

Primary Care Research Networks: What Do They Offer?

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Abstract

This article outlines the background to the development of primary care research networks and the UK Federation of Primary Care Research Networks (UKFPCRN). The format and function of both the UKFPCRN and a regional network, the West Midlands Primary Care Clinical Research and Trials Unit (PC-CRTU), are described. Some of the levers and barriers to research in the primary care setting are discussed. These may be relevant to research in all service settings. Some of the opportunities for, and impediments to, partnership working with social services are indicated.

Background

Over 90% of patient contacts with the NHS occur in primary care (White, Williams and Greenberg, 1961; Green et al, 2001; Mant, 1997). However many of the interventions used in this setting remain unproven. In the past 50 years, most medical research has been undertaken within secondary care and in particular within teaching centres. It has used a reductionist bio-medical model, which has greatly improved the care of patients including those in primary care (Green et al, 2001). However, the focus on this type of research has left many questions of relevance to primary care unasked and unanswered.

The natural course of any disease can be described as progression from the first occurrence of disease to the first episode of symptoms, which may lead to a primary care consultation and subsequent treatment. For some conditions patients will be referred to secondary care. The population available to the researcher at each of these stages differs in terms of severity of symptoms, stage of disease, patient attitudes, and response to treatment. Most patients seen in primary care have earlier or milder disease than those referred to hospital. Therefore, the positive predictive value of diagnostic tests in primary care is lower than in secondary care, and invasive investigations may be less justified and less acceptable to patients. Management decisions taken by primary and secondary care doctors may also differ systematically, reflecting different experience and priorities. Research undertaken in secondary care may underestimate the prevalence of disease and overestimate the impact on quality of life compared with observations in primary care (Wilson et al, 2000). Therefore, interventions shown to be effective in secondary care may have limited value in the community. Primary care research covers many areas including the natural history of illness,

the determinants of prescribing behaviour, the health beliefs of the public and often examines the role of the patient rather than the disease or organ (Anon, 2002). Hence, research that would be relevant and of interest to primary health care teams includes social as well as clinical research.

In addition to the need to strengthen the evidence base for primary care, participation in research should also bring other benefits to primary care; increased research awareness, improved clinical knowledge, and most importantly, improved patient care. It is also possible that involvement in activities other than solely direct patient care is associated with increased job satisfaction and staff retention.

During 1997, two reports (Mant, 1997; Medical Research Council, 1997) had a significant impact on the development of research in Primary Care and the primary care research networks which facilitate this research. The MRC Topic Review (Medical Research Council, 1997) recognised the need for increased research capacity in primary care and made several recommendations relating to training and infrastructure developments. The Mant Report into Research and Development (R and D) in Primary Care (Mant, 1997) also emphasised the need for infrastructure developments; including that 'R and D networking arrangements should be developed to provide expert support for local research'. This recommendation stimulated many regional NHS R and D offices to invest in primary care research networks.

The UK Federation of Primary Care Research Networks (UKFPCRN)

Primary Care Research Networks (PCRN) began to be established in the UK in the late 1980s. The first national meeting of PCRN was held in 1995

and attended by eleven networks, a second meeting in 1997, was attended by representatives of 24 networks (UKFPCRN, 2001).

The UK Federation was formally launched in May 1998 to 'co-ordinate collaborative primary care R and D activity taking place in more than one region' (Mant, 1997). The South West R and D Regional Office provided initial funding for this 'network of networks'. Membership is open to any PCRN or Research and Development Support Group (RDSG) in the UK. The unit of membership is the network rather than the individual. Members pay an annual subscription fee, are given the opportunity to take part in all decision-making activities, receive a discounted rate for conferences and are eligible for election to the steering committee. Twenty-six networks signed up as members in 1998-99 and we currently have over 40 members. It is now Government policy to develop research capacity through primary care research networks and the number of networks across the UK continues to increase (Department of Health, 2000a).

There is no single model for networks. They range from small groups of local primary care practitioners who develop and undertake their own research to large regional networks. Whilst some networks have practices as their unit of membership, others have individual practitioners. Some have no core funding, whilst in some areas, regional NHS offices recognised the contribution of PCRNs to building research capacity and were prepared to make a substantial investment. There are single specialty networks, for example, of practice nurses, and others that aim to meet the needs of all members of the primary care team including ambulance services, pharmacists, dentists and optometrists, as well as those clinicians working within primary care teams. The range of activities they engage in is largely dependent on the needs of local network participants, the aims of the network and their funding levels.

Despite the many differences between networks, they all have the same overall aim: to increase the quality and quantity of primary care based research by encouraging practitioners to participate in high quality research. A core set of objectives has been agreed with the Department of Health (Department

of Health, 2000b), which recommends that all networks should:

- Promote the use of research in clinical practice.
- Encourage practitioners to participate in research.
- Identify research training needs amongst its constituency.
- Organise research training.
- Facilitate research collaborations between primary care and other health related agencies, such as social services, local authorities and the acute sector.
- Provide access to information on potential research collaborations, research training opportunities, research funding.
- Provide academic advice.
- Facilitate change in the research culture of primary care.

Obviously the funding, academic strength and research expertise contained within each network determines the extent to which it can successfully deliver all of these objectives and lead externally funded high quality research of national relevance.

The Federation aims to provide the means and focus to enable networks to learn from each other and to promote their interests at a national level. Its objectives include:

- Facilitating communication between primary care research networks.
- Sharing strategies and resources for success.
- Collaborating with, or providing representation to, outside groups such as professional organisations, funding bodies or the government to ensure that the networks' interests are considered.
- Facilitating cross-regional research activity.

Communication, often through consultation amongst the networks, is probably the most important of the Federation's roles. Information is circulated to, and sought from, the membership via email; a newsletter, *NetConnect*, is published three times a year; and, a Directory of members is maintained and circulated. The Annual Conference is an integral part of the communication strategy; it provides an opportunity to share experiences and present research. The Annual General Meeting is

held during the conference to ensure that as many members as possible can be present and have an input into the running of the Federation. Specially organised meetings are convened as necessary; for example, in March 2000, a meeting was arranged, attended by representatives of almost every network in the UK, relating to the proposals for changes to NHS R and D funding and the potential implications for networks. In October 2001, the Federation jointly organised a meeting with the Royal College of General Practitioners about the Primary Care Research Team Assessment Scheme and last year, the UKFPCRN worked with Trent Focus, a regional network, in facilitating a conference on the highly relevant topic of consumer involvement in research.

In addition to promoting the networks at regional, national, and international levels and facilitating communication among the membership on matters of common interest or shared importance, the UKFPCRN also convenes subgroups to undertake work that is of relevance to all its members. The recent workforce survey, REACT (Responsibilities, Experiences, Arrangements for Contracts and Training needs of primary care research network staff), demonstrated that the staff employed by networks are mainly on part-time, fixed-term contracts within Universities, have a wide range of professional backgrounds and have a wealth of research skills and experience. Ongoing work aims to identify meaningful outcome measures to assist networks, and those providing the funding for them, in the complex task of evaluating networks. Collaborative research is fostered through three special interest groups that focus on cardiovascular disease, mental health and cancer.

West Midlands Primary Care Clinical Research and Trials Unit (PC-CRTU)

The West Midlands Primary Care Clinical Research and Trials Unit (PC-CRTU) is an example of a research network that, in addition to endorsing the core objectives for networks, has broader objectives. The PC-CRTU aims to facilitate quality assurance in the execution of research in primary care, and provide access to and engagement of practices to enable the successful completion of large-scale primary care based trials.

The PC-CRTU is the umbrella organisation for a Regional consortium of Primary Care Practices (MidReC) and a Research Support Facility (RSF). It is based in the Department of Primary Care and General Practice at the University of Birmingham. Membership is free and open to all primary care professionals that wish to participate in academically led primary care based R and D. At the moment, the network is supporting 12 externally funded, academically led studies. The PC-CRTU also aims to build a research infrastructure and enable a research culture to grow in primary care by facilitating both 'top down' and 'bottom up' research. Pilot studies have been encouraged into substantive research and individuals have been able to develop their research skills through training bursaries and small grants. Important concurrent aims are to enhance the professional satisfaction, motivation and skills of practitioners and the sharing of ideas and enthusiasms. We aim to help develop practitioners' abilities to question and reflect upon their practice in a learning environment thus enhancing continuing professional development.

The PC-CRTU currently includes more than 200 general practices with over half a million patients across the West Midlands which are involved in supporting academically led research. It administers almost £3 million of Budget 1 and 2 NHS R and D money; this enables reimbursement to practices for locum cover for meetings, pre-protocol and pilot research and covers the costs of their involvement in external grant funded research i.e. their time and infrastructure costs. The Budget 2 funding is used to increase research awareness, improve research skills and develop practitioner-led research. In addition to regular research skills training courses, a competitive small grant scheme is offered (maximum of £5,000) and bursaries to cover the fees for a Masters programme are awarded. One-to-one facilitation is available to those who apply for a small project grant. These grants have been extremely successful, almost all of the completed projects resulting in a peer reviewed publication. Most recently, we have awarded a PhD studentship; this was widely advertised, open to all non-academic primary care professionals in the West Midlands and secured by a community-based palliative care nurse.

The PC-CRTU has a staff of 12 whose roles include providing one-to-one facilitation and support for practitioner led research, running a series of research awareness and training courses, providing research governance training days for practices, calculating service support costs, developing minimally intrusive means of collecting practice data and feeding back information to practices.

Engaging Service Practitioners in Research

The need to develop primary care and to underpin this with good quality research has been recognised (Mant, 1997; Medical Research Council, 1997). However, to achieve this it is necessary to engage with and involve primary care practitioners in research. Some of the most obvious barriers to their participation in research include:

- Policy changes in the delivery of healthcare; the move to Primary Care Groups, and now Primary Care Trusts in England and the local Health Care Co-operatives in Scotland, have generated additional workload for practices.
- Competing clinical priorities; primary care has to respond to and implement a plethora of competing National Service Frameworks (NSFs), which also generate considerable additional workload.
- The seasonality of workload; certain times of year, such as the commencement of the 'flu campaign, may restrict the opportunities for clinicians to participate in research.
- Primary care is something of a 'swamp'; people arrive at 7-10 minute intervals for six hours a day five days a week with a diverse range of conditions.
- A relative lack of a research culture; general practitioners (GPs) have traditionally spent all of their time seeing patients and managing the practice and, unlike many of their hospital-based colleagues, many GPs and other primary care based independent practitioners, such as dentists, optometrists and pharmacists, are not used to routinely entering patients in clinical trials. Practitioners may need training in research methods and quality assurance. The organisation of the research is often not straightforward, for example, organising a research clinic where a group of patients with

the disease of interest attends, requires much more planning and administration than in the specialised hospital setting.

To successfully encourage members of the primary care team to participate in research, we need therefore to develop research designs and mechanisms that:

- Create minimal disruption to the daily routine of primary care; a study that does not respect the centrality of the daily routine and causes disruption is unlikely to generate much enthusiasm from practitioners.
- Pose and answer questions relevant to primary care. Inevitably not all practitioners will be interested in all questions, but research that is developed in collaboration with practitioners and where the results are likely to have a major impact on practice should generate greater levels of enthusiasm than research ideas which are perceived as being primarily of academic interest, imposed in a top down manner.
- Maintain regular but unobtrusive contact to encourage recruitment. In reality this means creating good organisational systems and arranging contact that is practice specific in both content and timing.
- Meet the additional service support costs (see below) that are incurred by practitioners who participate in R and D.

NHS Service Support Costs (Support for Science funding)

In Health Care R and D the division of costs into Research costs, NHS Support costs, NHS Base costs and Treatment costs is well established and funding sources for all four elements are equally well accepted (Department of Health, 2002). Research costs include data collection, analysis and the other costs involved in undertaking the research, including the direct and indirect costs of employing the staff involved. Those funding the research meet these costs. NHS Support costs comprise the additional costs of patient care associated with participating in research, such as the time taken to obtain informed consent, extra patient tests, extra in-patient days, extra nursing attention; these costs will not continue to occur beyond the period of the research study even if the

intervention assessed is subsequently accepted into routine practice. NHS Base costs are the costs associated with NHS staff managing and undertaking research projects Support costs and Base costs are met from NHS R and D Support for Science funding. Treatment costs are those associated with the intervention, 'treatment', that would continue to be accrued if the intervention became accepted as standard care and are met through the usual commissioning arrangements for patient care.

So, for example, we have recently been awarded £340,000 charitable funding to examine the clinical significance of sub-clinical thyroid dysfunction. However, in addition to the research costs associated with organising the trial, training the practitioners, collecting and validating the data, analysis and interpretation, there are significant service support costs. GPs and practice nurses need to take time out of surgery to participate in training sessions, they need to spend time seeking fully informed consent from patients, patients need to have extra blood tests and ECGs. If we could not make payments to the practices to enable them to obtain locum cover, for them to buy in additional nurse sessions and to cover the costs of the additional tests, they would not be able to collaborate in this research project. The service support costs are not insignificant, and for this trial are almost as much as the research funding that we have secured.

A pilot study has recently been undertaken to assess the value of locating a social worker in an Accident and Emergency department as an integral member of the emergency care team (McLeod et al, personal communication, University of Warwick). The pilot study concluded that this enhancement to existing services might provide important benefits for both patients, particularly those aged over 65 years, and their carers. However, the cost-effectiveness of this intervention needs to be established in a large, multi-centre, randomised controlled trial if robust and generalisable results are to be generated. The 'treatment' costs involved in this evaluation are likely to be substantial; they include additional social workers and may include new care packages and admission to residential care. Service support costs will include time to train the practitioners involved in the research

project and the time required to obtain informed consent from potential participants; it is unlikely that research staff could undertake this without compromising the trial. The definitive study has not yet taken place because, although we may be able to secure the research costs of the trial we cannot see a mechanism that would enable the treatment costs or the support costs associated with this research to be covered. Effective partnership working between the NHS and Social Services may be facilitated if the mechanisms that have been established to cover the costs of R and D in the NHS are extended.

Conclusion

Research into the effectiveness of interventions in primary care needs to be undertaken in the primary care setting. Trials in primary care should give more representative results and are preferable to applying results obtained in secondary care. The development of appropriately funded research networks, linked with academic centres, could lead to the development of a more rigorous and robust primary care evidence base and the provision of more informed and appropriate patient centred services. Networks play a pivotal role in enabling and encouraging a research culture in primary care, creating research opportunities, and encouraging bottom up as well as top down research. This research is enabled by the provision of NHS Support for Science funding to cover the service costs associated with participation in research. Mechanisms for the evaluation of networks need to be developed to see, for example, if they are a cost effective method of increasing the volume and quality of primary care based research. At the moment they appear at the very least to be a positive way to 'fast forward' primary care research.

At last, national policy is directed towards partnership working, where health and social services can join forces to provide integrated care to improve the health of the population as a whole (Department of Health, 1998). There are numerous areas where we can work together to improve care. There is a will to collaborate and many reasons to do so. What we need to do now is work out how we can progress these research collaborations. However, mechanisms for obtaining funding to

cover the additional 'treatment' and service support costs that will be incurred in social care need to be established if partnership research is to thrive.

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