



## Series: The research agenda for general practice/family medicine and primary health care in Europe. Part 5: Needs and implications for future research and policy

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**To cite this article:** Paul van Royen, Martin Beyer, Patrick Chevallier, Sophia Eilat-Tsanani, Christos Lionis, Lieve Peremans, Davorina Petek, Imre Rurik, Jean Karl Soler, Henri Ejh Stoffers, Pinar Topsever, Mehmet Ungan & Eva Hummers-Pradier (2010) Series: The research agenda for general practice/family medicine and primary health care in Europe. Part 5: Needs and implications for future research and policy, The European Journal of General Practice, 16:4, 244-248, DOI: [10.3109/13814788.2010.528385](https://doi.org/10.3109/13814788.2010.528385)

**To link to this article:** <https://doi.org/10.3109/13814788.2010.528385>



Published online: 12 Nov 2010.



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## BACKGROUND PAPER

# Series: The research agenda for general practice/family medicine and primary health care in Europe. Part 5: Needs and implications for future research and policy

PAUL VAN ROYEN<sup>1</sup>, MARTIN BEYER<sup>2</sup>, PATRICK CHEVALLIER<sup>3</sup>,  
SOPHIA EILAT-TSANANI<sup>4</sup>, CHRISTOS LIONIS<sup>5</sup>, LIEVE PEREMANS<sup>1,6</sup>,  
DAVORINA PETEK<sup>7</sup>, IMRE RURIK<sup>8</sup>, JEAN KARL SOLER<sup>9</sup>, HENRI EJH STOFFERS<sup>10</sup>,  
PINAR TOPSEVER<sup>11</sup>, MEHMET UNGAN<sup>12</sup> & EVA HUMMERS-PRADIER<sup>13</sup>

<sup>1</sup>Department of Primary and Interdisciplinary Care, University of Antwerp, Belgium, <sup>2</sup>Institute for General Practice, University of Frankfurt, Frankfurt, Germany, <sup>3</sup>Department of General Practice, Saint-Quentin University Versailles, France, <sup>4</sup>Department of Family Medicine, Emek Medical Center, Faculty of Health Sciences, Ben-Gurion University of the Negev, Israel e Afula and the valleys, Clalit Health Services, Northern District, <sup>5</sup>Clinic of Social and Family Medicine, and Department of Social Medicine, University of Crete, Crete, Greece, <sup>6</sup>Department of Youth Health, Vrije Universiteit of Brussels, Brussels, Belgium, <sup>7</sup>Department of Family Medicine, Medical School, University of Ljubljana, Slovenia, <sup>8</sup>Department of Family Medicine, University Debrecen, Hungary, <sup>9</sup>Mediterranean Institute of Primary Care, Attard, Malta, <sup>10</sup>Department of General Practice, School of Public Health and Primary Care (CAPHRI), Maastricht University Medical Centre, Maastricht, the Netherlands, <sup>11</sup>Department of Family Medicine, Acibadem University, Istanbul, Turkey, <sup>12</sup>Middle East Technical University Medical Centre, Ankara, Turkey, <sup>13</sup>Institute of General Practice, Hannover Medical School, Hannover, Germany

## Abstract

The recently published 'Research Agenda for General Practice/Family Medicine and Primary Health Care in Europe' summarizes the evidence relating to the core competencies and characteristics of the Wonca Europe definition of GP/FM, and highlights related needs and implications for future research and policy. *The European Journal of General Practice* publishes a series of articles based on this document. In a first article, background, objectives, and methodology were discussed. In three subsequent articles the results for the six core competencies of the European Definition of GP/FM were presented. This article formulates the common aims for further research and appropriate research methodologies, based on the missing evidence and research gaps identified from the comprehensive literature review. In addition, implications of this research agenda for general practitioners/family doctors, researchers, research organizations, patients and policy makers are presented. The concept of six core competencies should be abandoned in favour of a model with four dimensions, including clinical, person related, community oriented and management aspects. Future research and policy should consider more the involvement and rights of patients; more attention should be given to how new treatments or technologies are effectively translated into routine patient care, in particular primary care. There is a need for a European ethics board. The promotion of GP/FM research demands a good infrastructure in each country, including access to literature and databases, appropriate funding and training possibilities.

**Key words:** *General practice/family medicine, research agenda, policy, research methodology*

## Background

The 'Research Agenda for General Practice/Family Medicine and Primary Healthcare in Europe' is a comprehensive review of General Practice/Family

Medicine (GP/FM) research, published in September 2009 by the European General Practice Research Network (EGPRN) (1). It was developed upon request of Wonca Europe, related to the European

Correspondence: Paul Van Royen, Department of Primary and Interdisciplinary Care, University of Antwerp—Faculty of Medicine, Universiteitsplein 1, 2610 Antwerp, Belgium. E-mail: paul.vanroyen@ua.ac.be

(Received 28 September 2010; accepted 28 September 2010)

ISSN 1381-4788 print/ISSN 1751-1402 online © 2010 Informa Healthcare  
DOI: 10.3109/13814788.2010.528385

definition of GP/FM (2). It summarizes the current scientific evidence relating to the core competencies and characteristics of GP/FM, and indicates evidence gaps, research needs and action points for health and research policy. *The European Journal of General Practice* presents this document as a series of articles. Background, objectives and methodology were presented in part 1 (3). Results on all the core competencies were presented and discussed in part 2, 3 and 4 (4–6). This article reflects on the common aims for further research, appropriate research methodologies and the implications for general practitioners/family doctors, researchers, research organizations, patients and policy makers.

### Methodology

A general description of the methodology of our evaluation—key informant surveys, a comprehensive literature review and expert consensus—was presented in the first part of this series (3).

### Results

The various core competencies of the Wonca Europe definition of GP/FM seem to differ in their evidence base. Some domains and aspects have a large body of research, whereas others are poorly covered, and there is a need for much more research.

#### *Agenda for future research*

Within the six research domains, aims for future research and appropriate research methodologies have been formulated.

- Studying patients' and doctors' perceptions, perspectives and preferences regarding specific components or aspects of each research domain (for example, practice management issues, communication, patient involvement and choice).
- Evaluating effectiveness and efficiency of a person-centred approach, a comprehensive approach, a bio psychosocial care model and community orientated healthcare (as compared to a biomedical and specialist approach), including different models or management strategies. These should be studied in populations with different cultural, social, or geographic contexts.
- Developing primary care databases as a basic infrastructure for both health care and research including studying and improving the utility and validity of data from electronic patient records in GP/FM.
- Performing high quality longitudinal studies on primary care epidemiology and the development of illness in the course of time, and considering medical as well as functional and quality of life outcome measures. These studies should be based on primary care data featuring reasons for encounter as well as diagnoses, and mapping episodes of care. They will provide important background information, as well as information on the sustainability of effects.
- Furthermore, attempting to understand how social, cultural and environmental circumstances influence health difference between populations.
- Conducting primary care clinical studies dealing with common, everyday complaints and illnesses in non-selected GP/FM patients. Such studies should also address diagnostic reasoning (starting from complaints and symptoms and dealing with uncertainty and complexity, using stepwise strategies, including watchful waiting and assumptive treatment of symptoms, and focussing on simple or portable and point-of-care diagnostic methods) and therapeutic trials (including comparisons of established treatments, stop-trials, safety studies and non-pharmaceutical interventions).
- Exploring implications of multi-morbidity on curative and preventive aspects of care in the same patient.

#### *Appropriate research methodologies*

Most articles retrieved in the literature review were descriptive studies, short-term intervention analyses and hospital or specialist initiated research rather than studies conducted in a (more or less well defined) community setting. Many papers were unsystematic reviews or opinion papers. Therefore,

- Better understanding and clearly defining each competency or domain (or components thereof), because research data to underpin the concepts is still insufficient.
- Developing and validating instruments and outcome measures for each competency or domain (or components thereof), taking into account their complexity and interactions. For instance, although some aspects of person-centredness (enablement, satisfaction, participation) have been measured (7,8), instruments to assess the complex concept of person-centred care as a whole still need to be developed.
- Developing methods of education and training for components of the different GP/FM competencies, and evaluating their effectiveness, including the impact on health care and health outcomes, in the short- and long-term (sustainability).

on summarizing the results from the different competencies or domains, we formulated a list of recommendations for appropriate methodologies for future research in GP/FM.

- Studies should measure relevant health outcomes or assess quality of life instead of focusing only on patient satisfaction, service uptake, or surrogate (bio-) markers.
- Descriptive, cross-sectional questionnaire surveys (attitude studies) or chart reviews will not add much knowledge in most countries and settings. However, observational studies can be very useful to approach a new research topic or context.
- Qualitative studies are important to assess patient or doctor perspectives and preferences, to approach complexity, to understand the different concepts of the core competencies, to explore what relevant health outcomes are and as first step to develop measurement instruments.
- Randomized controlled trials (RCTs) provide high-level evidence on therapy or other interventions if they are original and externally valid (with regards to selection effects and bias).
- In intervention studies and quality improvement projects, adequate control groups should be defined. The expected added value to 'usual' general practice care (and its validity as comparator) should be considered carefully. In particular when planning studies on lifestyle interventions or on quality of care improvements, existing evidence should be reviewed thoroughly to assess originality and external validity.
- Prospective cohort studies or case control studies can be good options to assess risk or effects, or for implementations of care models or educational programmes.
- Longitudinal studies are important to assess continuous, comprehensive care and sustainability or intervention effects.
- Mixed methods are often helpful to study one theme under different angles or perspectives: to measure/observe what happens (and how much) and explains reasons why.

### Implications

The Research Agenda is a background paper and reference manual for GPs/family doctors, researchers and policy makers, providing advocacy of GP/FM in Europe. It may also serve as a reference paper worldwide, as no such documents exist for other Wonca

regions, either. Evidence gaps and research needs are pointed out to provide a basis for planning research for which there is a need for action that may influence health and research policy, i.e. applying/lobbying for research funds.

### *Implications for Wonca Europe, EGPRN and other research organizations*

The Research Agenda can assist Wonca Europe when refining the European definition and targets and discussing its future strategy and policy. Wonca Europe and its networks should look at the evidence base for the definition of GP/FM, and review their positions and statements if necessary. Possibly, the concept of six core competencies should be abandoned in favour of a model with four dimensions:

- Clinical or problem related aspects
- Person related aspects, including a comprehensive, holistic and person-centred approach
- Community oriented aspects (including equity and diversity)
- Management aspects (on practice or system level).

Both Wonca Europe and EGPRN should consider the agenda's research priorities when planning future conferences, courses or projects, and for funding properties. Research organizations should also provide or disseminate useful research tools, i.e. a thesaurus, appropriate classification systems and validated research instruments. Wonca and all GP based research networks should support and sustain a generalist view with respect to the core elements of GP/FM, thereby providing an umbrella for the many special interest groups, which sometimes tend to disrupt the field and adopt a specialist view. Each research project should reflect the four dimensions named above.

### *Implications for patients*

Patients are not only involved as objects of a study. Their needs should be the driving force for health-care and research. Research and the themes chosen should be relevant both to GPs and to patients, and should have a local resonance. The results of GP/FM research should, therefore, be relevant and applicable, either to the local community or to a larger (international) setting, or both. Relevant research has the potential to change practice and inform policy, and ultimately strengthens the discipline.

Future research and policy should consider the following domains: patients' preferences and choices,

patients' involvement (9–15), patients' rights and ethical aspects, matters of informed consent, the role of patient organizations.

Ethical research and patients' participation are key matters to GP/FM primary care research development. An ethical approach to research and the mechanisms of bringing ethics into research practice and formal ethical approval should be considered more. Research proposals should be developed with a consideration of over-arching ethical principles and sound governance. For international collaborative research, a European ethics board would be helpful.

#### *Implications for research*

So far, much of current health related research has a biomedical, often disease-centred focus. Insufficient attention is given to how new treatments or technologies are translated into routine patient care, in particular primary care, and whether they are effective and efficient in the everyday setting. This neglected field is a central premise of GP/FM research and should receive more attention and funding. Future research should not be centred on diseases; instead, it should integrate GP/FM principles like person-centeredness or equity, and have a primary care focus. Research should reflect that health is more than absence of disease and must be evaluated over time. The context of complex interactions of people and their family doctors (and other caregivers), possibly covering multiple health problems within the same patient, are important topics. New challenges for GP/FM research also include the implications of a multicultural society, diversity and equity issues, but also technological developments and evolving genomic knowledge.

GP/FM research provides the evidence base for guidelines, which are important tools enabling the implementation of medical knowledge into practice. They have the potential to reduce unwanted variability in delivery of care, set targets for quality of health care delivery and support medical education as well as continuous professional development.

Future research should focus on the priorities and needs highlighted in the Research Agenda, and respect the core characteristics of the discipline and the particularities of primary care patients. Studies focussing on health services research, humanities or bio-psychosocial medicine are an important part of GP research. The added value to existing knowledge should be considered carefully during planning. Existing instruments and outcome measures should be reviewed and considered, to be able to link and compare research. Research highlighting the benefits of GP according to the concepts described in the

definition may help to underpin the importance of the discipline towards other specialities and policy makers.

Primary care research across Europe could be enhanced by building sustainable networks and increasing research capacity (16,17). Across Europe, there are large regional differences in GP/FM and primary care research capacity. This situation suggests the need for a European infrastructure to support training and exchange in primary care research, which should be adapted locally ('act local, think global'). Exchange of scientific knowledge and methodology between researchers from countries with a well-established primary care research infrastructure and those from countries in the process of developing their infrastructure should be facilitated. This process of mutual exchange between 'experts' and 'novices' will enhance the development of academic GP/FM in countries that currently have relatively little infrastructure in this regard. This development is essential for the progress of the discipline in these countries.

In regard to the organization of intervention research, there is a need for the management of a large number of trial sites and research networks.

#### *Implications for journals*

Primary care and primary care research has to deal with differences in health care systems and cultural backgrounds, much more so than specialist or hospital medicine where scientific and technological progress has a more direct impact. Europe is a patchwork of different health care systems in countries that vary in their degree of societal and economical development. There also are large differences in primary care research capacity. Scientific journals of general practice/primary care should respect these regional differences in their peer review process and publication policy, while maintaining the highest possible quality standards. The Research Agenda provides some guidance for a publication policy.

#### *Implications for policy*

The Research Agenda should be considered when planning programmes for research or healthcare delivery, as it points out the evidence for the benefits of GP/FM and primary care in general, and for specific aspects of care. Not much is known yet about the consequences of the healthcare organization differences within Europe. Comparative studies of primary care management models and interventions could shed light on this important issue and inform European policy.



In funding decisions or strategic planning, the formulated research needs should be taken into account. Experts in GP/FM should be part of all decision-making organisms concerning health policy or funding of health related research. The promotion of GP/FM research as proposed in the Research Agenda demands a good basic research infrastructure to be provided continuously in each country. This includes:

- Facilitating access to scientific literature, databases and to the scientific community (through conferences, courses), independent from pharmaceutical companies.
- Appropriate funding for academic departments and research institutes as well as GP/FM research projects and primary care studies. The amount of funding must reflect the importance of the discipline within the healthcare system and should provide an adequate infrastructure with sufficient stability over time to enable longitudinal research.
- Implementation of electronic medical records using appropriate coding systems, which reflect the reality of primary care (ICPC) and provide adequate data for research databases.
- Providing and maintaining suitable research databases mapping primary care (i.e. based on electronic medical records). These data should respect privacy and safety, and must be accessible and suitable not only for public health or healthcare governance purposes, but also for:
  - Quality improvement projects (including feedback to the practices providing data, audits);
  - GP/FM clinical and health services research (including diagnostic studies, sampling for quantitative and qualitative studies, longitudinal studies).

The research agenda reviewed existing evidence and points out directions for the future. It is a document open for discussion and future amendment, on which comments are most welcome.

**Declaration of interest:** The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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