



# **A network of General Practices to monitor changes in chronic disease care?**

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## Table of Contents

<b>1</b>	<b>Executive Summary .....</b>	<b>1</b>
<b>2</b>	<b>Introduction.....</b>	<b>4</b>
	2.1 Scope.....	8
<b>3</b>	<b>Approach.....</b>	<b>9</b>
<b>4</b>	<b>Results.....</b>	<b>10</b>
	4.1 Question 1 - What are the potential uses of a network set up to monitor changes in chronic disease care?.....	10
	4.2 Question 2 - What are the implications of participating in a PBRN for a general practice?.....	12
	4.3 Question 3 - What would be needed to develop and manage such a network?.....	16
<b>5</b>	<b>Discussion .....</b>	<b>20</b>
<b>6</b>	<b>Abbreviations.....</b>	<b>22</b>
<b>7</b>	<b>References .....</b>	<b>23</b>

# 1 Executive Summary

This paper addresses the question of whether it is worthwhile to set up a network of general practices to monitor changes in chronic disease care: what would be the uses of such a network, what would it imply at the practice level and what would be needed at the network level to make it work.

Such a network is initially attractive for the following reasons:

- chronic disease accounts for a significant proportion of the burden of disease and is largely managed within general practice.
- there is a lack of detailed data on how it is managed in Australia and what data we have suggests that there is room for improvement.
- the Australian Government has introduced incentives designed to change the patterns of chronic disease care and it is important to know how these are being used and whether they lead to better outcomes.

Establishing a network is more complex than first appears:

- there is no standard data routinely collected in all Australian general practices which will permit monitoring of chronic disease care and the patient outcomes which result.
- IM systems are immature in general practice and there is no strong research culture amongst primary health care staff.
- Networks require sophisticated governance

While the collection of standard data from routine practice to monitor chronic disease care should remain as the long term objective, the question remains as to whether setting up practice based networks is a useful step on the way to this goal.

A select literature review was undertaken and in depth telephone interviews with key informants from across Australia who were asked the following questions:

1. What are the potential uses of a network of GPs/ general practices to monitor changes in chronic disease care?
2. What would be the implications at the general practice level of being part of such a network?
3. What would be needed to develop, manage and sustain such a network?

Four broad purposes were identified from the literature and the interviews for possible practice networks to monitor changes in chronic disease care:

1. to monitor care using routine data. (Type-1);
2. to permit multi-practice research studies of changes in care in and resulting outcomes. (Type-2);
3. to assess the impact of government policies on the pattern and outcomes of care. (Type-3); and
4. to increase the capacity and skills off primary care staff to engage in and apply research to their clinical activities. (Type-4)

To monitor care using routine data collected in the practice on a longitudinal basis is a very challenging long-term prospect for a research network. It requires the consistent recording of data within and between practices and would require whole practice commitment and major infrastructural investments at practice and network level with ongoing costs to maintain the network. Most informants felt that it was an important long term goal and that it was ultimately the only way to identify changes in chronic disease care and the outcomes of such changes.

Specific multi-practice research studies are also a challenging assignment. Credible RCTs in general practice requires the participation of up to 100 practices requiring a large network to allow practices to choose whether to participate in particular studies. The development of such networks could begin from a much smaller base but small networks will not be able to provide credible research on changes in practice and resulting outcomes. Such networks are more manageable since they are able to focus on particular chronic diseases.

Assessing the impact of government policies on the pattern and outcomes of care is attractive to health services researchers but likely to be less so to practices. It is more likely that these issues will be addressed as subsidiary questions alongside other questions.

Unless networks are limited to the provision of data they will need capacity building activities similar to those currently provided in PHCRED networks. These networks have experience and infrastructure which might contribute to developing networks to monitor chronic disease care.

From the practice perspective, membership of a network is a long-term commitment in and implies participation in more than one project or in ongoing data collection. Such membership requires some incentive. In the UK practices provide data as part of their contract under the Quality and Outcomes Framework and it is used to monitor the quality of their work. One informant spoke of a principle of “equal value”. If a practice is not to lose out from membership of a research network it has to receive equal value for the time and resources spent on network activities as it does from its other clinical and non-clinical activities. This might be achieved through an appropriately valued PIP for approved network research activities. Practices will also require staff with appropriate skills for data management, coding and entry. As one interviewee said “GPs make poor data entry clerks and we cannot use them to enter data when there is a serious workforce shortage”.

Each network would require an appropriate governance system which includes all network members, skilled and credible leadership, programme administration and communication, access to research skills and resources (such as those available through Universities and research institutes), to develop, implement and maintain IT/IM systems and the funds to make initial investments and to maintain and support the network in the development stages and between project and program grants. Dedicated infrastructure would be vital to ensure longer term sustainability

In conclusion, a network of practices which can monitor changes in chronic disease care and resulting outcomes using routinely generated data is a long term but important goal. In the short term it may be possible to develop networks which allow multi-practice research to take place combined with the development of research capacity in those practices and across the network. This might be a first step in developing the capacity to monitor changes in chronic disease care and the outcomes of such changes. Such a step requires careful planning and consultation, but it would be unwise to create a network which was unable to provide high quality data. As one interviewee said “Bad data is misleading”.

## 2 Introduction

This paper was commissioned by the Australian Department of Health and Ageing as part of a contract with the Centre for General Practice Integration Studies at the University of New South Wales.

It addresses the question of whether it is worthwhile to set up a network of general practices to monitor changes in chronic disease care, what would be the uses of such a network, what would it imply at the practice level and what would be needed at the network level to make it work.

Chronic diseases account for a large proportion of the burden of disease in Australia and most care is provided in general medical practices and primary care settings (AIHW, 2006). Patients require planned and continuous care from a variety of disciplines in a timely fashion if they are to experience the best outcomes. Disjointed care can result in acute exacerbations of their condition and greater use of costly secondary and tertiary care. Good chronic disease care also depends on the self management of conditions by consumers and support from family carers and other community and non-governmental sources. It follows that good outcomes, health and quality of life, are the result of a combination of processes in which GPs and primary health care providers play an important role, in conjunction with patients and their carers.

In recent years a number of protocols have been developed for the care of patients with chronic diseases and GPs have been encouraged to adopt evidence based care. The Australian Government Department of Health and Ageing has developed a number of MBS items to encourage GPs to plan care for patients with chronic diseases and to include primary health and other providers in that care. Take up of these items was initially slow but there is evidence that with recent changes in the definition of items and the incentives for delivering them, more consumers have GP management plans and there is an increase in the number of claims for completed cycles of care for diabetes ([www.medicareaustralia.gov.au](http://www.medicareaustralia.gov.au)).

There is limited information about the care that people with chronic diseases receive in general practice. The structure of general practice in Australia has not facilitated the collection of data on patterns of care and their outcomes. It is possible to count some specific elements processes of care such as the number of GP management plans that

result in a claim to Medicare, but that provides very limited information. Many elements of chronic disease care do not result in a claim for a consultation, a prescription for medication or a diagnostic or pathology test and so remain invisible. For instance, the practice nurse may give advice which does not result in a claim and is not recorded. In addition, it is often not possible to see how elements of care are linked in a pattern of treatment for a complex condition or whether they relate to the condition at all, except where a Service Incentive Payment provides an indication that a cycle of care has been completed.

In other contexts the structure of public health services has made it easier to collect data from general practices. For instance in the UK the collection of data is part of the GP contract and GPs can opt to provide care for chronic diseases or not. If the opt to provide such care they are paid accordingly and the contract includes the provision of data about the care provided to the Primary Care Trust. This data can be viewed by practice or PCT on the web site <http://www.primary-care-db.org.uk>. The GP blended payment framework includes quality payment for different items of chronic disease care and so comparative and longitudinal data is being collected which will enable monitoring to take place. In other contexts such as HMOs in the United States there are different, largely financial, motives for collecting practice data.

In Australia, the BEACH project has provided data on encounters in general practice over a number of years using a paper based system in which GPs across the country record information about 100 consecutive encounters. This data is collected, coded and analysed centrally. This encounter data is very valuable but it is cross sectional. It does not allow the linkage of treatments and outcomes and so is essentially descriptive. (Britt et al, 2005)

An important development in general practices has been the adoption of computers for prescribing medications and requesting diagnostic tests. In a recent paper Henderson et al (2006) reported that while computers are widespread in general practices their use is restricted. 94% of practices have computers compared with 31% in 1997 (AC Neilson, 1998). Of the GPs who use computers 94.7% use them for electronic prescribing, 82% for ordering tests, and 79.5% keep some information in a medical record. A third of GPs kept all patient information in an electronic format. About a fifth of GPs kept all data electronically and used the computer for prescribing, ordering tests, medical

records, billing and email, internet and administrative tasks. They found that about 11% of GPs do not use computers.

Henderson concludes that about 80% of medical records are hybrid, composed of paper and electronic records, reflecting a lack of confidence amongst GPs about the security of their computer systems. There is no information about the completeness of paper or computer records, or consistency between practitioners within practices or between practices.

This picture shows that while there has been significant development place in the last decade, general practices are not well positioned to take part in research which makes use of data collected in routine practice.

A number of initiatives have been introduced which encourage GPs and primary health care staff to adopt quality improvement cycles such as the “Plan, Do, Study, Act” processes which underpin the Collaboratives movement. There is a national evaluation of the Australian Collaboratives initiatives underway at the moment which is expected to inform our understanding of the effectiveness and efficiency of the approach (see [www.npcc.com.au](http://www.npcc.com.au)).

The national PHCRED initiative has recently received a favourable evaluation and has been funded for a second phase of 4 years from 2006-9. It aims to increase the capacity of the sector to conduct high quality research and to develop a research base for primary health care in Australia (AGDHA, 2005).

Despite these initiatives, General Practice does not yet have a strong research culture in Australia as it does in other countries such as Netherlands and the UK (Del Mar, 2003). This, combined with problems with the quality of data available from general practice, provides a difficult base from which to develop a research network to monitor changes in chronic disease care. This may not be important if practices are simply providing data as happens in some Divisional diabetes programs such as that in the Illawarra Division of General Practice where data is downloaded from general practice computers to a Division server overnight. In this case the burden on practices is minimal. If practices are to be more than data collectors, the development of a research culture is important.



**This scoping paper examines the possibility of setting up a network of general practices to monitor changes in chronic disease care.**

The phrase “a network of general practices” is capable of a wide range of interpretations and so it is important to be clear about our terminology

Sentinel practices have long been used for infectious disease monitoring and Australian examples include the Australian Sentinel Practice Research Network ASPREN which monitors influenza-like diseases with a very limited infrastructure. A recent paper based on an evaluation of ASPREN reported that its membership was falling and there were some difficulties in consistency of data yet it was performing as well as similar systems elsewhere. (Clothier, 2005)

The term Practice Base Research Networks (PBRNs) is popular in the literature and covers a variety of entities with often more than one purpose. These include the development of research skills and capacity among the network members (e.g. PHReNeT in NSW, and SARNET in South Australia), the conduct of research studies by some or all network members (Thomas, 2006 in UK), and, perhaps the greatest challenge the development of data definitions and collection processes to allow credible research to be undertaken using routine general practice data (van Weal, 2006. Netherlands).

The term “monitoring” can have a number of meanings. It can include observing care processes and procedures to see if they meet a set standard. This observation might take place by the providers or practices themselves or by an external party. It may focus on whether practices follow guidelines or employ best practice care. It is not intended to cover the monitoring of clinical practice undertaken by Medicare to identify unusual patterns of claiming or practice.

The focus on the process of chronic disease care implies a practice rather than a GP focus since the care processes are practice wide and the data is owned by the practice not by individual GPs.

Informants were very clear that describing processes of chronic disease care is of limited value if we cannot show how they contribute to patient outcomes. Alternatively, a case can be made for monitoring whether practices follow evidence base guidelines

without addressing outcomes at the practice level since there is reason to believe that the guidelines are well founded.

There has been a growing Australian interest in Practice based research networks (PBRNs) in the last five or so years. Recent papers by Gunn (2002), Beecham (2005) and Zwar (2006) have considered the issue and there have been attempts to set up such networks. Zwar et al suggest that research networks might be the missing link in allowing the development of large scale, high quality research rather than small scale descriptive work and surveys. Such networks in Australia would require strong links between Universities, Divisions of General Practice and practices; the building of research capacity; a continuing funding base and adequate remuneration for practices. While small networks of University based general practices have been set up progress in Australia has been patchy. The University of Melbourne is in the early stages of developing a network and at the time of writing is consulting with interested parties on the possible purpose and shape of such a network.

## **2.1 Scope**

While recognising that research capacity development is a key activity of most PBRNs, this paper does not consider those networks whose sole purpose is to develop the research skills of primary health care practitioners nor does it consider quality improvement networks.

### **3 Approach**

This paper is based upon a select review of the literature and a series of in-depth recorded interviews with key informants from general practice, primary care research and the Divisions network. Informants were based in Australia and included individuals who have been members of such networks in Australia and overseas, informants who have set up and managed such networks, researchers who have undertaken multi-practice research studies and others involved in the National Primary Care Collaboratives movement.

Informants were asked three broad questions:

1. What are the potential uses of a network of GPs/ general practices to monitor changes in chronic disease care?
2. What would be the implications at the general practice level of being part of such a network?
3. What would be needed to develop and manage such a network?

The interviews were transcribed and thematically analysed as the interviews proceeded which allowed later interviews to build on and develop ideas raised in early interviews. Opportunities were taken to discuss issues with key informants at other face to face meetings during the research period.

This research was approved by the University of New South Wales Human Research Ethics Committee.

## 4 Results

The findings in this section represent the views of the key informants. These comments were raised in interviews and the author probed for better understanding and raised issues in subsequent interviews for clarification and to test the breadth of support for the findings.

### 4.1 Question 1 - What are the potential uses of a network set up to monitor changes in chronic disease care?

The responses identified four types of uses, with rather different requirements. These are not mutually exclusive.

#### 1. To “monitor” changes in the activities or processes of care using routine data

Informants emphasised that we do not have reliable information on how chronic diseases are managed in general practice. We do not know the range or pattern of processes in place, whether evidence based protocols are followed and the extent of gaps in care processes. (NICS, 2003)

...the big issue is about the opportunity to collect information from general practices about what happens in general practice and the clinical care that is delivered and the outcomes of that care ..... I think it's a huge shortcoming of primary care in that we have an enormous amount of funding that is spent in this part of the health care system but we know very little about what it really does.

GP informant

To monitor changes in chronic disease care at the practice level, researchers need a system which enables the identification of patients with particular chronic diseases, records each element of treatment from different providers within the practice including plans, advice, information, physical treatments, referrals and reports as well as chargeable elements such as consultations, prescriptions, tests etc. The diagnostic information needs to be coded or capable of being coded using a standard classification such as the International Classification of Primary Care (ICPC) which has been adopted

as the Australian standard. This information might be recorded for a small subset of patients and could not be collected across the full range of conditions.

The information needs to be held on computer for easy retrieval and issues of privacy, confidentiality, consent and data ownership need to be resolved.

*2. To facilitate research designed to identify the outcomes of different methods of managing particular chronic diseases.*

Practices are often approached by researchers, quality improvement staff and evaluators to participate in individual studies, involving one off data collection systems. These have to compete with a wide range of other demands on practices. Informants commented that networks of practices might help identify interested practices who could take part in research studies on an ongoing basis. These practices would develop appropriate infrastructure and skills which would support high quality research. To account for the variation in general practice within Australia, large networks of 100 plus practices would be needed if credible controlled trials were to be possible. Less sophisticated research designs would be possible with smaller numbers of practices but they would not be able to produce the same quality of evidence.

*3. To assess the impact of government policies on the pattern and perhaps the outcomes of chronic disease care within general practice.*

A number of government policies have provided incentives for changing the pattern of chronic disease care introducing fees for care planning and for completing cycles of care. These policies might be piloted in a research network and fine tuned or adjusted to improve effectiveness, efficiency or acceptability before being implemented more widely. A network might also be used to track the use of measures and examine what assisted or impeded their uptake.

*4. To increase the capacity of primary care staff to engage in research and to apply the findings of research to their clinical activities.*

Interviewees discussed a number of research capacity networks developed under the national PHCRED strategy to develop the research skills of primary care practitioners and to strengthen the research capacity of the sector. Examples include the Primary Health Care Research Network (PHReNet) at the University of New South Wales and the South Australian Research Network (SARNeT). These were seen to have a different

objective although it was thought that the networks discussed above would need a capacity building component.

#### **4.2 Question 2 - What are the implications of participating in a PBRN for a general practice?**

Interviewees indicated that GPs and practice staff would generally not be interested in becoming data collectors for other people's research. Members of Practice Based Research Networks (PBRNs) would often want to take part in the identification of research questions, the choice of methods, the analysis and interpretation of results and to share in credit for the findings (Green, 2003). In short, interested primary health care staff and practices want to be co-investigators and not the subjects of research. This has implications for the design and governance of networks and the extent to which sponsors can govern the direction and activity of PBRNs (see page 16).

As noted above, the research culture in Australian primary health care is not well developed, and the number of GPs and primary health care staff who are currently equipped to act as co-investigators is small. Informants emphasised that general practices vary considerably in their staffing, pattern of care, maturity of IT and other systems, population served and a wide range of other factors. A few could be ready to take part in a research network, but most would require considerable investment and skill development before they could play such a role. Networks would require a capacity/skills development component as a key part of their activities (Del Mar, 2003) that took account of the variation between practices and between staff within practices.

Another challenge is the long term commitment and significant investment in human and material infrastructure required before research produces outcomes. Even if such resources are available there may be few practices in the short term willing to sign up to the length of commitment necessary to plan, resource, design, conduct and report on quality research in chronic disease care.

Several informants pointed out that practices willing to sign up to such a commitment will be atypical and therefore it might be difficult to generalise between them and the wide provider population.

One informant commented that a principle of "equal reward" was needed. Taking part in research needs to be as rewarding as other activities undertaken by practices,

particularly patient care. The current National Primary Care Collaboratives program is moving some way towards this principle by paying practices for their participation and paying Divisions of General Practice to recruit and support those practices. Unlike the collaboratives which are designed as a relatively intense short term investment in quality improvement in practices, membership of a network must be a longer term commitment. Other informants have suggested that there should be a PIP payment for participation in (approved) research.

Green (2003) reports that from the American experience PBRNs require a minimum of 15 GPs or 15 practices to be viable. The Australian interviewees felt that membership by one or more GPs in a practice would not be sufficient to enable the monitoring of care or the conduct of good quality research. Chronic disease care is a collaborative activity and so all members of the primary health care team need to be involved in the research process. The recruitment, participation and retention of whole practices is a demanding yet necessary requirement in a context where institutional ethics committees require informed consent from all participating staff and patients involved in a project.

The impact on and requirements of a practice would depend on the task and design of a PBRN. In some cases the design would allow network members to participate in some projects and to opt out of others depending on their interests and competing commitments.

Four broad purposes for networks were identified in the last section. The differing practice requirements for each are set out below;

*Type 1            Monitoring changes in care processes using routine data*

Monitoring changes using routine data would place the highest demands on the practice since it requires that the practice adopt standardised methods for recording processes of care. These would need to be consistent with other network members to permit comparisons to be made over time and between practices. This dataset might be limited to a small number of conditions and indicators but the data collected would need to be consistent and complete.

In the Netherlands small practice networks associated with their local University meet together on a monthly basis to determine the best way of recording and classifying activity so that research is possible based on the collection of routine data. This is a long term activity ..... In many cases the GPs involved have completed research degrees and hold conjoint academic positions.

Van Weel 2006

Although accepted classifications such as the International Classification of Primary Care (ICPC) and databases such as NDOQRIN for diabetes and CVdata for vascular disease have been adopted in Australia, they are not currently integrated into practice management software in general practice. This will be required if routinely collected data is going to be used to monitor changes in chronic disease care.

The key informants identified a number of reasons why data routinely collected in general practice could not be used at present for monitoring chronic disease care:

- Practice software is not designed for monitoring care processes or for creating consistent records based on standardised definitions and classifications.
- Many practices have a combination of computer and paper based records. This would make data extraction difficult.
- Often, different practitioners in a practice record activity in their own way using paper, computer or both.
- Records are constructed during and after consultations by providers who are not considering possible research uses for those records. They often commence with symptoms, record treatments medications and referrals. It may be hard to link this record of activity with underlying condition and treatment processes.
- Part of the record is a list of medications which may not be explicitly linked to a problem or to treatment plan.
- It is hard to estimate the extent and significance of missing data in practice records.
- These records may resemble an aide-memoir rather than a comprehensive record.

If data for monitoring chronic disease care is to be collected routinely a number of significant infrastructural investments will be necessary



- Investments would need to be made in developing or purchasing appropriate data sets and classifications of disease and clinical activity. These would be informed by the purpose of data collection and the means of implementing this in clinical practice.
- Resources would be needed for the collection and entry of data. One informant commented that GPs make poor data entry clerks and in a time of manpower shortage the opportunity cost is very high. It was noted that data entry clerks undertake this function in the hospital system and that sophisticated systems are in place for this purpose.
- Practice software needs to be developed to facilitate data entry and given the market structure in medical software products; it must be possible to extract data from different commercial programs.

Appropriate incentives need to be provided for practices since monitoring based on routine data requires a long term investment before it will be possible to monitor care and outcomes.

*Type 2: Participating in multi-practice research projects*

Participating in multi-practice research is in some ways a simpler task than routine monitoring and may be a step towards the development of networks capable of such monitoring.

In multi-practice research projects the task is usually time limited and the range of variables/data required confined to specific research questions. In this type of activity, practices are likely to expect to be involved in the governance and management of the network, including the choice of projects.

Participation in such network activities may bring benefits for the practice, its staff, patients and the wider community. These include the opportunity to take part in research that reflects the perspectives of primary health care clinicians, whose priorities may be different from University based researchers or government funders. Evidence from the UK suggests that have been given a good deal of freedom in the first instance to pursue questions of interest to the partners rather than an imposed research agenda from a sponsor or funding agency. It appears that recent developments in the UK are emphasising the role of Primary Care Trusts in negotiating local priorities within the network's research agenda. (Chen, 2006)

Informants reported that practices are looking for short term benefits as well as making long term contributions to knowledge and clinical practice. These short term benefits include improvements to patient care, a contribution to the practice as a business and a contribution to the quality and challenge of work within the practice. In the longer term practices could contribute to important developments in knowledge about what constitutes effective chronic disease care in primary care settings. Practices joining in such network activities would expect that the costs of participation would be met and that the commitment would be medium or long term since they are reluctant to make significant changes without appropriate guarantees.

*Type 3          Assessing the impact of policies and procedures.*

A network might also monitor the impact of new policies and procedures for chronic disease care. This would address national policies and priorities while practices are likely to be interested in local issues. It is possible that network members might be willing to address policy issues as part of a wider set of purposes since policy developments may be necessary to support best practice chronic disease care.

*Type 4          Developing the skills of network members*

Research Capacity development networks *per se* are outside the scope of this paper but informants were unanimous that networks to monitor chronic disease care would require mechanisms for capacity development for members.

**4.3 Question 3 - What would be needed to develop and manage such a network?**

The design of a network to monitor changes in chronic disease care will depend very much on its particular purpose. However there are some elements which will be required by any network. There was broad agreement among informants that a network would require some form of:

- governance system
- leadership
- administration
- communication systems
- IT development and support
- access to appropriate expertise

- physical and financial infrastructure

## **Governance**

All members of a network would expect to contribute to agreements about the purpose, activities and rules under which the network operates. Clearly those who contribute resources would expect to influence the direction and activities of the network as would participating practices and their staff. Since chronic disease care is a longitudinal process which involves providers working together with the patient, the governance arrangements will need to recognise these legitimate interests and be responsive to them. Membership of such a network is likely to raise issues of confidentiality and privacy which are more complex than those which arise in single research studies.

The networks would also have to meet the requirements of institutional ethics and stakeholder accountability procedures and would need to be able to ensure compliance, monitor activity and respond to unexpected difficulties.

Informants were strongly of the view that networks to monitor changes in chronic disease care and resulting outcomes should be made up of practices and not of individual practitioners, although there would be leaders within member practices.

## **Leadership**

Networks would require leaders who are credible in a number of senses. Professional credibility to GPs and primary health care practitioners implies that the leadership includes leading practitioners from a range of disciplines. Leaders will need a research track record to attract funds for research projects and programs and the skills to take part in the recruitment and retention of network members. They would have to be credible to stakeholders including governmental, professional and educational/research entities.

## **Administration**

The administrative function of a network would be crucial and practices would be expected to be able to communicate with the network at times to suit the practice. The administration would need to maintain roster of members and a record of activity. It

would I need to have means to manage resources and record activity along with strong problem solving skills.

### **Communication systems**

Informants emphasised that networks are based on communication and must be able to facilitate communication between member practices and provide access to electronic information such as journals and research publications that are assumed to be provided for university and hospital staff but often not available to clinicians in practices. They would have to be able to facilitate face to face meetings as well as maintaining a virtual network. The network would be likely to need a web site or intranet. Even networks which focus on data collection will want to maintain good links with member practices who will be interested in the findings relative performance of their practice.

### **IT development and support**

It was noted above that IT maturity in general practices is generally low and would require support within the network. This extent of this task would depend on the type of network activity, its size and the level and skills of resources within practices.

Almost all informants agreed that data collection needed to be electronic and noted that current systems were not designed for this.

### **Access to appropriate expertise**

Many informants mentioned that a network needed access to high levels of expertise if to interpret data that could be collected in what would be likely to be an atypical group of practices. Examples included the need for experienced statisticians able to assist in the design of network research, and in the analysis and interpretation of data. Access to appropriate clinical specialists would also be needed.

### **Physical and financial infrastructure**

Particular emphasis was placed on the importance of there being face to face contact in a network. The ability to speak to and meet people rather than simply send emails was thought to be very important.

### **Location of a network**

A series of problems were suggested concerning the possible location of a network. Many University departments would like to lead and develop a network. This could be shared across departments, but at the cost of further complexity. The need for member practices to meet face to face suggests a relatively local network, although this might be less representative of Australian general practice than one which was more widely dispersed.

## 5 Discussion

This study has confirmed that there is considerable attraction in the idea of a network of practices to monitor changes in chronic disease care. This could provide much better understanding of this complex but very important area of health care, and highlight what is involved in primary health care approaches to chronic disease care. It could also show changes over time and allow those who support the development of chronic disease care to target their efforts more accurately.

However as well as endorsing the potential benefits, the key informants involved in this study were aware of many difficulties in setting up networks, sustaining their work and enabling them to produce valid and important results. These included the variety of purposes that a network could pursue, the varying interests of the participants (including the great variety within general practice), the need to engage network members in the business of the network, the challenge of developing systems to support high quality data collection and the overall requirement to foster a culture that would value such activity. One particular issue for the Australian context is the lack of incentives for participating in a network and the challenge of creating them in the mixed economy of general practice funding.

Against this, a number of research networks already exist as part of the PHCRED program, and other networks are under active consideration.

One possible conclusion from this work is that it is currently too difficult to set up a network to monitor changes in chronic disease care. If, however, there were interest in pursuing this idea further, it would be possible to review the PHCRED experience and identifying opportunities within existing PHCRED work plans to learn more about the building of such a network. This could be supplemented by monitoring the experience of overseas networks. It would also be possible to support one or more of the emerging proposals for developing a research network, using the findings in this paper to anticipate problems and identify questions which the project might answer about the operation of such networks in the real world.

Another strategy might be to find ways of supporting research in general practice which could create a more favourable environment for such networks. Thus one might identify ways of enhancing the incentives and support for research within Australian general

practice, perhaps through changes to current funding arrangements, or exploring how the Divisions network might take a stronger role in supporting research networks. It would also be possible to further develop standards for data items and for electronic connectivity in practice software systems.

Perhaps the most important lesson from this work is that developing any network will need to be done carefully, with detailed planning, consultation with stakeholders and sufficient resources to support its work.

## 6 Abbreviations

APHCRI	Australian Primary Health Care Research Institute
ASPREN	Australian Sentinel Practice Research Network
DOHA	Department of Health and Ageing
ICPC	International Classification of Primary Care
MBS	Medical Benefits Scheme
NICS	National Institute of Clinical Studies
PBRN	Practice Based Research Network
PIP	Practice Incentive Payment
RCT	Randomised Control Trial
PHReNet	Primary Health Care Research Network
SARNeT	South Australian Research Network



## 7 References

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