is – could they be a lot better, and the answer is yes – a lot better. We've got high degrees of computerisation, but the quality of the datasets is highly variable.

Are the practices research-ready? Not particularly. They are more research ready than the average corner practice that has never done any research...they understand there is ethics, that there needs to be a consent process that doesn’t involve harassing the patients. They understand that if they say they are going to mail out to a database list of patients between 45 and 49 that they can’t just grab 10 patients between 45 and 49, they actually have to mail out to their database list...and they will go ‘Yeah, yeah, we will do that’. And they won’t. And that’s a bit of a worry and it limits the external validity of the research.

We rely on the PHN working with the practices to bring data entry up to scratch and ensure the processes are there for data extraction.

Our experience is that practices won’t sign up to research training if there isn’t an obvious need for them to be involved in research training. We don’t really subscribe to that idea that you train up a cohort of practice in case there is a research project coming. As much as that sounds desirable the pragmatic reality is that practices are just flat strapped on what they need to do at the best of times.

I’d say there’s several practices that are research ready, but none of them would have done a clinical practice course or anything like that because it wasn’t required.

We have a larger group of 50-60 practices, and a smaller group of 10-20 which do the bulk of the research. Those are the practices that are research-ready.

There’s probably a few of them, mainly because the original nurses are still strong....I know if there is a particular nurse at a practice I can sort of go to them and they would be a practice champion and generally drive the study.
## WHAT’S WORKING WELL IN YOUR PBRNS?

<table>
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<tr>
<th>Appendix 5: RESPONSES FROM INTERVIEWS</th>
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<tr>
<td>Right place, right time and lots of really, really good people</td>
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<td>Fantastic core team</td>
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<td>Strong foundation of relationship with the general practices and that they have an orientation to research involvement. A single person who communicates with practices so they are not bombarded with different people getting in touch with them.</td>
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<td>University support for ongoing academic positions which support GP research</td>
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<td>What works well is where practices can see the immediate benefit for them and their patients</td>
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<td>Willingness of practices to engage</td>
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<td>We have undertaken several large trials in general practice and we have had good results in those trials. We've run a national influenza surveillance network from South Australia for almost 30 years. And that has contributed to pandemic preparedness, and also provides important results to the World Health Organisation and Australian Government about vaccine effectiveness. I think the fact that we've been steadily engaged with these practices indicates that we have been able to undertake a lot of these processes without alienating the practices and, they've have wanted to continue to collaborate with us on these, on research projects.</td>
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<td>Amping up our external communications and being really visible. We have worked really hard to create a message, that we spread out which says what we do and why people should engage with us. I think that’s working really well.</td>
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<td>Key members that we have participating in our regular activities really understand the benefit of being in the PBRN. They see the value....</td>
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<td>The visible champion is a really important thing. The visible champions bring people to the PBRN.</td>
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