Submission to the
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and Research

2011 Strategic Roadmap for Australian Research Infrastructure

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Executive summary

The vast majority of all health care interactions in Australia are conducted in the primary care setting, yet the bulk of clinical research in Australia is conducted in hospitals by hospital-based clinicians. This means that primary care practitioners often must base their decisions on prevention, diagnosis and care on relatively poor evidence which compromises the quality of care provided to patients.

The Department of General Practice at the University of Melbourne is an internationally recognised unit which focuses on high quality research around the provision of primary, comprehensive, and continuing care. In keeping with leading international research in primary care, the Department has established a practice-based research network (PBRN); a collaboration between researchers and clinicians which allows the undertaking of real-life research, relevant to practitioners, the results of which can have an immediate impact.

PBRN allow for the production of timely and relevant clinical evidence using rigorous and relatively inexpensive methods. A number of specific benefits of this model of research are outlined below. A rationale for the development of a nation-wide practice-based research network system in medical research is discussed, including suggestions for a possible implementation model. This response concludes by considering several of the focus questions provided in the Discussion Paper for the 2011 Strategic Roadmap for Australian Research Infrastructure and responding to these from a general practice research perspective.
1. Introduction

This document is a response to the discussion paper on the 2011 Strategic Roadmap for Australian Research Infrastructure by the Department of General Practice of the University of Melbourne. It argues that research situated in general practice settings and co-ordinated by practice-based research networks is critical to the development of both best and cost-effective practice. Modest infrastructure support to develop and maintain practice-based research networks will have a tremendously positive effect on both the health of all Australians and the professional satisfaction of the health workforce.

2. Background

a) University of Melbourne, Department of General Practice

This Department of General Practice at the University of Melbourne was established in the 1990's and has a national and international reputation as a centre of excellence in primary care research. It is known for multi-method, rigorous research programs, strong national and international collaborative research, and high quality research higher degree training. The research agenda of the department is firmly based in general practice and primary care and focuses on the provision of primary, comprehensive, and continuing care.

b) Practice-Based Research Networks

A practice-based research network (PBRN) is a group of medical clinics, typically practicing in non-university based community environments, that are networked for the purpose of examining and evaluating the health care processes that occur in real world practices. PBRNs work by bringing primary care practitioners (GPs, practice nurses, community and allied heath practitioners) together with academic GPs and other researchers in long-term collaborations. They provide a “laboratory” for studying populations of patients and care providers in community-based settings in a cost effective way. Undertaking research, particularly large scale research, at a general practice workforce shortage level is very difficult without such support. The current general practice workforce shortage means that practices are kept very busy simply providing clinical services. While many practitioners may wish to be involved with research, without support (financial, logistical, technological) it is simply not possible for them to make such commitments. PRBNs facilitate appropriate support so that research can be successfully conducted in primary care environments.

c) VicReN

The Victorian Primary Care Practice-Based Research Network (VicReN) is based at the Primary Care Research Unit, Department of General Practice at the University of Melbourne, and is a collaboration between the this Department and approximately 100 primary care practices around Victoria. VicReN was established in 2007, with funding from the University and the Commonwealth through the Primary Health Care Research, Evaluation and Development (PHCRED) Strategy. VicReN is one of seven PRBNs currently operating in Australia: Appendix A provides an overview of the current status of Australian PBRNs.
d) **International trends**

For almost 50 years now governments have supported the introduction and maintenance of PBRN activities. Appendix C provides a brief overview of PBRN activities in three leading nations: the United Kingdom, the United States of America and the Netherlands. PBRNs flourish with appropriate support and now in these countries many PBRNs have hundreds of practitioner and clinic members who treat thousands of patients. Their size and sophistication allow them to conduct research on a scale that would otherwise be unthinkable in a general practice context. Increasingly, well established PBRNs are expanding their purpose by supporting quality improvement activities within primary care practices and championing the adoption of an evidence-based culture in primary care practices. Some PBRN leaders are broadening their vision to include an educative aspect, where clinicians are engaged in reflective practice inquiries.

3. **Advantages of a PBRN approach**

PBRN research differs from much traditional health research for two main reasons: this research is highly relevant to practitioners and the implementation of its findings have the potential to make an immediate difference to the delivery of primary care. Every stakeholder in the health care arena stands to gain from the work that is undertaken by practice-based research networks.

- Patients gain by receiving well-evidenced healthcare.
- Practitioners gain by both having relevant research to guide their practice as well as the professional benefits that come from being directly involved in research.
- Health networks gain by having more effective and better evidenced care delivered to patients within their regions.
- Governments gain when research findings facilitate a more efficient and effective use of both health care and medical research resources.
- Australia gains by being a healthier place to live, work and play.

4. **Disadvantages with the current approaches**

Primary care episodes form the majority of all health care interactions in Australia. Indeed 85 per cent of the population attends a general practice on average 6.5 times every year. Yet the great majority of clinical research in Australia is conducted in hospitals by hospital-based clinicians. This mismatch between the locations of health care delivery versus health care research is problematic for two significant reasons. Firstly, the results of hospital-based research are often of limited relevance to the primary health care setting because of the differences in the health problems, patients and conditions. This is particularly evident in the area of preventative health care. General practices are highly focused on the preventative aspects of health care, that is, keeping patients out of hospital. Using primary health care settings to conduct large scale research trials into subjects such as preventative health care practices makes good fiscal and clinical sense.

Secondly, the relative dominance of tertiary health sector research means that many
health problems or service issues pertinent to primary care simply go un-investigated. For example, General practitioners spend countless consultations helping patients manage a myriad of chronic health issues that may have a significant impact on their quality of life. These health issues may never result in an admission to a tertiary care facility. As a result of this and other differences in patient profiles, the gap between evidence and practice in primary care remains wide. This lack of appropriate evidence compromises the quality of care provided to patients.

5. Why does Australia need a national PBRN?

The development and maintenance of the infrastructure necessary to support the provision of suitable evidence to primary care givers is a hallmark of world class healthcare systems. Given that in Australia most health care occurs in the primary care sector, ensuring that general practice decisions are guided by high quality, relevant evidence is essential. Apart from benefits received by individual patients at the time of each consultation, trends in patient care interactions in general practice are felt across every sector of the Australian health care system. Providing the infrastructure for the development of PBRNs on a national level is the best way to ensure that relevant high quality research findings are adopted in a timely manner by health professionals working in the primary care setting.

PRBNs can provide the kinds of support needed to make rigorous general practice research a reality. They can provide recruitment support, including having research staff within practices to assist with recruitment on a practical level. PRBNs can develop and implement information technology solutions that allow general practices to collect research data. PRBNs provide a ready-made network of practices interested in undertaking research as well as implementing findings.

Research and experience tell us that it is not enough to simply produce good evidence: evidence needs to be put into practice to make a difference. For research to be taken up by practice communities it must be not only high quality but also highly relevant and applicable. Research produced by PRBNs is always relevant to clinical practice, and so easily adopted by health care professionals. The establishment of a national PBRN will assist in not only producing high quality research but also developing leaders within general practice who will adopt these changes and disseminate these changes through their professional networks.

The successful implementation of national health policies and competent health service planning rely upon relevant, high quality research being properly implemented at the practice level. Increasingly the Australian government turns to the realm of primary care to deliver health policy initiatives from immunisation of infants to the management of complex chronic diseases. The grass roots nature of this general practice as well as the relative speed by which research can be conducted by PRBNs make them ideal vehicles for working with health policy-makers in shaping and implementing primary care health policies. Consequently this kind of medical research is always attractive for fiscal and clinical reasons.

6. How might a national PBRN be realised?

It is recommended that three different PBRN models are piloted in different states / territories and monitored and evaluated over five years. All comprise one academic department and a number of practices. They differ with respect to number of practices
and network purpose (Appendix B provides more details here). They are:

- small network (up to 15 practices) with greater support per practice
- medium-sized network (up to 50 practices) with less intensive support per practice
- large, topic-specific network (up to 150 practices) spanning several states or territories.

This arrangement would allow the performance and effectiveness of the three different models to be compared over the five year time frame. It would also enable the conduct of a variety of studies: smaller, regional studies within the first two networks; medium-scale, interstate studies through the collaboration of the first two networks (up to 65 practices in two states / territories); and large and national studies through the topic-specific PBRN. The total cost over five years is estimated to be approximately $7.5 million. This figure is made up two parts - funding for the three academic departments for their coordination role / network infrastructure and support to network member practices for their participation in research.

7. A primary care response to the Expert Group on Promoting and Maintaining Good Health Review

This response has argued that a new direction in primary care research should be supported by the provision of appropriate infrastructure to support a nation-wide Practice-Based Research Network. Given this perspective, we now turn to the review questions contained in the discussion paper on the 2011 Strategic Roadmap for Australian Research Infrastructure and respond to these directly.

1. What are your views on the key future research directions identified and are there any other areas that have not been included?

Important advances are made in healthcare through basic science discoveries; however, the direct health care related benefits, if any, of such research may not be felt in the clinical environment for decades. As research conducted by PBRNs is usually designed to resolve an existing clinical problem the efficacy of both the research and the results are relatively easy to measure. In addition, research undertaken by practice-based research networks is likely to provide a more timely response to a clinical problem of relevance to practitioners. The dissemination of such evidence may have immediate positive benefits to the health care community, often at a fraction of the cost of more traditional methods.

2. What are your views on the research infrastructure capability areas identified, including their relative priority and their ability to support the current and future research needs?

The current Promoting and Maintaining Good Health Expert Group has emphasised the need for funding of infrastructure such as bioinformatics, genomic, proteomic analyses, biomedical imaging, biobanking and biostatistics. Such infrastructure will do little to
directly support the current and future needs of research in the general practice context, where the vast majority of medical care is undertaken. In the 2008 Review of the National Collaborative Research Infrastructure Strategy Roadmap Discussion paper, the then Promoting and Maintaining Good Health Expert Group emphasised the need to increase Australia’s capacity to run community-based clinical trials using a PRBN-style model. We believe that infrastructure to support such an approach to research is as relevant now as it was then.

3. What are your views on the existing funded facilities, including their ability to meet the current and future research needs?

Currently there is no national infrastructure in place that allows for the development and co-ordination of PBRN activities on a national basis. Presently there are seven PBRNs nation-wide, each of which is funded primarily through the local academic department of general practice. While the provision of resources to support PBRNs may not seem significant in the overall scheme of national research infrastructure, such support is beyond the means of academic departments of general practice on a sustainable basis, and unaffordable for general practices.

4. What are your views on the cross-disciplinary requirements identified, including their relative priority and ability to support the current and future research needs?

The messiness of real-life healthcare situations can only be understood by an equally complex approach to research. Further investment in infrastructure that supports excellent research in the humanities disciplines and allows for cross-disciplinary research will further enhance the depth and quality of research in the health care environment. The social, personal, financial, ethical, and cultural elements of primary care must be taken into account to ensure that we reach an authentic understanding of wellness and illness and all that falls in between.

5. What areas do you expect to increase their reliance or would benefit from increased reliance on eResearch infrastructure in the future?

Disseminating knowledge, whether it be between research centres or clinical settings, is key both to validating results and to ensuring practitioners have access to best practice guidelines. Sophisticated information and communication infrastructure is needed to achieve this goal. Significant investment over the past couple of decades in the computerisation of general practice has resulted in a highly computerised work environment. As a result GPs are usually better equipped electronically than the specialist cousins and state managed public health systems. The ability to share research, indeed to research together across the nation, will be a great boon to practitioners.

The use of computers, smart databases, telemedicine, videoconferencing and the like will facilitate large trials and shared knowledge across the country. Such collaborative work can also provide a realistic representation of health of the nation. Health policy and practice may then be enhanced by a richer understanding of the context within
which healthcare occurs.

8. Concluding comments

In responding to the Discussion Paper on the 2011 Strategic Roadmap for Australian Research Infrastructure, we have shared our vision for a rigorous and relevant primary care research sector. An investment in the infrastructure to support such research is well overdue and is demanded by those with a passion for providing evidence-based care in the community. A substantive investment in the kinds of research capabilities that would allow a national PBRN make a real difference to health care at the clinical coal face, that is, during the provision of primary health care.
Appendix A: An overview of Practice-Based Research Networks in Australia

There are seven general practice PBRNs currently operating in Australia, primarily along the eastern seaboard. There are a variety of funding models underpinning their viability. These generally involve a mix of funding from the local university, PHCREd and various research grants. A brief overview of each network is provided below.

PracNet
PracNet is a network of 6 ACT and 4 regional general practices which jointly plan and conduct research in primary healthcare. PracNet also provides a patient pool for external researchers, who have approached the network for assistance, attracting additional funding & further building capacity.

Primary Health Care Research Network - GP (PHReNet-GP)
PHReNet-GP, a PBRN that evolved from the broader PHReNet research network group aims to facilitate and streamline the participation of GPs in high quality primary health care research projects led by the UNSW Research Centre for Primary Health Care and Equity.

VicReN
The Victorian Primary Care Practice-Based Research Network (VicReN) based at the University of Melbourne, brings together primary care practitioners (GPs, practice nurses, community and allied health practitioners) with academic GPs and other researchers in long-term collaborations to conduct research that matters to practitioners and that makes a difference to the delivery of primary care.

Network of Research in General Practice (NRGP)
In 2007, the Departments of General Practice and Rural Health at the University of Newcastle collaborated to establish the Network of Research General Practices (NRGP) in the Hunter, Central Coast and New England regions of NSW. The NRGP includes PHC practitioners (GPs, practice nurses and allied health staff) who are interested in being supported to conduct research and evaluation projects within their own general practice setting.

North Queensland Practice Based Research Network (NQ PBRN)
Members of this network include Practice Nurses and GPs with a common interest in answering questions through developing practice-based research and gathering data. The Network’s main interests are skin cancer, sexual health and enhanced primary health care.

Greater Green Triangle Research Network
This research network which is predominantly a PBRN, evolved over time from the original Greater Green Triangle CVD Prevention Partnership in 2001. Members of the research network participated in a diabetes prevention program and risk factor studies from 2004-2006, and in the evaluative trial of a collaborative care model for comorbid depression, diabetes and heart disease.

South-East Queensland Research Network (SEQRN)
Originally established by the University of Queensland the SEQRN has now expanded to include Griffith and Bond Universities.
Appendix B: Indicative budget for national PBRN infrastructure investment

It is recommended that three different PBRN models are piloted in different states / territories and monitored and evaluated over five years. All comprise one academic department and a number of practices. They differ with respect to number of practices and network purpose. They are:

- small network (up to 15 practices) with greater support per practice
- medium-sized network (up to 50 practices) with less intensive support per practice
- large, topic-specific network (up to 150 practices) spanning several states or territories.

Model 1 - Smaller network, more intensive support per practice

The aim of this model is to enable member practices to develop their own research projects as well as participate in academically-led research. Given that the level of support per practice is relatively high the number of practices is small - up to 15. Each practice would receive facilitation visits, funding support for a research nurse (part of his / her salary as well as training), and / or IT and information management support.

Each practice would receive funding support to be allocated at its discretion towards a research nurse and / or IT / IM support, depending on its particular needs. In addition, a practice facilitator would be employed by the academic department. Over five years the approximate total cost would be $1.25 million, in addition to network infrastructure funding to the academic unit.

Model 2 - Medium-size network, less intensive support per practice

This model is aimed at supporting practitioner participation in research led by the academic department. It involves a larger number of practices - up to 40. Under this model, the academic department would employ up to four practice facilitators who would each service up to ten practices. Practice facilitators (PFs) are health care professionals or research assistants who assist primary care clinicians in research and quality improvement activities and have been used in Australia, the US, England and the Netherlands. Practice facilitators would visit their assigned practices on a regular basis to support their participation in research through such activities as:

- providing training to increase research literacy;
- supporting improvement in practice data systems;
- assisting with recruiting, data collection, reporting, and implementation of new interventions / research findings; and
- liaising with the academic department.

The cost of this model will be determined by the number of practice facilitators.
involved. Over five years the total cost would be $1.25 million, in addition to network infrastructure funding to the academic unit.

Model 3 - Large, topic specific network

This model is a smaller version of the network established for the second Australian National Blood Pressure Study (ANBP2). From 1995 - 1998 ANBP2 recruited close to 2,000 GPs and over 6,000 patients from over 900 practices in five states across Australia to investigate the treatment of hypertension in the elderly in general practice.

The aim of this model is to facilitate participation of a large number of practices - up to 150 - in research around a particular topic (for example, one of the National Health Issues). Studies would be designed by the academic department, requirements for participation would be minimal, and each practice would receive a modest annual payment (to spend as they liked) to facilitate their participation. It is recommended that each practice would receive an annual payment. The total cost over five years would be $1 million, in addition to network infrastructure funding to the academic unit.
Appendix C: An International View of Practice-Based Research Networks

**United Kingdom**
The General Practice Research Database is a highly successful UK initiative, involving some 450 practices in collecting routine data from over 3 million patients. Academic and commercial researchers are able to access the database and have investigated diverse subjects including migraine, fracture risk, congenital abnormalities, antipsychotic treatments, epilepsy, diabetes, blood pressure, stroke, and depression.

In 2007 the Department of Health launched the Primary Care Research Network England (PCRN-E), building on several decades of experience with primary care research networks. The PCRN-E is a national research network comprising eight regional primary care research networks linked to universities. It is funded by the National Institute for Health Research and is one of seven national research networks that make up the UK Clinical Research Network (the others being topic-specific networks).

**United States of America**
There are more than 130 PBRNs operating throughout the USA. In the last five years more than 300 referred journal articles have been produced as a consequence of PBRN research. Funding for PBRNs in the United States of America has come from a variety of sources, particularly the United States government’s Agency for Healthcare Research and Quality Centre for Care, Prevention and Clinical Partnerships (AHRQ). In addition to competitive grant rounds the AHRQ supports the work of PRBNs through a national resource centre, an annual national conference, peer learning groups, an electronic PBRN research repository, and a secure web-based PBRN portal.

**The Netherlands**
The Dutch government established The Netherlands Institute for General Practice in 1965 with a permanent grant and mandated it to bring together interested physicians to conduct collaborative studies on general practice, leading to the development of the Dutch Sentinel Network which has conducted more than 70 longitudinal research studies in addition to its disease surveillance function.