

# **A Research Agenda for Primary Health Care / General Practice in Europe**

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# 1. Introduction

## Background

General practice/family medicine, being the core discipline of primary medical care, is the cornerstone of many healthcare systems in Europe. Its potential is large: 80% of all reasons for encounter can be solved in primary care. Open access and being the point of first contact for all health related complaints, a holistic, bio-psychosocial approach to differential diagnosis, treatment of common disorders, prevention as well as long-term management of chronic diseases, and coping with multi-morbidity and poly-pharmacy are some of the key features to describe the specific content of family medicine. This generalist domain implies multidisciplinary research and the use of a wide variety of research methods.

Research in primary care was first developed in those countries (mainly North-western Europe) who built their health care systems on the principles of generalist-based access to more specialized levels of health care ('gate-keeper', 'referral'). Countries where family physicians work in parallel with other specialists found that research was more difficult to initiate and develop. The general pattern is that: individual pioneers perform practice-based research and obtain degrees (stage 1), then gradually academic chairs focussing on medical education are installed (stage 2), and finally, more extensive research projects are developed through which further research capacity can be built (stage 3). Currently, Southern and Eastern European countries show a variety of stages of development of academic family medicine: countries where academic family medicine is virtually non-existent (stage 1), countries where university departments of family medicine are mainly involved in medical education (stage 2), and countries where - clinical or health services - research is developing (stage 2-3)<sup>1,2</sup>.

Primary care research has been a subject of animated discussion in recent years and editorials<sup>3,4</sup>. The authors have even questioned whether GP/FM research has any future.

The necessity of primary care research can be described as follows: "Research in primary care is essential because: (1) clinical and preventive care must be underpinned by research evidence; (2) the bulk of such care in most countries, especially poorer countries, is delivered in primary care; and (3) evidence to underpin this care cannot be informed by laboratory and hospital-based research alone. Absence of research in primary care will lead to over-investigation, inappropriate treatment, and diagnostic delay through wrong-track referral."<sup>5</sup> Furthermore, "through family medicine research the effectiveness and efficiency of health care could be improved. Strengthening family medicine research is essential to enhance the role of family physicians in health care systems, to improve the optimal functioning of health care systems, and to improve the health of populations".<sup>6</sup> General practice research is also necessary to make general practice an attractive discipline for medical students and graduates.

## **1.2. From the WONCA Definition of FM/GP towards a vision on FM/GP and Primary Care**

Starting point for a research agenda is the domain or specific content of General Practice in Europe. In 2002 a new European definition of General Practice/Family Medicine was published to inform policy makers, funding organisations and others outside the field about 'the essential role of family medicine within health systems at both national and pan-European levels'. The definition describes essential characteristics of the discipline irrespective of the health care system in which it is applied. These have been translated into six core competencies for primary care<sup>1,7</sup>:

1. primary care management (first contact, unlimited access, all health problems; co-ordinating care, managing the interface between generalist and specialist care),

2. patient-centred care (individual, family, longitudinal continuity),
3. specific problem solving competence (wide spectrum of diseases, specific incidence and prevalence, all stages, acute and chronic, co- and multi-morbidity),
4. comprehensive approach (health promotion, prevention, early intervention, cure, care, palliation),
5. community orientation and
6. a holistic approach (biomedical as well as psychological, social, cultural and existential dimensions).

The interrelation of core competencies, implementation areas and fundamental features characterizes the discipline and underlines the complexity of the specialty. This complex interrelationship of core competencies should guide and influence the agendas for teaching, research and quality assurance in GP/FM in Europe<sup>7</sup>.

Primary Health Care (PHC) is a concept defined by the WHO (Alma Ata 1978) as follows: Primary health care is essential health care made universally accessible to individuals and families in the community by means acceptable to them, through their full participation and at a cost that the community and country can afford<sup>8</sup>.

Specific features of PHC<sup>9 10</sup> are largely overlapping with the definition of general practice/family medicine:

- direct accessibility, first contact ambulatory care for unselected health care problems
- offering diagnostic, curative, rehabilitative and palliative services
- offering prevention to individuals and groups at risk in the target population
- taking in account the personal and social context of patients
- coordinating the care for patients, by adequate referring and supporting patients.
- A long-standing relationship between the patient and the doctor, covering individual's health care longitudinally over substantial periods of their lives and not being limited to one period of an illness.

There is a substantial body of evidence on the comparative advantages, in terms of effectiveness and efficiency of patient-centered primary health care<sup>11</sup>. A strong primary care system is associated with improved population health<sup>12</sup>. Primary care can provide much better value for money than its alternatives.

The core discipline of primary health care is general practice or family medicine. While in some countries, general practitioners have a gate-keeping function and thus exclusively ensure primary medical care, in other countries primary care is a territory which is debated between GPs and multiple community based specialist which patients can access on their own initiative. Almost everywhere, nursing is an important profession in PHC with community and practice nurses. Other health care providers working in PHC are pharmacists, physiotherapeutic workers and midwives. Home-helpers, giving domestic support are indispensable. However, primary care nursing is not the focus of the research agenda.

In fact there is a difference between the concepts 'primary health care' and 'general practice/family medicine', not only on the definition level, as described above, but also on the level of the different countries and health care systems. This had certainly some impact on the literature searches we performed and the outcome of found research articles (see methods part)

The research agenda should also take into account *the challenges for, the vision on and future developments of the discipline*.

### 1.3. Aims of the research agenda

The research agenda (RA) is meant to be a background paper and reference manual for GPs, researchers and policy makers, providing advocacy of GP in Europe. It could serve as a reference paper worldwide, as no such documents exist for other WONCA regions, either.

The RA should be closely related to the WONCA EU definition of GP in 2002/2005, indicating the evidence base of the definition, and its degree of implementation in real life practice and academics. In WONCA EU there are 2 agendas related to the definition:

- the EURACT teaching agenda, which is a clear and straightforward consensus document to be used in a context of academic and vocational training
- the EGPRN research agenda, which
  - should be based on facts/evidence (including the national colleges' point of view), indicating the state of GP research in Europe
  - should focus on topics that are of relevance
  - should provide a research strategy and policy
  - indicates to which extent the core competencies and characteristics of GP have been covered by research and provide the (landmark, probably not complete) references
  - points out research gaps

The RA will be a reference paper ...

- Defining the evidence base of the definition, and its meaning for researchers and policy makers.
- Indicating what is of imminent importance for developing countries
  - Existing evidence on definition aspects, clinical GP
  - Development plan for GP / GP research in a “new” setting: how to get started, how to develop it
- Pointing out research needs and evidence gaps, i.e. for matters of research funding/funding decisions:
  - Collaborative studies - do they fit into the agenda.
  - Redundant topics should not be accepted anymore for EGPRN/WONCA conferences.
- Providing a basis for proactive, positive action influencing health and research policy, i.e. applying/lobbying for research funds

## 2. Methodology

The basics for the European research agenda were the prerequisites, needs and priorities of European GP research as reflected by key informant surveys and SWOT analyses among EGPRN national representatives. A first workshop was held in 2002 (Bled, Slovenia), brainstorming on research needs and perceived barriers to GP research in the countries represented, and prioritizing the results. This first overview was published in 2004<sup>1</sup>. Another approach to the needs and requirements for GP research in the various European countries were (semi-) structured yearly reports delivered by the EGPRN national representatives over several years. Data of all incoming EGPRN national representative (NR) reports of the year 2003 were analyzed quantitatively and qualitatively with respect to research infrastructure, policy and organization. Several rounds of SWOT analyses in successive EGPRN meetings helped to further focus and prioritise research topics and requirements.

The starting point for our research agenda was the domain or specific content of General Practice in Europe, as described in the new WONCA definition of GP/FM, including six core competencies (primary care management, patient-centred care, specific problem solving competence, comprehensive approach, community orientation and holistic approach)<sup>7</sup>

A second frame for developing a research agenda is the core content of GP/FM research.

Consensus on the core content of primary care research is growing and can be summarized as: (1) research on clinical issues (common diseases, chronic diseases, risk groups) incl. diagnostic and therapeutic strategies, health promotion and long-term management; (2) health services research incl. primary care morbidity registration (electronic record keeping); (3) research on education and teaching of and in general practice<sup>1,6</sup>. Defining clinical research/clinical issues in contrast to problem solving related health services research, we found they have largely common grounds, but differ largely relying on the outcome of each study/study domain. Clinical research has outcomes on a patient level, measuring patients' health issues (possibly including function or QOL), while health services research focuses on doctor or system related questions and outcomes.

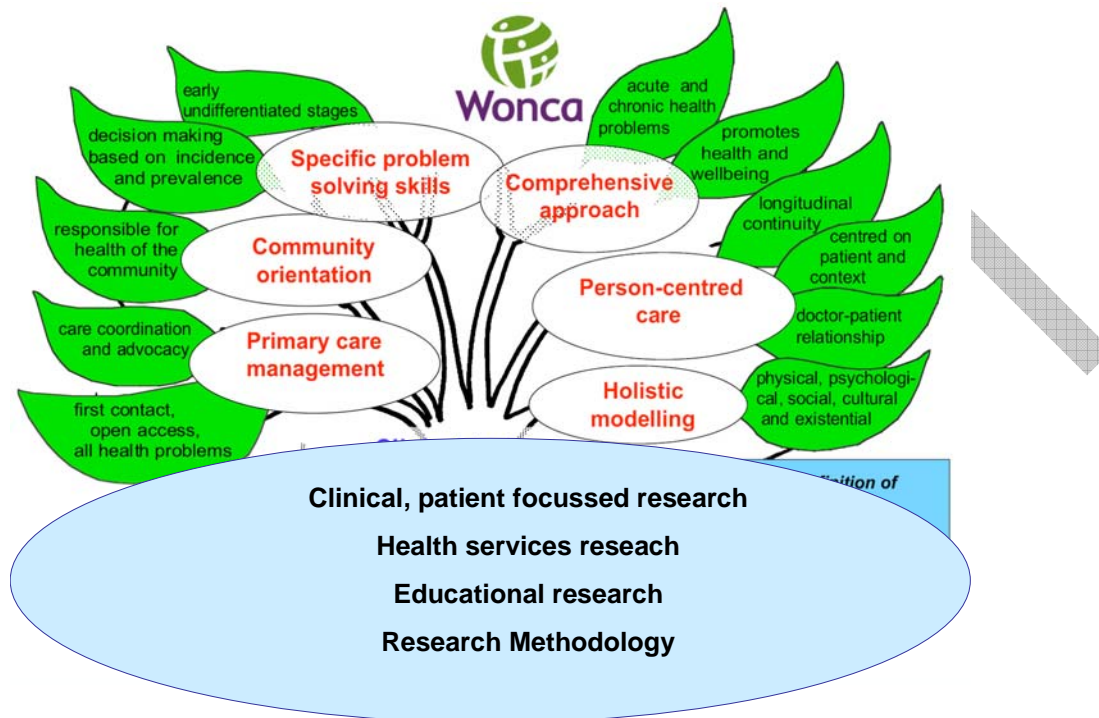
Information and communication technology is playing an increasing role in modern life, including the patient's life. It is also a challenge for the health care professional. The internet is becoming an essential part of patient-centred health care, enabling fast access to information and exchange of experiences, efficient collaboration between primary and secondary care ('multidisciplinary electronic medical records') and on-line consultations ('telemedicine'). Primary care morbidity registration and the exchange and analysis of practice-based data for research are other areas where the application of information technology could have major advantages. ICT and the internet also increase the opportunities for collaboration in research and research training ('networks').

Another challenge for primary care is the application of evolving genomic knowledge in preventive (e.g. 'cardiovascular risk management') and therapeutic (e.g. 'pharmacogenomics') health care of multifactor diseases, with yet unknown medico-ethical and medico-legal implications.

From these starting points, we performed a comprehensive literature review, searching for relevant information on the research base of the WONCA core competencies. When the Mesh-terms were rather poorly adapted, we looked at relevant articles and looked how they were linked to

mesh terms and keywords. All references identified through our searches were assessed and selected based on the following criteria:

- Clear formulation of the research question
- Clear description of methodology including the setting, appropriate to answer the research question
- Clear presentation of the results, consistent with the research questions and methodology
- Conclusions based on the results
- Relevance of the study (addressing a clinical topic and/or results relevant for GP/FM or primary care, from or adaptable to a Western/European context).



Data extraction was also done within the subgroup of authors, using the following steps:

- Linking the selected abstracts to the defined concepts- domain description and to methodologies used
- Indicating the landmark articles, the found evidence, the research gaps and needed methodologies.

Conclusions on these items were made by reflection, small group discussion and consensus. Each subgroup summarized the findings, regarding the search strategy and results, also according to the domains and concepts.

We agreed to compile results according to the following scheme:

- Definition of the domain
- Description of the literature search strategies
- A summary of the findings from these searches: what is already known about the topic?
- Research aims, formulating the research gaps, research questions and needs for further research
- Identify and suggest appropriate research methodology

### 3. The WONCA core competencies and their research base

#### 3.1. Primary Care management

##### Definition

Primary Care Management includes the ability:

- to manage primary contact with patients, dealing with unselected problems
- to cover the full range of health conditions
- to co-ordinate care with other professionals in primary care and with other specialists
- to master effective and appropriate care provision and health service utilisation
- to make available to the patient the appropriate services within the health care system
- to act as advocate for the patient

A characteristic of primary care is accessibility. First contact involves assessment of both accessibility of a provider or facility and the extent to which the population actually uses the services when a need for them is first perceived.

Coordination in primary care requires an information system that contains all health-related information; and assessment includes the extent and speed with which the information is recognised and brought to bear on patient care<sup>11</sup>.

The research domain includes clinical research on health problems in primary care, disease management programmes and the interface between primary and secondary care. Health services research focuses on aspects such as first contact, unlimited access, the interface primary-secondary care, interprofessional collaboration, electronic patient records and efficiency issues. Educational research will deal with interprofessional education and management skills.

There is overlap with other competencies such as community orientation and specific problem solving.

##### Literature searches

- “Organization and Administration” [MeSH Terms] combined with “Primary Health Care” [Majr Mesh] and/or “family practice” [MeSH]-
- Practice Management combined with “Primary Health Care” [Majr Mesh] and/or “family practice” [MeSH]- , “Health Services” [MeSH], “Education, medical” [Majr Mesh]
- "Health Services Accessibility"[Majr] combined with “Primary Health Care” [Majr Mesh] and/or “family practice” [MeSH]
- “Medical Records Systems, Computerized” [MeSH] combined with “Primary Health Care” [Majr Mesh] and/or “family practice” [MeSH]

##### Summary of findings

The whole research field of primary care management is very large. The retrieved literature gives a very scattered result, not a meta-view.

Many of the retrieved papers are related to the management in primary care of patients with a specific disease (mainly on depression, mental health care, diabetes care). Very different primary care management interventions were studied: outreach preventive visits, nurse practitioners, collaborative care, pharmacist-led interventions. The effect of various primary care management interventions was studied in different patient populations, i.e. in geriatric care. Both clinical and non-clinical outcomes were studied.

The impact of *consultation length* process and outcome has been studied in observational studies, but without conclusive findings. Further trials are needed focusing on health outcomes and cost effectiveness.

*Access to primary care* is very differently organised in the different countries. Many of the retrieved papers are disease related studies or nursing research papers. Improving access is a key policy issue in improving quality of (primary) care but the topic is until now mostly studied from a local point of view.

An important focus of research is the *interface between primary and secondary care*. There is a wide variation in the referral rates of individual general practitioners. Active local educational interventions involving secondary care specialists and structured referral sheets are the only interventions shown to impact on referral rates based on current evidence. The effects of 'in-house' second opinion and other intermediate primary care based alternatives to outpatient referral appear promising. Secondary care specialists should be incorporated in active educational activities, and structured referral sheets are efficient. *Cooperation with the pharmacist and pharmacist led medication control* may reduce medication related adverse events; more randomised controlled trials of primary care based pharmacist-led interventions are needed, to decide on its effectiveness.

*Effectiveness* of various primary care management interventions is assessed mostly with regard to costs or quality aspects/quality indicators, often with a benchmarking approach rather than outcomes that reliably reflect patient health outcomes.

*Efficiency (with regard to costs)* is studied in different papers. Several studies suggest that appropriately trained nurses can produce as high quality care as primary care doctors and achieve as good health outcomes for patients. But employing a nurse practitioner in primary care is likely to cost much the same as employing a salaried GP according to currently available data. Interventions of practice organisation seem to influence service uptake, but the effect on health outcomes is rarely studied.

There has been quite a lot of research on the place and function, the potential effect of *electronic medical records (EMR)* in primary care. ICPC and record coding based on reason for encounter is a central concept of many papers, showing the usefulness, potential and possibilities for further development of family practice / primary care epidemiology based on electronic medical records kept and coded according to episodes of illness. However, in many European countries, medical records are far from being ideal as a research database, for multiple reasons of incomplete records, legislation, no use of ICPC, pragmatic approaches to 'everyday' records.

There is a rapidly increasing body of literature both on methodological and quality issues of research on EMR / routine data and of research projects which used these as a database.

There has been quite a lot of research on the potential of these databases to generate data for quality management (audit) and on EMRs to serve as a platform for implementing guidelines or recommendations, to identify patients eligible for treatment or preventive services, or to prompt drug warnings. Results are mostly positive, but not overwhelming, and may depend on the EMR system used. Effectiveness with regard to health outcomes is rarely studied.

There is limited *educational research* on primary care management aspects, such as studies of educational interventions aimed at doctors – mostly academic detailing – to implement specific service approaches, mostly prevention activities, interprofessional collaboration, or care strategies for specific diseases (detection of disease, prescribing), which usually show either small or insignificant effects; sustainability of these effects is not studied.

### **Aims for further research**

Further research should therefore focus on

- better understanding and clearly defining the different aspects of primary care management – and also developing instruments to describe and measure it

- patient and doctor's perceptions, perspectives and preferences on practice management issues (such as open access, telephone consultations, telemedicine)
- evaluating effectiveness of different primary care management strategies or interventions, not only on the level of patient satisfaction and/or service uptake, but also on the health outcome level
- validity and utility of electronic patient records in a general practice
- the feasibility/validity of the routine collection of GP morbidity data from electronic medical records and the use of appropriate denominators effective methods of inter-professional education and to teach management skills to (future) GPs

#### **Appropriate research methodology**

- Instrumental research is essential to develop clear measures for practice management issues
- Interventional research ( controlled trials – comparing different primary care management strategies, or comparisons with usual care)
- Implementation studies of effective strategies (observational)
- Mixed study designs

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## 3.2. Patient centeredness

### Definition

Person- and/or patient-centeredness have been accepted as an important, central value in medical care and it is nowadays universally advocated in medical education. Even more, it is one of the core-elements of general practice/family medicine care- and therefore a key-element in the new definition of the discipline in 2002.

The concept was described by several authors and different basic elements were distinguished<sup>13-15</sup>, such as communication, partnership and health promotion. Most development of the patient-centeredness concept has occurred within general practice. But also other disciplines have an increasing interest in patient-centered medicine.

**Literature search** Patient-Centered Care [Majr Mesh] combined with

- “Primary Health Care” [Majr Mesh] and/or “family practice” [MeSH]
- “Continuity of Patient Care” [MeSH]

### Summary of findings

Many of the retrieved papers, dealing with the concept of patient-centeredness are opinion papers. Several papers studied patient and doctor experiences, beliefs and preferences of a bio-medical versus patient-centred approach/communication, mainly using a qualitative research methodology (interviews, focus groups, videotapes). It appeared that not every situation or each patient group in general practice requires a patient centred approach/ communication, involvement or shared decision making. The body of research in this area remains small and showed significant limitations. Better understanding the diversity of patient and doctor preferences may lead to more effective and individualized care.

Several papers also explored the preferences and experiences of patients on (interpersonal) continuity of care. Continuity was valued for serious and psychosocial issues and also for routine checks for a chronic illness.

The effects of a patient-centred approach or communication have been studied with regard to patient satisfaction and treatment adherence, improved medical outcomes and decreased mal-practice claims. Most RCTs showed minor effects mainly on patient satisfaction, or no statistically significant results. .

Limited research has studied the effect of training programmes in patient centred care for practitioners on clinical and non-clinical outcomes.

In conclusion, the concept of a patient centeredness remains poorly defined. A clear definition in practical terms and instruments to measure the complex concept as a whole are still lacking. However, there is research on individual aspects, i.e. instruments to measure patient participation, enablement, or satisfaction, both generic and disease specific. Most research is on patient and doctor preferences and experiences. There is limited research on its implications or outcomes.

### Research aims

Further research should therefore focus on

- better understanding and clearly defining (components of) patient-centeredness
- developing additional instruments to describe and measure the complex aspects and outcomes

- patient and doctor's perceptions, perspectives and preferences on patient centeredness, communication, involvement and shared decision making (including social, cultural and environmental circumstances, affecting these preferences)
- evaluating effectiveness of an patient-centered approach with regard to relevant clinical health and non-clinical (satisfaction, knowledge, QOL) outcomes
- effective methods of training (future) GPs to practice an patient-centered approach and the sustainability of these training/education effects

### **Research methodology**

- Qualitative research provides an approach to patients' and doctors' concepts and expectations
- Instrumental research is essential to develop clear measures for patient-centeredness
- Interventional studies- starting with simple patient-centred interventions – to assess effects
- Observational studies will be needed to follow-up patient-centeredness with a longitudinal perspective

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### 3.3. Specific problem solving

#### Definitions

This is a vast field, comprising most clinical, disease or diagnostic related research. While epidemiological research on primary care morbidity and availability of care does not directly relate to problem solving, it provides the necessary background to develop and apply these competencies. In the area of specific problem solving, there are large common grounds between clinical research (with patient related outcomes) and health services research (with outcomes on a physician or system level). Besides descriptive studies of GPs' current way of working, this research domain includes the following

#### Diagnosis

- Diagnostic studies in an unselected primary care setting, starting from complaints
- Diagnostic/predictive values of simple clinical examination or history taking
- Step-wise diagnostic approach, incl. red-flag issues
- Severity scores and their practical and clinical consequences

#### Treatment

- Continuity between health and disease – when to start or stop treating
- RCTs in typical primary care populations, regarding effectiveness/efficiency/safety
- Safety issues, risk-benefit-assessments in unselected populations
- Non-pharmacological treatment (i.e. counselling, physiotherapy, complementary medicine)
- Compliance/adherence issues, acceptability, patient priorities (overlap with patient centredness, comprehensive care)

#### Specific approaches of problem solving (overlap with primary care management)

- GPs decision making, shared decision making, prioritization
- Quality management, guidelines
- Chronic disease management, multimorbidity, long term care
- Clinical skills (communication, examination, counselling, family orientation)
- Home visits
- Watchful waiting, tentative treatment without a confirmed diagnosis
- Problems related to specific patient groups or gender
- Special or local interests in GP/PC

#### Educational research

- Education of students and trainees
- Continuing medical education/professional development.
- Evaluation of methods to teach clinical problem solving competencies skills in primary care with regards to effectiveness and sustainability.
- Instrumental research on methods to measure clinical and problem solving competencies.

Due to the vastness of this field, the research agenda cannot cover it in detail or even give an overview on the state of knowledge on individual clinical fields. This is a domain of the Cochrane Collaboration and the many organisms and scientific societies working on guidelines for primary care. This research agenda aims at pointing out general, systematic characteristics or

weaknesses of research in this field. Additionally, a very rough semi-quantitative overview of research themes was attempted in order to identify well-covered topics and blank spots.

## **Literature Search**

### **General, for semiquantitative classification:**

- “family practice”[MeSH], limits: last 5 years, clinical trials, RCTs

### **Diagnostics**

- ”diagnosis” [MeSH] AND “primary care” [MeSH] OR “family practice” [MeSH]
- Specific disease mesh term AND „epidemiology“[MeSH]
- Specific disease mesh term AND „decision making“[MeSH]
- “Diagnostic Errors “[MeSH]
- “False Negative Reactions” [MeSH]
- “False Positive Reactions” [MeSH]
- “Observer Variation” [MeSH]
- “Watchful waiting” (general term)

### **Therapy**

- Specific disease mesh term AND „therapeutics“[MeSH] OR “Drug therapy” [MeSH]
- Specific disease mesh term AND “Drug therapy” [MeSH]
- Specific disease mesh term AND “Complementary therapies” [MeSH]

### **Chronic care**

- Specific disease mesh term AND „long term care“[MeSH]
- AND “family practice” [MeSH]

### **Rehabilitation**

- Specific disease mesh term AND „rehabilitation“[MeSH]
- AND “primary health care”[MeSH]

### **Quality of care**

- Specific disease mesh term AND „quality assurance, health care“[MeSH]
- AND "family practice"[MeSH]

“Pharyngitis” (linked to “sore throat” in MeSH) was used as a specific disease term in exemplary searches on diagnosis and therapy, and “heart failure” as an exemplary chronic disease. Dysuria / urinary tract infection and diabetes were other conditions used for exemplary searches. As for conclusions, authors also drew on their general expertise as researchers and reviewers.

### **(Shared) decision making**

- “Physician-Patient Relations”[MeSH] AND “family practice” [MeSH]: gives a very wide and unspecific approach.
- “Decision making” [MeSH] with and without “family practice” [MeSH] (“Shared decision making” is no mesh term)

**Health services research**

- “Problem solving” with all subheadings AND “Health Services” AND (“General practice” OR “Family Physician”)
- add “Quality management” [MeSH]
- “Primary care” [MeSH] AND “Disease management” [MeSH] AND “Health services” [MeSH]
- add “Collaborative care management”, “Rehabilitation”, “Patient-centred care”, “Frequent attenders”, “Promoting healthy life style”, “Continuity of health care”

**Educational research**

- "education, medical"[MeSH Terms] AND "problem solving"[MeSH Terms] AND (("family practice"[TIAB] NOT Medline[SB]) OR "family practice"[MeSH Terms] OR general practice[Text Word]) OR (("primary health care"[TIAB] NOT Medline[SB]) OR "primary health care"[MeSH Terms] OR primary care[Text Word])

**Summary of the findings****Retrieval and appreciation of literature**

Generally, MeSH-terms are very poorly adapted to GP literature on a taxonomy level and also on a practical how articles are indexed-level. Not every study declared as RCT or meta-analysis is really one. Symptom terms are often linked to a disease or diagnosis immediately. Many studies from GP or relevant to primary care are not labelled with the MeSH terms “family practice” or “primary health care”. On the other hand, many studies are labelled so, as their authors seem to believe their findings are relevant for GPs, while really they are not. There are quite a lot of specialist studies published in specialist journals which are highly relevant for GP, in particular in field of paediatrics.

A MeSH- based search is a trade-off between a sensitive approach, yielding very large non specific results, and very sophisticated search strategies which are still not fully specific but exclude a lot of possibly relevant literature, in a research field where GP and specialist approaches overlap a lot. In many clinical trials, the exact setting and degree of sample selection is not well described, and thus the external validity or relevance for GP is not easy to verify. This can be problematic for meta-analyses or systematic reviews. There is no consensus on how to judge the quality and relevance of an RCT for GP. Authors of systematic reviews may come to contrary conclusions based on the same RCTs, depending on their judgement of quality and relevance. One example is the debate on the value of drugs to treat dementia (Kaduskiewicz et al, BMJ). There are some attempts to establish a system to rate the quality of research articles, i.e. by the SIGN network, or some Cochrane Groups (COINS).

**Predominant research themes in the last 5 years**

The surprisingly low number of just approximately 500 clinical trials or RCTs was retrieved by the MeSH based search, probably due to labelling problems. 70 % of these had patient-related outcomes, the remainder focussed on doctors or system related outcomes. The largest bulk of research (23%) dealt with health system or public health questions. Other frequent themes were acute and chronic airway disorders (9%), mental health (8%), diabetes (6%), heart failure (5%), hypertension (3%), or children (3%) and urogenital disorders (3%).

### **Diagnostic research**

Mesh searches for symptoms retrieve mainly results on diagnoses/diseases, the MeSH terms being linked. There are relatively few papers on symptoms which are either on very specific themes or about syndromes. For acute disorders, there is some research on symptom scores or utility and predictive values of near-patient tests. However, they are rarely assessed for their added value to history, signs and symptoms or analysed in a context of a step-wise approach. In general, GPs' symptom- or reason-for-encounter based approach is very poorly reflected in the literature. There is little research on diagnostic strategies: Most diagnostic studies are done on specific, usually sophisticated technical or laboratory tests in selected settings. There is a lack of studies about those diagnostic tests which are relevant to GP decision making / and subsequent management, and very little evidence of predictive values of all kinds findings or tests in primary care settings. Many tests have not been formally evaluated in primary care; low prevalence settings are then used to screen more or less unselected populations, and often result in unrealistically high prevalence estimates for chronic disease. This is problematic as these results are then used to conclude that GPs are not good at detecting disease and many articles then recommend tests for preventive screening in unselected populations or to identify patients to be treated. This approach tends to mistake point prevalence of screening results or individual symptoms (not complaints) for an indication to treat,

### **Research on therapy**

There is a lot of clinical and health services research related to therapy, information can be found on almost any question related to the treatment of specific diseases. However, there seem to be very few real clinical RCTs being performed in general practice settings; instead, there is a lot of observational research in primary care settings, often in form of cross sectional surveys which are likely biased and of limited external validity. In general, many clinical RCTs are relatively small, sometimes underpowered even for the main outcome and definitely for secondary effects, and quite often there are randomisation problems. However, recent studies tend to be better designed and powered. Pragmatic trials of therapies which are specifically relevant in GP are lacking: There are very few studies comparing several standard treatments, or a standard treatment versus placebo, or different doses of the same drug, or optimal duration of treatment. Most RCTs feature new or expensive drugs. Sometimes, the control treatment is deliberately chosen to be not best standard, but under-dosed or second-choice; some obviously industry-triggered drug trials are poor in ways of recruitment, randomisation or follow-up. Outcomes are often surrogate markers of questionable value. Many studies on chronic diseases suffer from limited external validity: Often there is selection bias at recruitment (i.e. patients recruited in walk-in clinics or secondary care, or either privileged or disadvantaged regarding access to care). Most patients recruited into trials are younger and healthier than the average GP patients with chronic diseases, and women are underrepresented. Although there is some research on alternative/complementary therapy, it is often of relatively poor quality. Patients' self management or safety issues are rare research topics. There is very little research on or accounting for *co- or multi-morbidity*.

### **Chronic care / disease management**

There is some research on chronic care, specific disease management programmes or rehabilitation of patients with chronic diseases. However, most of these studies bypass the general practitioner or take "usual care" as a presumably poor comparator. Most intervention studies are designed by specialists, the intervention is usually administered by nurses. Most of these studies fail to be effective, or show marginal effects, and follow-up is usually short (max. 1 year).

**Research on (shared) decision making**

A lot of studies relate GPs decisions in particular clinical situations (URTI, depression care etc) to predictors on patient or doctor/practice level, usually with a cross-sectional design.

Qualitative research explores doctors' decision making process or preferences. Qualitative methods or specific measurement tools for satisfaction, patient preferences, compliance and involvement are used to explore patients' experience with consultations in general or shared decision making in particular. Results of these studies are quite variable. A substantial part of patients less satisfied with shared decision making than with a classical (more paternalistic) consultation style. Patients who prefer SDM are usually younger and more educated, or have chronic disorders. A few studies show that patients who are more involved in their own care fare better. There are multiple studies on decision making aids for doctors (i.e. synthesized evidence, electronic decision support) or patients (information materials), mostly related to individual disease related situations, some with an observational design (development or implementation), some comparing the intervention with control groups (cf. also educational research).

*Practice or community based epidemiology*, morbidity registration, prevalence studies or description of current care are very common themes, mostly with a cross-sectional approach. Longitudinal designs are very rare.

**Quality of care related research** quite often takes *cost-effectiveness* as an outcome in studies on referral, treatment / prescribing or screening. *Doctor related quality of care research* includes studies on knowledge, but also clinical competence and performance. Guidelines or recommendations are often used as a reference standard in studies with a benchmarking approach, though they are originally intended to be decision making aids. Many disease-related articles feature diabetes, depression, or stroke. Multidisciplinary or collaborative care is studied quite often, as is the issue of frequent attenders.

Quite a lot of studies aim to improve quality via educational interventions, either targeted at patients who are supposed to alter their lifestyle, or at physicians. Most of these try to show the superiority of their specific intervention to "usual care" as a comparator. This results in an unfavourable image of general practice. However, the vast majority of these studies fail to show substantial effects.

**Educational Research**

These searches retrieved a very large body of literature, including many meta-analyses and RCTs, so only a rough overview can be given. Most studies were not done within the context of primary care/family medicine; however, they addressed teaching methods and educational interventions to enhance clinical competence.

Early experience in primary care helps *medical students* to acquire professional attitudes and skills. It can influence career choices.

Educational interventions in the context of continuous professional development (CPD) appear to have a small to medium effect on physician knowledge; however, the effect size is generally small for performance and (much more rarely studied) patient outcome, across many individual educational methods. Dissemination of material, didactic lectures, but also uncommented feedback seem to be largely ineffective. Interventions are more successful when interactive, using multiple methods, and designed for a small group of physicians from a single discipline. Multifaceted interventions aiming at physicians, patients and other stakeholders simultaneously seem to be effective as well. It is essential, however, that interventions are well tailored to local factors like physicians' current performance and barriers for change. Even thoughtfully designed inter-

ventions may be unsuccessful. Bias may be introduced by the fact that in many health systems, quality of care studies rely on volunteer participants. These self-selected practices may perform better at baseline, but also tend to implement experimental strategies better than average practices.

There is very little research on the sustainability of teaching/learning effects, in particular on interventions targeting practising physicians. Instrumental research on assessment methods for educational studies is needed.

### **Aims for future research and appropriate research methodology**

Descriptive, cross-sectional surveys and attitude studies will not add much knowledge in most countries / settings.

Future research should focus on

- Good quality studies on primary care epidemiology, on complaints which were not researched so much yet, and with a longitudinal perspective
- Clinical studies dealing with common, everyday complaints and illnesses
- RCTs on non-selected general practice patients and on treatment which are relevant for primary care, including comparisons of dosages, established treatments and research when to stop treatment. Observational and interventional research on diagnostic reasoning in (low-prevalence) primary care settings, starting from complaints and symptoms, using step-wise strategies, including watchful waiting, assumptive treatment of symptoms, and focussing on low technology strategies
- Research on primary care patients with multi-morbidity, acute and chronic diseases at the same time, or specific preferences
- Large observational and interventional studies which focus relevant health outcomes, less common health problems, or safety issues, i.e. unwanted effects of treatment
- Longitudinal research, both observational and interventional, with longer follow-up
- Instrumental research on GP specific tools and outcomes
- Mixed method studies measuring patient perspectives and preferences, changes of health over time
- Observational and interventional Research on the impact and sustainability of educational interventions

### 3.4. Comprehensive Approach

#### Definition

The core competency “comprehensive approach” includes two domains:

- a focus on management of illness, it means managing simultaneously multiple complaints and pathologies, acute as well as chronic health problems;
- a focus on well-being and health promotion according to the biopsychosocial model and better care to the patient.

General practitioners have to manage and co-ordinate all of these aspects: health promotion, prevention, cure, care and palliation and rehabilitation, enhanced by a specific long term general practitioner-patient relationship.

The MESH-term “comprehensive health care” is explained as providing the full range of personal health services for diagnosis, treatment, follow-up and rehabilitation of patients. This means that this research domain includes health promotion and prevention, diagnosis, treatment and follow-up of all diseases but also palliation, requiring research not linked to specific diseases, but to patient groups or to health themes in all their aspects.

#### Literature search

“comprehensive health care” [Mesh]

- and “Primary care/ Family Practice” [Mesh]
- and “Health Promotion” [Majr]
- and “prevention and control” [Subheading] OR “Primary Prevention” [Mesh]
- and “Teaching” [Mesh] OR “Education” [Mesh] OR “education” [Subheading] OR “Teaching Materials” [Mesh]

A lot of articles focused on nursing, are not relevant for family practice. So we excluded them to put in the search string ‘NOT nursing’.

There is a specificity problem with this search: comprehensive health care is very large as a term, i.e. primary health care and patient-centred care appear as subheadings. Many articles are retrieved that do not have comprehensive health care as individual MeSH term. When searching for references with the keywords ‘health services research’ and ‘comprehensive health care’, we found a lot of articles related to community oriented care. So there is clearly overlap between the different searches.

#### Summary of the findings

Comprehensive care means the care for the full patient, while almost all research until now seems to be related to the prevention of one particular disease, i.e. alcohol abuse or cardiovascular diseases, specific activities like disease screening, or complex interventions (counselling, implementation of a chronic care model, lifestyle modification). Concerning prevention and comprehensive care, there seems to be not much good research in family practice so far. Often, the setting of these studies and their relevance for general practice is not clarified. Comprehensive care is a term commonly used in nursing and nursing research, which was not studied here. Most research on medical comprehensive care is disease-related, very often on depression/ mental health, or cardiovascular disease. This gives a very scattered view with multiple small pieces

of knowledge highlighting very specific situations (often without well defining the setting of care), but not resulting in a good picture on comprehensiveness as defined by WONCA.

There is a considerable amount of research on lifestyle interventions for primary care patients, often labelled with the term “comprehensive”. Only some of these studies are really primary care based, quite often they were undertaken by specialists on more or less selected samples. Meta-analyses concluded that there is evidence does not support an effect of stages-of-change- based interventions on levels of physical activity. There is limited to no evidence for an effect on stages of change for quitting smoking, just a positive trend. Some positive evidence was found for an effect on fat intake at short- and long-term follow-up. Individual studies on lifestyle interventions often claim positive effects, which are, however, usually small, and often described by surrogate or disease-specific outcome measures, thus covering only very limited aspects of health. In conclusion, scientific evidence on lifestyle interventions to modify health behaviour is limited. There is limited material on **medical education** for a comprehensive approach. In a review of educational interventions in primary care, the authors concluded that there are only 2 articles who met the criteria for good research in this field. One of the studies was done in Zambia.

Almost all existing research is either cross sectional or prospective with relatively short follow-up times. Sustainability and impact on long term, relevant health outcome is rarely studied. There is an important lack of methodologies and outcome measures as well as longitudinal studies..

### Research aims

So far, there is very little evidence supporting this competency understood in the WONCA definition. The concept of a comprehensive approach in general practice is not well defined in a way which is applicable for designing research. We do not know well how the concept is understood by primary care doctors, and whether patients share this view and recognise activities as comprehensive care. There is almost no research on a generally comprehensive approach towards the patient irrespective of specific medical problems. “Usual” and “good” (definition-conform) general practice care are not well described in a practical way. There is a lack of studies and thus evidence on it’s effectiveness and efficiency. We need better assessment and appreciation of this comprehensive, complete work of a GP, but lack the specific research tools and outcome measures or indicators of comprehensiveness.

Maybe “comprehensiveness” is a concept on a higher level, which should cover the other five competencies. It is questionable if “comprehensiveness” as a whole can be the focus of research. For research purposes, the concept needs to be broken down into individual specific approaches and aspects of comprehensiveness, which can then be subject to research.

Studies can be done on general practice care aspects including simultaneously both curative (illness management, rehabilitation) and preventive activities (health promotion and disease prevention) in the same patients. More studies need to be done in the specific contexts of primary health care, studying the effectiveness and cost efficiency of a comprehensive, general practice based (or coordinated) care in specific situations or specific target groups:

- Health promotion and disease prevention programmes;
- Care and active follow-up in emergency situations;
- Care and active follow-up of acute and chronic patients;
- Care and active follow-up of high-risk groups;
- Palliative care

Longitudinal research is particularly important here to assess the effectiveness of continuous, comprehensive care and its impact on people's well-being over time.

In case additional lifestyle intervention studies are planned, existing evidence should be studied carefully to assess originality and the external validity of the planned study. The expected added value to "usual" comprehensive general practice care should be considered, as well as its validity as a comparator – beware of generic or Hawthorne effects.

### **Research Methodology**

Research on the specific aspects of comprehensive approach should start with a definition of the precise aspect and research question. Observational studies (not questionnaire surveys) on the experiences, attitudes and needs of patients and doctors can then be helpful. Qualitative methodology is appropriate to clarify this complex, poorly defined field. Instruments need to be developed and validated.

Mixed research designs and intervention studies will be needed to assess the effectiveness of more specific aspects of comprehensive care.

Longitudinal studies both with retrospective and prospective designs are particularly important to assess the sustainability and long-term effects.

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### 3.5. Community orientation

#### Definition

Presentation of new paradigm of community oriented medicine started with work of Kark in 1950', 1960' and received more structured definition in 1980' <sup>16</sup>. With the last Wonca definition of family medicine from 2002 it became one of six core competencies. Community orientation includes the ability to reconcile the health needs of the individual patients and the health needs of the community in which they live in balance with available resources.

According to this definition, the following topics can be included: health needs (individual health needs in the context of the community health needs), specific decision making process (probability based decision making process determined by incidence and prevalence of illnesses in the community), cooperation with other professionals and agencies in the community and health promotion. These domains are overlapping with other competencies such as primary care management and comprehensive approach.

#### Literature search

As there is no explicit Mesh term for community oriented primary care (COPC), a combination of several terms was used:

"Community Networks"[Mesh] OR "Community Health Services"[Mesh] OR "Community Health Planning"[Mesh] OR "Community-Institutional Relations"[Mesh] OR "Community Health Aides"[Mesh] OR "Community Health Nursing"[Mesh] OR "Community Health Centers"[Mesh] OR "Community Medicine"[Mesh] OR "Consumer Participation"[Mesh] OR "Delivery of Health Care"[Mesh]

combined with

- "Primary Health Care" [Majr Mesh] and/or "Family Practice" [MeSH] NOT "Public Health"[Mesh]

Minority Groups"[Mesh] AND "Health Services Needs and Demand"[Mesh] "Community Networks/utilization"

combined with

- "Primary Health Care" [Majr Mesh] and/or "Family Practice" [MeSH]

#### Summary of findings

Community orientation is a rather new competence. Several articles in the last decades are descriptive, explanatory opinion papers. They describe the development and tent to define the concept of community oriented primary care. The English language concept of "community", however, includes both small entities like for example a family, and large communities of for example a school, a city or country. This makes the concept difficult to operationalize for research, and results in considerable overlap between public health and primary care research. Several studies on various clinical topics and preventive care are community/population based, but not about community orientation from a primary care point of view. Many studies including Cochrane Reviews are community oriented, but related to specific problems, but neither patient oriented nor dealing with community orientation in general. .

The COPC approach is specifically studied in the following fields: geriatric care, maternal and newborns' care, or focussing on risk factors and preventive medicine (immunisation, smoking cessation, dentistry), or within minority and underprivileged groups, or for common conditions (such as diabetes, arthritis) and psychiatric care.

Some articles also described methods of disease management in COPC, by cooperation between PC and institutions in community, collaborative care, GPs' referral to several community programmes. There is a lot of nursing research.

Several editorials and trials were found on health needs, in the primary care setting and for minority or underprivileged groups, some with combination of qualitative and quantitative research methods.

Educational research:

There are several descriptive studies on teaching of students, describing the content of educational programmes or teaching experience, less on teaching evaluation, and even less of controlled studies.

### *Methodology*

A lot of narrative and descriptive reports were retrieved, pseudo-research without precise outcomes. Some trials on health needs used a combination of both qualitative and quantitative research methods, but in general there is a lack of qualitative research. There are hardly trials on COPC, and most of the studies lack control groups or comparators. So far, studies focus on specific issues, diseases, screening, preventive services, often either too specific or too general, hardly any with relevant, GP related outcomes. Most of the current research which covers community based studies does not really focus on a community oriented approach.

### **Aims of future research**

Further research should therefore focus on

- comparing different approaches/models of primary health care in the community - with regards to relevant outcomes
- community approach for specific areas of clinical work such as palliative care, drug addiction programs
- information technologies in COPC
- education of COPC- regarding evaluation of programs, validated instruments, with a clear methodology and adequate statistical analysis

### **Research methodology**

- Instrumental research
- Longitudinal observational studies
- Observational cohort studies comparing different approaches/models - also in education
- Mixed design studies

### 3.6. Holistic approach

#### Definition

Holistic approach can be defined as “caring for the whole person in the context of the person’s values, his family beliefs, the family system, and the culture and the socio-ecological situation in the larger community, and considering a range of therapies based on the evidence of their benefits and cost”. The holistic approach recognizes that humans are complete, integrated beings rather than aggregates of separate organs, and that all illnesses have several components which relate dynamically. This also refers to the bio-psycho-social model<sup>17 18</sup>, which also respects the cultural and existential dimensions. Ethical issues are considered an important part of a holistic approach to health and health care.

#### Literature search

Holistic Health [Majr Mesh] combined with

- “Primary Health Care” [Majr Mesh] and/or “family practice” [MeSH]
- “Biomedical Research” [Mesh] OR “Clinical Nursing Research” [Mesh] AND “Psychology, Social” [Mesh] Or “Sociology, Medical” [Mesh] combined with “Primary Health Care” [Majr Mesh]
- Holistic Health [Majr Mesh] combined with “Primary Health Care” [Majr Mesh] or “Family Practice” [Majr Mesh] AND “Health Services Research” [Majr Mesh]
- Holistic Health or Holistic Nursing [Majr Mesh] combined with “Primary Health Care” [Majr Mesh] AND “Education” (Subheading) AND “Research” [Mesh] OR “Research” [TextWord]

#### Summary of findings

Almost all of the retrieved papers are opinion papers or non-systematic reviews. There is almost no real research. A majority of the papers relate to nursing, a considerable amount to complementary medicine. A few deal with “holistic care” for various conditions, but usually the definition does not seem to follow the core competency’s concept.

However, many of the reviews and opinion papers agree that it is important and valuable, and that care providers and patients hold similar views on this issue. There seems to be a consented implicit concept of holistic care which is shared by care providers and patients across many countries. It is claimed to be commonly included in daily practice of primary care. From a theoretical or consensus point of view, it seems that a holistic approach becomes ever more important as populations are evolving towards more chronic diseases, their care requiring both a holistic, comprehensive and person centred view on the patient and aiming at a broad concept of health and well being. It has been postulated that a holistic approach improves patients’ satisfaction and coping, and probably their health, but there is not much research proving that this is true.

In conclusion, the concept of a holistic approach remains poorly defined. It is almost inexistent as a research topic; both a clear definition in practical terms and instruments to measure it are still lacking. There is almost no research on its implications or outcomes.

**Aims of future research**

Further research should therefore focus on

- clearly defining a holistic approach,
- possibly identifying components/aspects which can be studied, and developing instruments to describe and measure them
- understanding the social and environmental circumstances which may have an effect on different aspects of health of patients
- evaluating effectiveness of an holistic approach with regard to satisfaction and relevant health outcomes
- effective methods of training GP to practice an holistic approach, if proven valuable

**Appropriate research methodology**

- Qualitative research seems to be appropriate to approach this complex, not yet defined field.
- Instrumental research is essential.
- Observational and later comparative studies will be needed to assess efficacy.

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#### 4. Draft Manual: How to start building GP research in a country with low capacity or limited resources for research in general practice

**Aim:** to advise countries which are in a process of building general practice and/or who have little or no experience or skills in GP research (and possibly little infrastructure):

- How to start – how to not start,
- What classical errors to avoid,
- Understand what implications your choice has

The six principles of capacity building are the fundamentals for this part of the research agenda even as the level of research network (individual, local network or department, national and international network).

##### The fundamentals or how to start a project, plan?

##### Identify research needs in your country, list of priorities

Description of

- Healthcare system
- State of research (hospital, secondary care) in your country
- GP/primary care activity who are they, what do they do, how do they work
- Morbidity, patient population, health needs

##### Choose your subject:

Research marketing is an important issue and related to the following steps?

- Relevant for your , GPs, patient, setting, country
  - Is it a primary care/GP topic? (look at the morbidity, mortality rates)
  - GP working conditions, health services
  - Patients health, well-being
  - Education (continuing professional development in practice, patient education)
  - Disease related clinical trials (also for local populations)
  - Context-specific for your country, even if structural conditions are poor, start with problems, culture and means you have (Witchcraft in Africa)
  - Where can you have the largest improvement?
  - Are results of your study useful/applicable in practice, or in teaching, or on a policy/health services level

First look at what poses a problem in daily practice, but keep also in mind what are the topics of interest in your network. Make a plan on a longer term with clear research aims for your research unit (local network, department...). This means building up sustainability and continuity.

But don't exclude research projects for which you can get resources, if they are relevant for primary care and if you have manpower for it.

Look at its systematic/theoretic context (continuity line between holistic <--> health system based approach)

- Original, not repetitive
  - Assess what has already been done by a good literature search.
  - Look to what extent these research topics have been done (outcome parameters, research methodology...)
  - Repeat studies in a local context or with context specific research question, not too general and disease related study
  - Do not repeat the same question without an original (contextual or follow-up) touch to it
  - “Russian doll” system of local teams and expanding research themes and circles, protecting each small team. Not research for research, clear aim
- Feasibility
  - Where is the money? How can it be turned to our question?
  - Is there sufficient manpower? Are they skilled enough or can you have support?
  - Can I build up a network from research units (practices, health care centres...)?
  - Can you implement, publish it later?
  - Would the research plan be accepted by an ethical committee?
  - Is the research topic and methodology feasible in your setting? (religious, social, cultural aspects...)
  - Sample size could be an obstacle, depending on the prevalence of the disease, the outcomes ...

### Needs for good research

#### A good team and a good research plan:

Who is participating in your research team, steering group? Try to find people with experience to support and to give feedback. How much time can you spend on your research?

Formulate clear the purpose of your research plan

Why to start, for what kind of goal or objective?

What is the key of the exercise in a practical point of view?

Research is not just for philosophy or to keep researchers busy,...

Think forehead! What will be the added value of my research?

Write a research protocol.

- Research ideas have to be translated in answerable research questions?  
Common errors: questions which are too complex, “make a better world” type of aims
- A good research question can be translated in an appropriate research methodology
- Define outcome parameters
- How to make a research network? (practices, patients..)
- Which skills do I need?
- Which material do I need?
- Time schedule (be realistic!)
- Funding
- Implementation strategies

**Requirements for a good research protocol:**

Determine the nature of your research question

Choose for the appropriate research methodology

- quantitative methods (looking for numbers, measurements, generalisability (in a defined context))
  - beware of questionnaires which only measure attitudes - what people think they are doing, usually nowhere close to reality, questionnaires are rarely useful
    - direct observation (qualitative)
    - or using existing real life data (quantitative)may be more appropriate to see what really happens
  - beware of complex or interventional designs in the beginning to start with, cross sectional studies or a cohort study (not-too-long longitudinal follow up with repeated measurements on the same subjects) are fine, but don't copy too much. Give it an original touch. Use validated instruments or at least if you don't find any, use a validation procedure.
  - case control or intervention studies are a lot more difficult
  - RCTs / classical clinical trial are very difficult and expensive, originality is a major issue here
  - Improving quality is a honourable goal, but not a research project, and tends to motivate excessively complex designs
- common errors:
- wrong/irrelevant/surrogate outcomes
  - wrong/invalid instruments, home grown questionnaires
  - forgot to make a sample size
  - interventional studies: forget to compare the different subgroups at the baseline (just for age, gender is not always enough)
  - neglecting selection effects, overestimating generalisability
  - neglecting other sources of biases
  - wrong statistics/analysis
  - overestimating your data
- or qualitative (looking for concepts, ideas, not generalisable, explorative leading to hypotheses)
  - choose for the good technique (interviews, focus groups, observation...)
  - purposeful sampling (make the good selection of participants)
  - make a good script for the interviews

- look for a skilled moderator
- don't forget the infrastructure
- make a plan for the analysis (manpower, software...)

common errors:

- no good research question
- wrong technique (keep in mind local context)
- wrong sampling
- being too superficial
- lack of a defined method of analysis
- lack of abstraction, sticking with citations
- defending a high generalisibility

### Networking

is needed on two levels:

- The research team
  - if you are a single researcher in your own practice or health centre try to find other colleagues in your environment or try to find support of a college or university department
  - make a network with other departments at your university (statistics, social sciences, nursing, pharmacy..)
  - national networking is beneficial for the total population of your country (networks on qualitative research exist, and certainly also for other research methodologies and topics)
  - international networking (EGPRN, collaborative studies, EU-projects..)

- Participants

Practices, health centres, individual GPs

- How to recruit participants? Start to make a research network that is sustainable. Spend some time on it.
- Let a 'peer' GP participate in your research team. He/she can be very motivating for other GPs to participate.
- Give them training in aspects of research necessary for your project
- Motivate participants: feed back results to them, value their input, offer them a network/support group and the most important: show them the possible benefits for their quality of work and their patients
- Who are conference attendees (locally)
- Database or contact directory of GPs (if possible with more information on experience, activities...)
- Be honest with the workload, but keep it feasible

Skills, Research courses

- Place of research in the medical education
- Place of GP in medical education
- What kind of vocational training?
- Specific research skills
  - Critical reading, retrieve and understand literature
  - Calculate funding
  - Choose design, sample size
  - Write a proposal
  - Write a paper, start with letters in good journals

## Possibilities to improve research skills

- invite people of other departments (f.i. statisticians...)
- organise a research method course and invite people from abroad
- participate in existing research courses (EGPRN, ...)
- learn from the feedback on conferences

calculate participation to research courses in your funding proposal

Infrastructure (the more of these can be established, the better)

- Registration system, good electronic patient records
- Good ethical committee
- Journal, publication possibility for publication, dissemination, contact
- Conferences
- Scientific society/ college
- Academic representation, university departments
- Money, consider conflicts of interest (sources of bias)
- Access to (full text) scientific literature
- “Eye” clearing and resource house, overview of funding possibilities
- How to start a professional environment which is discovery-friendly

Time schedule

Funding

Implementation

When you start a project think already at implementation! This is related to the question: what does this research mean for primary care.

## 5. General summary / Conclusions

Our approach to a research agenda as well as our literature review strategy started from the competency terms of the European definition. In this way, we used the European Definition of General Practice/Family Medicine as a guide.<sup>7</sup> However that was not the way how research is usually initiated. For most scientific projects, the starting point is the initiative of a researcher wanting to respond to a research question. Our definition-based approach to a very vast and complex field is described in the introduction and methods sections. Some problems or limitations are, however, engendered by this methodology.

### Search strategy based on MeSH terms

Overall, MeSH labelling is highly inappropriate for primary care research. For example MeSH taxonomy does not treat symptom terms appropriately from a PHC perspective (they link back to diagnoses immediately). Some of the core competency terms are not MeSH terms (i.e. community orientation) or they are so general that they cover large bodies of literature in a completely unspecific way. For instance, comprehensive care is cross-linked with primary health care and patient centred care as subheadings. Not every study declared as RCT, clinical trial or meta-analysis is really one; on the other hand, appropriate terms or search limits to identify observational research designs are missing. Concerning the actual labelling of studies, it was found that many relevant studies from GP or relevant to primary care are not labelled with the MeSH terms “family practice” or “primary health care”. On the other hand, many studies are labelled such, as their authors seem to believe their findings are relevant for GPs, while really they are not. Each MeSH-based search is a trade-off between a sensitive approach, yielding very large non specific results, and very sophisticated search strategies which are still not fully specific but exclude a lot of possibly relevant literature, in a research field where GP and specialist approaches overlap a lot.

### Generally defined competences and focussed research

Most of the published studies had been conducted to answer local or else quite specific, focussed research questions, as is the practice of good research. Thus, their contribution to a large-scale core competence was sometimes rather small, resulting in scattered pieces of evidence rather than in a meta-view. Therefore, this problem is related to the methodology of establishing the research agenda. It seems, however, to be inversely proportional to the precision and practicality of the definition, the competencies with a very large, philosophical definition being more difficult to grasp. Generally, the core competences of PC management, specific problem solving, patients and patient centred care are better covered by research. Concerning community orientation, the definition usually applied in studies does not fit the one given by WONCA very well. There is very little evidence supporting comprehensive and holistic care. This indicates a considerable gap between the WONCA definition – reflecting the self-image of GPs - and the field of primary health care research. This is a taxonomy problem - the more or less well defined definitions used in the literature do not comply well with the WONCA definition – but also reflected by the absence of measurement instruments. It is possible that the terms of comprehensive and holistic rather reflect an (ill-defined) ideal or maybe superordinate principle rather than a competency which can be measured or operationalised. They may need to be reviewed as part of the core competencies if no better evidence for their usefulness can be provided.

### **Disease orientation vs. patient orientation**

Though not always directly related to general practice, clinical research papers can be found on almost any condition. While much of this is relevant to primary care, the external validity or generalisability is often hard to determine. Both clinical studies and health services research usually feature specific diseases in their research question, inclusion criteria and outcomes, instead of a larger, patient-centred view. Most clinical trials have been done with male, relatively young and healthy patients, while typical primary care patients tend to be older and multi-morbid.

Diagnostic studies reflecting general practitioners' way of working are very rare. They should be performed in an unselected population, starting from signs and symptoms or patients suspected of having a disorder, and evaluating the added value of (simple or sophisticated) tests in a step-wise approach. Trials on therapy or management strategies should be pragmatic and performed in general practice settings. There is a need of trials comparing simple or standard treatments, or evaluating stepping down or stopping treatment. Co- or multimorbidity as well as aspects of patient preferences and prioritisation and general safety should be considered in research.

### **Quality of care research**

GP research has a strong emphasis on quality of care. This is one of the general strongholds of primary healthcare research. However, there are some drawbacks with the methodology of most of these studies. Assessment of quality of care is very often performed with a benchmarking approach; comparing current care to some reference standard, often a guideline. It is then often concluded that care needs improvement, as the physicians under study do not fully adhere to the guideline. However, this approach lacks calibration; usually there is no evidence on an optimal level of adherence. Furthermore, it is often not known whether better adherence to guidelines actually results in better health for patients, and if the efforts to implement guidelines are efficient.

Another common, but problematic type of study is the educational intervention study, targeting either physicians or patients: Most of these aim at showing that some specific "model of care" or initiative is superior to usual GP care. This poses some problems: The general assumption of most of these studies is that GP care is poor, or at least not good enough. Another methodological problem is that starting from this assumption, a successful study is one which succeeds in showing an improvement. Studies that fail to do so are then less likely to be published. In many "successful" trials, the effect or improvement is marginal. Sustainability is either poor or not studied. This could either be taken as a proof that educational interventions are generally quite ineffective and should possibly be abandoned; or due to a ceiling effect, proving that usual GP care is good enough, non- or marginally inferior to more sophisticated (and expensive) approaches. Research aiming to show the benefits (and not just the shortcomings) of general practice care may be appropriate in many instances.

### **Outcome measures**

Appropriate research instruments and outcome measures are lacking for many research questions in primary care. Current research, to a large extent, uses either satisfaction or other attitudes or surrogate markers for health, i.e. guideline adherence or physiological measures. Usually, the perspective is cross sectional or one with a short follow up. This does not reflect reality in general practice. Mortality and morbidity/incidence of severe disease or complications are important and valid outcome measures. However, they reflect relatively rare incidents, therefore requiring either very large sample sizes or very long follow-up when applied to a primary care population. Besides, they usually do not apply to the majority of patients under study, and therefore may be

too rough as a scale to estimate primary care interventions. Validated research instruments exist for some aspects of research on specific problem solving and patient-centred care (i.e. general and disease related quality of life, satisfaction, enablement etc.). However, they are still lacking with regard to more complex concepts.

### **Longitudinal research**

There is an overall lack of studies with a longitudinal perspective, both cohort studies and interventional studies with a longer follow-up (one year is often the maximum). This is particularly striking for a discipline priding continuity of care, thus failing to show its benefits. While it is known that many patients value continuity, most current research actually pictures scattered care. Longitudinal studies are difficult to organise and expensive. It is quite possible that in Europe, many countries lack the infrastructure (in ways of research personnel and availability of data) and the funding possibilities to perform longitudinal research, thus failing to provide much-needed evidence.

### **Overall aims for future research:**

Future research should aim at filling blank spots, and thus provide important evidence and contribute to medical knowledge and the discipline of General Practice. Important areas of research could be:

- General and primary care epidemiology in countries where there is a lack of local knowledge, and a reason to believe that results from other countries do not apply
  - Longitudinal research
  - Research on and taking into account multi-morbidity
  - Step-wise diagnostics in primary care
  - Randomised controlled therapy trials in primary care patients, assessing typical primary care treatments
  - Instrumental research in fields where instruments and outcomes are lacking
- Evaluation of management strategies, aids and technology, focusing doctors' and patients' perspectives as well as valid health outcomes
- Evaluating students' and trainees' educational programmes with regards to the specific aspects of general practice management and care

Appropriate methodology must be applied throughout. In the complex setting of primary care, qualitative methodology is often best for explorative research, and mixed-method designs may be appropriate in many projects. Observational cohort studies can be appropriate to study the implementation of evidence-based principles of care or education. Rigorous methodology should be applied in diagnostic and therapeutic studies, and care must be taken to choose appropriate settings, study populations and comparators.

## **6. Vision/ Perspectives**

*A vision on and perspectives for primary health care research have not yet been formulated in this research agenda*

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