



## Current Issue

### LECTURE

#### **Practice-based research networks for studies in family medicine**

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#### **Abstract**

This paper reviews the state of practice-based research networks (PBRN) in family medicine research. Essential for the development of family medicine is the availability of data from regular patient care in family practice: on the illness and diseases encountered and effectiveness of their treatment, the views, values and needs of patients and the use of health care facilities. PBRNs provide a structure to collect these data and make research more valuable for family practice.

PBRNs also provide a forum to expose family physicians or general practitioners (GPs) to research and improve the sensitivity of family practice for research developments in implementing research findings and raising the scientific level in family practice. GPs from PBRNs are particularly valuable for academic careers, combining patient care and research.

This enables the collaboration between PBRNs and research institutes, to oversee methodological expertise in data collection. For data collection the International Classification of Primary Care presents a logical framework. This highlights the international support and exchange for PBRNs in building the capacity of family medicine research.

**Key words:** family medicine, practice-based research networks

The development of family medicine is directly related to the ability to produce empiric data from regular patient care. This way, its health problems, and the family physician's or general practitioner's (GP) unique role and function in medicine can be analyzed. This comes forward in the work of the founding fathers of the discipline of family medicine that is related to data collection from their own practice – for example Will Pickles' infectious diseases<sup>1</sup> or the family histories of illness and disease of Frans Huygen.<sup>2</sup> They changed, with their practice-based research, the face of medicine. In 2003 the World Organization of Family Doctors (Wonca) held a conference on the future of family medicine research.<sup>3</sup> The aim of that conference was to foster research as a means to improve health – through better primary care – of people around the world. For this, access to practice and patients' data and networking of family practices for research was one of the key recommendations for the building of a research infrastructure.

#### **Practice-based research networks (PBRN) and family medicine research**

This infrastructure, referred to as 'practice-based research networks' (PBRN) has become a feature of family medicine research.<sup>4,5</sup> PBRNs can tap into the realities of everyday family practice: the health problems, needs and expectations of patients, the diagnostic and therapeutic performance of GPs and the guidance of patients through the health care system. These elements are directly related to the research domain of family medicine.<sup>3</sup>

- primary care morbidity;

- patients' expectations;
- use of health care facilities.

PBRNs are able, through the very nature of family practice, to access the continuity of patient care, and extend the time-window of study in research projects: longitudinal research<sup>6</sup> essential in assessing the outcome of illness and disease.

### **PBRN: a concept**

PBRNs are networks of practices and practitioners with the objective of collaborative research on problems and questions derived from patient care. PBRNs are driven by practitioners' research interests, resulting in ownership of research. The level of actual commitment for practice and practitioners varies. PBRNs can be involved in on-going data collection<sup>6,7</sup> but many PBRNs have a much less demanding structure with GPs, opting in and out of studies according to their preference. GPs' involvement can be directed at the choice of projects and their aims, their planning and designing, and data collection and interpretation. This can help in making research better directed toward the needs of primary care and a fuller application of its results.

PBRNs collect data, from which comprehensive databases can be formed. Particularly with computerization of practices, very large primary care databases have been developed.<sup>8-10</sup> But to consider PBRNs as just a means to collect data or build a database ignores its real potential: PBRNs are a means to change the culture of (family medicine) research and (family) practice. Its true virtue is an on-going exchange between practice and research. For that reason, a particularly attractive option in PBRNs is to involve GPs in the role of researcher and train practitioners by doing research skills.

### **Examples of PBRNs**

PBRNs have long established their place in the Netherlands (related to most of the university departments of family medicine)<sup>5,6,11,12</sup> the UK<sup>5</sup> and US<sup>4,5</sup> but particularly relevant examples come from countries where primary care and family medicine research do not have a track record. The South African sentinel network<sup>13</sup> illustrates the value of information on the main health problems in the population to build responsive primary care. The Italian PBRN<sup>14</sup> is probably the best example of how even in the absence of external stimuli, GPs can set the research agenda: a PBRN as a bootstraps approach to collect and implement evidence in practice. The Italian example underlines also the value of collaboration of PBRNs with a research center – a feature as well of the Dutch networks. These models of success emphasize the possibility of training of GPs and their staff in data collection and introducing a scientific esprit de corps in family practice.

### **PBRNs, standardization of data and structure of primary care records**

PBRNs constitute a multicentre research setting and standardization of data and terminology is essential. This is particularly important for longitudinal research: 'data' do not only have to mean the same between different centres, but even more important is its consistency over time. Standardization of data and adherence to data collection protocols are essential for methodological rigor and this emphasizes the need to link PBRNs to a research center or university. To structure data, information on visits and contacts must be organized. The International Classification of Primary Care (ICPC)<sup>15</sup> offers a framework to classify health problems with their relevant components (reason for contact, diagnosis, and diagnostic and therapeutic procedures) and structure information of subsequent visits and contacts into episodes. It provides diagnostic criteria<sup>16</sup> applicable under primary care conditions, and as the ICPC structures the Electronic Medical Record, this creates a user-friendly way of collecting and recording data under regular care conditions.

Allocation of disease information to individual characteristics is essential to place information in a meaningful context: sex, age, socio-economic and family characteristics.<sup>17</sup>

To protect confidentiality, data can be stored under a unique individual code, with only the practice in possession of the key to identify the individual.<sup>6</sup> This is essential if studies would require later collection of additional information.

### **Quality of GP registration**

For the quality of research data, training of GPs in recording, registration and coding is important. Initial training, using vignette cases, should be done, but equally important are regular meetings to discuss data recording and receive feed-back of these data. Peer review of cases and comparisons of data from different

practices are also valuable strategies. Training should be combined as much as possible with review of studies based on the data collection. Nothing guarantees the quality of data better than their use in actual studies and the feed-back of study results to the PBRN.

### Data for practice and/or research

GPs collect data for the care of patients, and the more these data can be used in that form for research purposes, the more the work of PBRNs is facilitated. In exploring research data, there are two concerns: whether the data represent the GP's meaning, and whether the data represent the actual status of the patient. The first category has to do with typing, spelling and coding errors that may cause the data to differ from the GP's true conclusions and actions. The second category marks differences between the GP's interpretation and the true status of the patient. In appreciating the importance of these two types of 'errors' it is important to distinguish between clinical research and quality of care research. When studying the (natural) history of a disease, it is essential that all patients studied actually have the disease – whether or not the GP made a correct diagnosis.

This is more than a theoretical issue: payment of GPs is often directed at specific interventions (for example prescribing, or a home visit) but not for others (reassurance and advice). Consequently, GPs may perform for reimbursement, whether or not the patient's health problem makes this imperative: the so-called 'perverse incentives'.

For clinical research it is particularly important to train the GPs and their staff in the use of classifications and the application of (diagnostic) criteria, and clinical research is vulnerable for perverse incentives.

When quality of care or the use of health care recourses is the topic of study, on the other hand, a key point is that a GP did record as he/she performed – whether or not this was relevant in respect to the underlying health problem. Coding errors, but not 'perverse' incentives influence the study.

## Conclusion

PBRNs are an important infrastructure for family medicine research. Although its recognition as such is recent, its principles have been used since the very first studies in family practice. PBRNs collect data and are indispensable for primary care databases, but their real value is in the change of culture of research and practice. PBRNs offer the opportunity of a dialogue between practitioners and researchers: to make research more relevant for problems encountered in practice and to make practice more receptive for research findings. Development of PBRNs should therefore be placed in a larger context of family medicine research capacity-building. University departments with a research mission and research institutes could provide methodological support, with the PBRN from its side providing access to family practice data.

In training research skills in the profession of family practice, GPs working in a PBRN are particularly attractive candidates. This would facilitate their further involvement in studies beyond the collection of data or implementation of results. Combining the role of researcher with that of clinician will further strengthen family practice and the best way to learn master research skills is by undertaking a project. This way GPs from PBRNs are likely candidates for an academic career. Within family medicine there is internationally sufficient experience in PBRNs available<sup>18</sup> for mentoring its development and that of its participating GPs.

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