Research Agenda for General Practice / Family Medicine and Primary Health Care in Europe

EUROPEAN GENERAL PRACTICE

EGPRN

RESEARCH NETWORK

EGPRN is a network organisation within
WONCA Region Europe - ESGP/FM

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The Research Agenda for Europe

Although it is one of the wealthiest regions, Europe is also a continent of vast diversities. This is true for all areas of human activity, including medicine. When looking at the European continent from the perspective of academic family medicine, the situation is equally varied: there are countries with well established academic departments of family medicine, with developed research infrastructure and stable research funding, but also countries that are only beginning to develop its research potential. The importance of research in family medicine has often been recognised, especially in recent times, when emphasis on primary care and family medicine is growing. It has also often been stated that the research potential of family medicine is big, but we are often struggling how to achieve it. One of the main problems with family medicine research is to develop research protocols and conduct research projects that would reflect the nature and problems of the discipline.

The role of international organisations of family medicine is to be aware of these differences and to try to bridge the gap between the developed and the developing. The role of WONCA Europe is to promote the scientific aspects of family medicine on a global level. In the past, WONCA Europe has done that by publishing a series of documents on principles of family medicine in partnership with its networks. The first one was the European definition, which was followed by the Educational agenda. The most recent document in this series is the Research Agenda for General Practice / Family Medicine and Primary Health Care in Europe. Its aim is to promote research in family medicine and to help family doctors to develop research proposals that are in line with the problems of practising physicians and their patients. It can also be seen as a tool for policy makers and other agencies interested in funding innovative research, since it identifies areas where research is needed. In that way, the agenda may be used as a guide for deciding about priorities in research at national or international levels. I am certain that the document will also be used for other purposes.

I am very pleased that the document has been developed and I congratulate the European General Practice Research Network for this achievement.

Professor Igor Švab, MD, PhD, Hon FRCGP
President of WONCA Europe

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Introduction

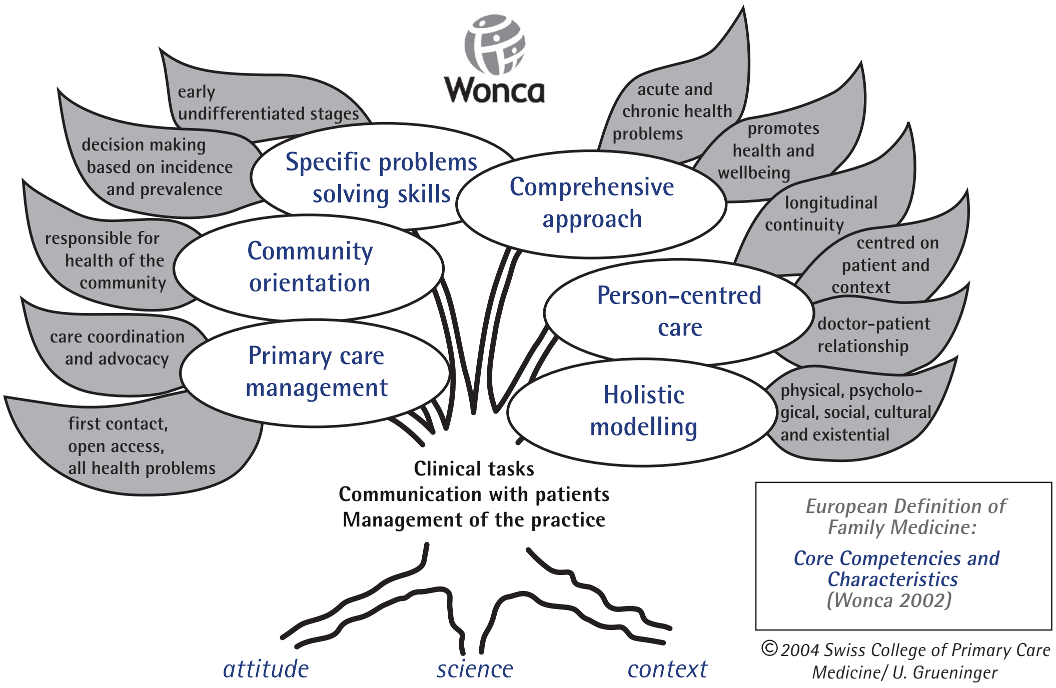
General practice/family medicine (GP/FM) is the core discipline of primary medical care and the cornerstone of many healthcare systems in Europe. Its potential is large: the large majority of European citizens have a general practitioner (GP) and regular contact with him or her. In healthcare systems where the GP acts as a gate keeper, 90-95% of all patient complaints remain in long time primary care (even when specialists are temporarily involved). Of all reasons for encounter, 80% can definitely be solved in primary care (1, 2).

In 2002, a European Definition of General Practice/Family Medicine was published, and revised in 2005. It informs 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': "General practitioners/family doctors are specialist physicians trained in the principles of the discipline. They are personal doctors, primarily responsible for the provision of comprehensive and continuing care to every individual seeking medical care irrespective of age, sex and illness. They care for individuals in the context of their family, their community, and their culture, always respecting patient autonomy. They recognise they will also have a professional responsibility to their community. In negotiating management plans with their patients they integrate physical, psychological, social, cultural and existential factors, utilising the knowledge and trust engendered by repeated contacts. General practitioners/family physicians exercise their professional role by promoting health, preventing disease and providing cure, care, or palliation. This is done either directly or through the services of others according to health needs and the resources available within the community they serve, assisting patients where necessary in accessing these services. They must take the responsibility for developing and maintaining their skills, personal balance and values as a basis for effective and safe patient care." (3)

The definition describes eleven essential characteristics of the discipline and translates them into six core competencies. The interrelation of these core competencies, implementation areas and essential features characterises the discipline and underlines the complexity of the specialty; it should guide and influence the agendas for teaching, research and quality assurance in GP/FM in Europe (4):

Core competencies (and essential characteristics) of the European Definition of GP/FM (4)

1. **Primary care management** (first contact, open and unlimited access, care for all health problems; efficient use of resources through co-ordinating care, working with other professionals in the primary care setting, managing the interface between generalist and specialist care, and taking an advocacy role for the patient when needed, i.e. protecting patients from harm which may ensue through unnecessary screening, testing and treatment)
2. **Person-centred care** (orientated to the individual, his/her family, establishing a relationship over time, effective communication, longitudinal continuity of care)
3. **Specific problem solving competency** (specific decision making determined by the incidence and prevalence, need to manage simultaneously in individual patients both acute and chronic health problems in all stages, a wide spectrum of complaints and diseases, co- and multi-morbidity)
4. **Comprehensive approach** (managing illness presenting in an undifferentiated way, managing risk and uncertainty, health promotion and prevention as well as cure, care, and palliation)
5. **Community orientation** (responsibility for the health of the community)
6. **Holistic approach** (health problems in their biomedical as well as psychological, social, cultural and existential dimensions)



European Definition of Family Medicine:
Core Competencies and Characteristics
(Wonca 2002)

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General practice / family medicine and primary health care play an important role in the functioning of the whole system of healthcare, which was only recently underpinned by WHO (5) and Rawaf et al. (6). Primary health care (PHC) is a concept originally developed in the UK in the 1920s and defined by the WHO declaration of Alma Ata 1978 (7-9). Several recent reviews (10, 11) present strong evidence for the role of primary care. Starfield (12-14) has shown that the strength of a country's primary care system is inversely associated with all-cause mortality, all-cause premature mortality and cause-specific premature mortality from asthma and bronchitis, emphysema and pneumonia, cardiovascular disease and heart disease. Strong primary care systems and practice characteristics, such as geographic regulation, continuity of care over time, coordination and community orientation are correlated with improved population health (15). The evidence also shows that primary care (in contrast to specialty care) is associated with a more equitable distribution of health in populations (16), a finding that holds in both national and international studies. The gatekeeper role of the GP is seen to be an important cost-control measure and prevents harm due to unnecessary hospitalisation and over-investigation (17). These papers refer to PHC as being delivered by a cooperating multi-professional team. In a European context (and in most other well resourced countries), the concept of PHC is used and has been studied with reference to the medical speciality of general practice/family medicine. In these countries, most PHC teams are coordinated by GPs who provide the primary medical care. This teamwork concept, however, is not yet implemented fully in all European countries and forms of organisation of PHC and general practice vary a lot. Whereas in some countries GPs have patients registered at their practice and the doctors perform a gatekeeping function, thus exclusively ensuring primary medical care, in other countries primary care is a territory, which is debated between GPs and multiple community based specialists that patients can access on their own initiative. Nursing is an important profession in PHC almost everywhere. In the various European healthcare systems, nurses work either as part of a PHC team (i.e. as a practice nurse), or as independent or community nurses. Research labelled as primary health care research, consequently, has been conducted in general practice settings as well as in nursing and sometimes also within community specialist settings or within other healthcare professions. The focus of this Research Agenda, however, is primary care delivered by general practitioners and multi-professional practice teams coordinated by them.

General practice research must reflect the context, meaning the complex relationships within PHC and PHC teams, as well as the patients' circumstances. The domain of general practice research therefore implies studies within the primary health care setting and the purposive use of a wide variety of research methods. Studies in a realistic, pragmatic setting are needed; diagnostic and therapeutic strategies for primary care have to be assessed in an unselected population and needs, perceptions, and preferences of patients and healthcare providers should be explored. General practice research has reached different stages of professionalisation and capacity in different European countries. It was first developed in those (mainly north-western European) countries that have built their health care systems on the principles of generalist-controlled access to the more specialised levels of health care ('gate-keeper', 'referral'). Countries where GPs work in parallel with other community based specialists found that the academic establishment and therefore the ability to do research in general practice settings 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, European countries show various stages of development of general practice research capacity: 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) (18, 19). General practice research is also necessary to increase the attractiveness of general practice to medical students and graduates.

General practice research has been a subject of animated discussion in recent years (20-22). Some authors have even questioned whether GP/FM research has any future. The necessity of primary care research has been described as follows: "Research in primary care is essential because: (a) clinical and preventive care must be underpinned by research evidence; (b) the bulk of such care in most countries, especially poorer countries, is delivered in primary care; and (c) 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." (23) Furthermore, "through family medicine research, the effectiveness and efficiency of health care services 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" (24).

Upon request of the European branch of the World Organisation of Family Doctors (WONCA Europe), the European general Practica Research (EGPRN) founded an expert group to work on a European Research Agenda for General Practice / Family Medicine in 2006. The main aims of this project were to provide guidance for further research and research related policy. The Research Agenda also takes into account the challenges for, the vision and future developments of the discipline. The Research Agenda is a background paper and reference manual for GPs, researchers and policy makers providing advocacy of GP/FM in Europe. It could serve as a reference paper worldwide, as no such documents exist for other WONCA regions yet. The Research Agenda intends to complement the EURACT Educational Teaching Agenda, which addresses academic and vocational training (25).

The Research Agenda will be a reference paper

- Summarising the existing evidence on aspects of the definition of GP/FM and related tasks of GPs, and it's meaning for researchers and policy makers
- Highlighting research needs and evidence gaps, i.e. for the purpose of research planning and funding or for funding decisions
- Providing a basis for proactive, positive action thereby influencing health and research policy, i.e. applying/lobbying for research funds
- Indicating issues of imminent importance for countries with a low capacity for research in view of a development plan for GP/FM research in a start-up setting

Methodology

Historical overview

Towards a European Research Agenda – a historical overview

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. After the publication of the WONCA definition of GP/FM, the initial workshop was held in 2002 (Bled, Slovenia) to brainstorm on research needs and perceived barriers to GP research in the countries represented, and to prioritise the results. This first overview was published in 2004 (1).

A second approach to the needs and requirements of GP research in the various European countries were (semi-)structured annual reports delivered by the EGPRN national representatives over several years. Data of all incoming EGPRN national representatives' reports from 2003 were analysed quantitatively and qualitatively with respect to research infrastructure, policy and organisation. Several rounds of SWOT analyses in successive EGPRN meetings helped to further focus and prioritise research topics and requirements (2).

A third approach was a review and classification of all abstracts presented in EGPRN conferences held since 2001, for theme and methodology, thus giving an overview of research activity of European GPs presenting in EGPRN (3). WONCA Europe abstracts could not be classified likewise, as they are neither published in a scientific journal nor archived systematically.

The **EGPRN Research Agenda Working Group** was then formed in 2006 consisting of the EGPRN Research Strategy Committee and other volunteer members. Building on the documents named above, the group took up the responsibility to compile a comprehensive review of GP/FM research in order to develop the Research Agenda.

The **starting point** for developing the Research Agenda was the domain of general practice in Europe, as described in the six core competencies (and the eleven characteristics comprised therein) of the WONCA definition (4). A second framework was the core domains of GP/FM research, summarised as:

- Clinical research
- Health services research
- Research on education and teaching in general practice (1, 5)

When attempting to define clinical research in contrast to health services research, we found these areas overlap considerably, but differ with regards to the outcomes of each study or study domain. Clinical research has outcomes at a patient level, measuring patients' health issues (including function or quality of life) whereas health services research focuses on doctor or system related questions and outcomes. These three domains (and adequate research methodology as a fourth column) were then superposed to the core competencies of the GP/ FM definition to essentially form a virtual grid that in doing so linked these areas of research. This grid helped to structure the subsequent literature review into thematic research domains, but was not used restrictively. There were repeated and extensive brainstorming sessions and discussions within the author group on the formulation and content of the individual research domains, until consensus was reached. Feedback from several public workshops and key informant discussions (see below) also added to this discussion. Challenges for primary care, which were not mentioned in the original document of the WONCA definition but of potential importance for future GP/FM, were added to the research domains and topics to be searched. These included, for example, the application of the continuously evolving genomic knowledge in preventive (e.g. cardiovascular or cancer risk management) and therapeutic health care (utilising pharmacogenomics), and the associated medico-ethical and medico-legal implications that this entails, and the use and potential of electronic medical records or information technology.

Literature review

From these starting points, we performed a comprehensive literature review, searching for relevant information on the evidence base of the WONCA core competencies and characteristics of GP, and for related research papers. For each core competency, the literature review was carried out by a subgroup of authors.

Search strategy

PubMed was searched using MeSH terms related to the core competencies or specific sub-fields (for details see the appendices) crossed with “family practice”, “general practice” and “primary health care”.

Several strategies were used to extend searches where findings were either scarce or a domain seemed poorly covered:

- Keywords of relevant studies for each core competency were retrieved in addition to MeSH terms and included into the searches.
- All related MeSH terms for each entry term (or key word) were identified and included in the search strategy.
- MeSH terms of relevant articles were used for further searches, and “explode” searches for related articles of relevant papers.
- In some instances, searches were not limited to articles labelled with “family practice”, “general practice” or “primary health care” in order to extend coverage of the domain.

This mainly applied to the research domains of primary care management, comprehensive approach, community orientation, holistic approach, and some subchapters of specific problem solving (genetics, chronic care, disease management programmes).

In domains with a large volume of references, additional filters were used and reviews limited to meta-analyses, systematic reviews, clinical trials or randomised controlled trials (RCTs), thus excluding editorials, unsystematic reviews or opinion papers. Articles which were only related to nursing (and not to general practice) were also excluded. This mainly applied to the research domains focussed on person-centred care and partly to specific problem solving, namely diagnosis, therapy, and quality of care related research. Literature searches were mostly limited to English and to some extent French, German, or Dutch language papers.

Additionally, a very rough semi-quantitative overview of research themes was attempted in order to identify well-covered topics and blank spots. This was achieved by searching PubMed for RCTs or clinical trials labelled with the MeSH term “family practice” or “general practice”, and published since 2003.

Critical appraisal

All articles identified through the searches were initially screened by title and abstract, 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)

Summarising the literature

Selected abstracts were compared to the domain descriptions and the methodologies used. Abstracts and full text articles were reviewed and methodology, results, and conclusions from the texts compiled. Landmark articles were identified if present. Findings were then discussed in the group of authors.

Compilation of results

Compilation of results

Each subgroup then summarised its results with regard to the research domains and concepts. Existing evidence on competencies and related research questions was identified and summarised, as well as the type of study and methods/instruments used. Conclusions were drawn after reflection and repeated small group discussion until consensus was reached. Subsequently, missing evidence and research gaps were identified by comparing the search results to the particular domain description, both in small group and plenary author group discussions. Results and conclusions were then compiled in separate chapters for each research domain and core competency domains, according to the following scheme:

- Definition of the domain
- Summary of the findings from these searches, indicating which topics are covered by research, and giving a rough overview of research results where feasible
- Research aims and needs, focussing on current evidence gaps and indicating future research themes
- Appropriate methodologies for the suggested themes

The chapter „How to start research in general practice in a country with low capacity or limited resources“ is a consensus document reflecting the wide experience of EGPRN members rather than the results of a systematic review of the literature.

Eva Hummers-Pradier and Paul van Royen then edited the summary documents. This was done initially by amalgamating all search strategies, references and draft texts summarising results (spring 2008), from which a more comprehensive, concise document emerged that drew up conclusions for each of the 6 core competencies (autumn 2008).

Preliminary and full results of the whole process were presented and discussed in various workshops and council or executive meetings at the WONCA Europe conferences in Paris (2007) and Istanbul (2008), and EGPRN meetings in Antalya (May 2008) and Budapest (October 2008). Feedback was sought from EGPRN members. Additionally, the WONCA Europe executive board, the WONCA World president, representatives of EQuIP and EURACT, editors of several European general practice journals, national colleges of GP/FM, the European Forum of Primary Care and other European opinion leaders were sent the document and asked to give feedback. A draft version was published on the internet pages of EGPRN and WONCA Europe in October 2008, inviting further feedback from interested individuals and organisations.

In a meeting of the authors (January 2009) all feedback received was discussed and incorporated into the draft document. Literature search strategies and the most relevant references were compiled into the appendices to the result chapters. The introduction, methodology and discussion chapter were revised thoroughly. A conclusion chapter with implications for research and policy was drafted. This version was further discussed in the author group. Eva Hummers-Pradier and Paul van Royen then edited the final document in spring 2009.

Results

Primary care management

Definition of the research domain

Primary care management according to the WONCA Europe definition of GP/FM includes the ability to:

- Manage primary contact with patients, dealing with unselected problems
- Cover the full range of health conditions
- Co-ordinate care with other professionals in primary care and other specialists
- Master effective and appropriate care provision and health service utilisation
- Make available to the patient the appropriate services within the health care system
- Act as an advocate for the patient

Starfield (1) defined primary care as having four central components, which also could be used as outcome measures or indicators for health services research:

Primary contact is a central component which includes 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 (2).

Longitudinality or continuity is person-focused care over time. (In this Research Agenda, this component is covered in the research domain "person-centred care")

Comprehensiveness requires that the primary care provider offer a range of services broad enough to meet all the common needs in the population - and assessment includes the extent to which the provider actually recognises these needs as they occur (Starfield's concept is somewhat different from the WONCA Europe definition of a comprehensive approach, which is itself a research domain within the Research Agenda).

Coordination is the degree to which the primary care provider manages all the patient's health care, including that provided at secondary and tertiary levels. This also requires an system of record-keeping or information which contains all health-related information (i.e. an electronic patient record); and an assessment that includes the extent and speed with which the information is recognised and brought to bear on patient care (1, 3) .

The research domain also includes the clinical effectiveness and health systems effects of models of managing particular health problems in primary care, i.e. defined disease management programmes and ways of organising care within a practice or PHC team. Educational research in this field comprises management skills at a health system- and practice-level, as well as education for collaborating medical professionals with a range of backgrounds and expertise. There is an overlap with other competencies such as community orientation, patient centred care and specific problem solving.

Summary of findings

The whole research field of primary care management is very large. The retrieved literature gave very scattered results, rather than a meta-view. Though there have been few systematic comparisons, it seems that there is little evidence in favour of any particular organisational, funding or workforce model, but it seems obvious that the organisation and workforce of general practice has to be developed further in order to better meet current and future requirements of primary care management. Evidence shows advantages for health systems that rely relatively more on primary health care and general practice in comparison to those systems tending towards specialist care in terms of better population health outcomes, improved equity, access and continuity and lower cost (4, 5).

Many of the retrieved papers are related to the management in primary care of patients with a specific disease (mainly depression, mental health and diabetes) or of a defined patient population i.e. in geriatric care (6-10).

The effect of various **primary care management models or interventions**, such as outreach preventive visits or care by nurse practitioners, was studied in different patient populations. Several studies suggest that for some well defined conditions, care provided by appropriately trained nurses is of a similar high quality to care provided by doctors and health outcomes for patients are comparable. However, primary care by nurse practitioners is likely to cost as much as care provided by (salaried) GPs according to currently available data. Interventions on practice organisation seem to influence service uptake, but the effect on health outcomes was rarely studied (11, 12).

The impact of **consultation length** 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 differently organised across various countries both inside and outside Europe. Many of the retrieved papers were disease related studies or nursing research papers. Improving access is a key policy issue in improving quality of (primary) care and in guaranteeing equity in health care, but the topic has until now mostly been studied from a local point of view rather than as a general characteristic or in a comparative way (13-18).

An important focus of research is **collaborative care** and the **interface between primary and secondary care**. This interface is, however, organised very differently in various European countries, implying that studies have to be interpreted in their local context and cannot really be generalised to another setting. Much research has been conducted with regard to referral rates and it shows a wide variation between individual general practitioners. Local educational interventions actively involving GPs and secondary care specialists, and structured referral sheets are the only intervention shown to have an impact on referral rates based on current evidence. The effects of an ‚in-house' second opinion and other intermediate primary care based alternatives to outpatient referral appear promising in settings with otherwise strict gate-keeping by GPs. Secondary care specialists should be incorporated in active educational activities and structured referral sheets are efficient (19-30). Cooperation with pharmacists (i.e. for control or coordination of prescriptions) may reduce medication- related adverse events; more randomised controlled trials of primary care based pharmacist-led interventions are needed, to decide on the effectiveness of this (31).

There has been quite a lot of research on the role and potential effects of **electronic medical records (EMR)** in primary care. **ICPC** (32) and coding of GPs' daily practice activity based on patients' reasons for encounter is a central concept of many papers. These show the usefulness, potential and possibilities for further development of GP/FM and primary care epidemiology based on the electronic medical records coded with ICPC and structured according to episodes of care (33-36). However, in many European countries, medical record utilisation and quality are less than ideal from the perspective of primary care epidemiology or collection of national and international research databases, due to the lack of standard classifications or national legislation imposing use of ICD based coding. Often, this results in incomplete records. For research purposes, a pragmatic approach to 'everyday' EMR or secondary routine data must be adopted (37, 38). There is a rapidly increasing body of literature both on methodological and quality issues of research on EMR /routine data, and of research projects using such records as a data source, for example eHID, QRESEARCH and other morbidity/EMR databases in UK, Belgium and the Netherlands (39-43). A substantial proportion of research papers deal with the potential of these databases to generate data for quality management (including audits) and of EMRs to represent a platform for implementing guidelines or recommendations, to identify patients eligible for treatment or preventive services, or to prompt drug warnings. The results that have been obtained are mostly positive, but not overwhelmingly so, which may depend on the EMR system used. Effectiveness with regard to health outcomes is rarely studied.

Common **outcome measures** in research on primary care management aspects included effectiveness with regard to costs or quality aspects/quality indicators, often with a benchmarking approach (44-53), or efficiency with regard to costs. Outcomes which reliably reflect patients' health or well-being were rarely used.

There has been a limited amount of educational research on primary care management aspects. Of the studies performed, the vast majority focuses on **educational interventions aimed at doctors** to implement specific service approaches, for example prevention activities, inter-professional collaboration, or care strategies for specific diseases, detection of disease, and prescribing. Most studies show either small or insignificant effects; sustainability of these effects has not been studied (54-58).

Needs for further research

Research needs

Further research should therefore focus on

- Developing instruments to describe the different aspects of primary care management and to measure it
- Patient and doctor's perceptions, perspectives and preferences on practice management issues (such as open access, telephone consultations, telemedicine)
- Comparing different models of care and evaluating effectiveness of different primary care management strategies or interventions, not only at 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
- Routine collection and the feasibility/validity of data from GPs' electronic medical records, their use for studies of morbidity and GP care (incl. appropriate denominators), and as a means for recruitment and data collection/management in research
- Effective methods of inter-professional education and teaching management skills to (future) GPs

Appropriate research methodology

Appropriate methodology

- Instrumental research to develop and validate measures for practice management issues
- Epidemiology of GP/FM, including specific aspects and outcomes of care, with a longitudinal perspective
- Interventional research (controlled trials – comparing different primary care management strategies, or comparing innovative strategies with "care as ususal")
- Implementation studies of effective strategies (observational)
- Mixed study designs

Person-centred care

Person-centred care

Definition of the research domain

Definition

According to the WONCA definition, person-centeredness includes

- Adopting a person-centred approach in dealing with patients and problems
- Establishing an effective doctor-patient relationship respecting the patient's autonomy
- Communicating, setting priorities and acting in partnership
- Providing longitudinal continuity of care

Patient-centeredness has been accepted as an important, central value in medical care and is nowadays universally advocated in medical education. In medical literature, the term patient-centeredness is usually used instead of person-centeredness. Nevertheless, their meaning is not identical, as person-centeredness implies that a person is acknowledged beyond his or her specific role as a patient. Person-centeredness is one of the core elements of GP/FM care- and therefore a key element in the new definition of the discipline. The concept of patient-centeredness has mostly been developed within general practice, as early as in the 1950s with the work of Balint and the Tavistock team, translating psychotherapeutic observations and methods into the context of primary care (1, 2). Also other disciplines show an increasing interest in patient-centred medicine. The concept was described by several authors and different basic elements were distinguished (3-5), such as communication, partnership and health promotion. According to Starfield (6), longitudinality or continuity, meaning person-focused care over time, is one of the core components of primary care. She suggests assessing it by the degree to which both provider and clients agree on their mutual commitment.

The research domain of person-centeredness also includes studies on patients' perspectives and preferences, as well as the effectiveness of a person- or patient-centred approach as defined above, and aspects of patient involvement and shared decision making, though there is an overlap with aspects of specific problem solving.

Summary of findings

Summary of findings

Many of the retrieved articles dealing with the concept of patient-centeredness are opinion papers. Several papers studied patient and doctor experiences, beliefs and preferences of a biomedical versus patient-centred approach/communication, mainly using a qualitative research methodology (interviews, focus groups, videotapes) (7). It appeared that not every situation or each patient group in general practice cherishes a distinctly patient-centred communication style, or shared decision making. The body of research in this area remaineds small and showed significant limitations. A better understanding of the diversity of patient and doctor preferences in different situations may lead to more effective and individualised care.

Several papers have also explored the preferences and experiences of patients on (interpersonal) continuity of care. Both patients and doctors valued continuity was addressing serious and psychosocial issues and also for routine checks for a chronic illness. However, continuity is considered less important than good doctor-patient communication. Being able to achieve fast access to care for acute disorders more important than interpersonal continuity for many otherwise healthy patients. Continuous care performed by the same doctors seemed to be beneficial concerning regular follow-up examinations in chronic disorders and some compliance with guidelines, i.e. for diabetes. 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 malpractice claims. Most RCTs showed effects mainly on patient satisfaction, or no statistically significant results. Recently, some research has been done on self-management education for patients with various chronic conditions. It appears that these programmes are more effective than information-only patient education; small, short-term effects were recorded with regard to increased satisfaction, health behaviour decreased symptoms and health care utilisation (8, 9, 10). Despite this relatively weak evidence, it is believed that the concept of patient self-activation or self-motivation.(11) and establishing a pro-active team-patient relationship in GP/FM will gain in importance in the future, especially for chronic diseases (12).

There is limited research on the effect of training programmes for practitioners in person-centred care on clinical and non-clinical outcomes.

In conclusion, the concept of person-centeredness remains poorly defined. A clear definition in practical terms and instruments to measure this 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 examined patient and doctor preferences and experiences. To date, there has been limited research conducted on its implications or outcomes.

Needs for further research

Research needs

Future research should therefore focus on
- Better understanding and clearly defining (components of) person-centeredness
- Developing additional instruments to describe and measure the complex aspects and outcomes
- Patient and doctor perceptions, perspectives and preferences on person- centeredness, communication, involvement and shared decision making (including social, cultural and environmental circumstances affecting these preferences)
- Evaluating effectiveness of a person-centred approach with regard to relevant clinical health outcomes and outcome measures such as satisfaction, knowledge, quality of life
- Effective methods of (future) GP training to practice a person-centred approach and the sustainability of training/education effects

Appropriate research methodology

Appropriate methodology

- Qualitative research provides an approach to patients' and doctors' concepts and expectations
- Instrumental research is essential to develop clear measures of person-centeredness
- Interventional studies- starting with simple patient-centred interventions – to assess effects
- Observational studies will be needed to follow-up person-centeredness with a longitudinal perspective, especially longitudinal epidemiological studies collecting data on reasons for encounter and doctor's sensitivity/response to patient requests

Specific problem solving skills

Definition

Specific problem solving skills

Definition of the research domain

Specific problem solving skills, according to the WONCA Europe definition, include the ability to

- Relate decision making processes to the prevalence and incidence of illness in the community
- Selectively gather, interpret and apply information from history-taking, physical examination and investigations, in collaboration with the patient
- Adopt incremental investigation, using time as a tool and to cope with uncertainty
- Manage conditions which present early or in an undifferentiated way
- Make effective and efficient use of diagnostic and therapeutic interventions, both in urgent or chronic conditions

This field is vast, comprising most clinical, disease related or diagnostic research. Epidemiological research on primary care morbidity and provision of care provides the necessary background to develop and apply problem solving competencies. Effective problem solving by GPs is often the cue to adequate primary care management and to adequate resource use in medical care. Therefore, the research domain encompassing specific problem solving has substantial common ground clinical research (with patient related outcomes) and health services research (with outcomes at a physician or system level). Research on specific diseases is mostly not confined to primary care researchers, but is also undertaken by the other medical disciplines. However evidence; which is to be useful to primary care needs to meet specific requirements in setting (patient selection), research questions and methodology. This research domain includes the following:

Diagnosis

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

Therapy

- Continuity between health and disease – when to start or stop treating
- RCTs in typical primary care populations, regarding effectiveness and efficiency
- 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-centeredness, comprehensive care)

Specific approaches of problem solving

(overlap with primary care management)

- GP decision making , shared decision making, prioritisation
- Quality management, guidelines
- Chronic disease management, multi-morbidity, long term care
- Clinical skills (communication, examination, counselling, family orientation)
- Home visits
- Dealing with complexity and uncertainty, watchful waiting, tentative treatment without a confirmed diagnosis

- Problems related to specific patient groups or gender
- Special or local interests in GP/PC
- Genetics/genomics

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 all evidence in detail or even give an overview of the state of knowledge on individual clinical issues. This is a domain of the Cochrane Collaboration and the many organisations and scientific societies working on guidelines for primary care. This Research Agenda aims to highlight general, systematic characteristics or weaknesses of studies in this field. We therefore selected exemplary conditions, namely, a sore throat (an acute illness) and congestive heart failure (CHF; a chronic disease), to retrieve and evaluate the relevant evidence (for primary care purposes), and to estimate the contribution of general practice research. Dysuria/urinary tract infections and diabetes were used as secondary examples. In order to define relevant clinical problems for primary care, we identified the core problems and recommendations from evidence-based, high-quality guidelines. Additionally, a very rough semi-quantitative overview of research themes was attempted in order to identify well-covered topics and blank spots.

Summary of findings

Summary of findings

Retrieval and appreciation of literature

In MeSH, 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". Frequently in 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 contradictory conclusions based on the same RCTs, depending on their evaluation of quality, external validity and relevance. One example is the debate concerning the value of drugs to treat dementia (1, 2). There are some attempts to establish a system to rate the quality of research articles, i.e. by the SIGN network, or the GRADE collaboration (3).

Predominant research themes 2003 – 2008

Predominant research themes

The surprisingly low number of around 500 clinical trials or RCTs retrieved by the MeSH based search for 2003-2008 was possibly due to the fact that many relevant papers are not labelled with the MeSH term "family practice". 70% of the retrieved articles had patient-related outcomes, the remainder focussed on doctors or system related outcomes. The largest bulk of research (23%) dealt with the health system or public health questions. Other frequent themes included acute and chronic airway disorders (9%), mental health (8%), diabetes (6%), heart failure (5%), hypertension (3%), children (3%) or urogenital disorders (3%).

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 or representative studies are very rare (the topic was also discussed further above, Chapter primary care management).

Diagnostics

Research on diagnostic reasoning and diagnostic tests

MeSH searches for symptoms retrieved results mainly concerning diagnoses/diseases: symptom terms are mostly not MeSH terms, but linked to disease terms. There are relatively few papers on symptom assessment and these are either on very specific themes or about (unspecific) syndromes. For acute disorders, there is some research on symptom scores or utility and predictive values of near-patient tests. However, these are rarely assessed for their added value (as an increase in positive or negative likelihood of a disease) to history, signs and symptoms or analysed in a context of a step-wise approach. In general, GPs' symptom- or reason-for-encounter based diagnostic approaches are very poorly reflected in the literature. For example there is almost no evidence to assist GPs in the assessment of the primary presentation of chest pain, as the proportion of manifestations of serious disease (such as acute coronary syndrome or pulmonary embolism) is relatively rare (< 15%, compared to 50% in the emergency room)(4). In general, there is little research on diagnostic strategies: Most studies on diagnosis focus on specific, usually sophisticated technical or laboratory tests in selected settings. There is a lack of studies addressing step-wise diagnostic reasoning or diagnostic tests relevant to GP decision-making and subsequent management. Evidence on predictive values of all kinds of findings or tests in primary care settings is scarce. 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.

Therapy

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 clinical RCTs being performed in primary care settings; instead, there is a lot of descriptive research, often in form of cross-sectional surveys, which are likely to be biased and of limited external validity. In general, many clinical RCTs are relatively small; sometimes they fail to be sufficiently powered for the main outcome and more frequently for secondary effects, and quite often there are randomisation problems. However, recent studies tend to be better designed. Most RCTs feature new or expensive drugs and study their efficacy in small, selected patient samples. Comparators are often less than ideal: sometimes, the control treatment is deliberately sub-optimal, being either under-dosed or second-choice. Some obviously industry initiated and sponsored drug trials are poor with respect either to recruitment, randomisation and/or follow-up. Outcomes are often surrogate markers of questionable value. There is an obvious lack of investigator-initiated trials of established, frequently prescribed drugs with no significant marketing potential and for whom industry sponsors can not be found. Many studies suffer from limited external validity, particularly those focussing on chronic diseases (5). Often there is selection bias at recruitment (i.e. patients are recruited from walk-in clinics or secondary care, or are either privileged or disadvantaged regarding access to care). Most patients recruited into trials are younger and healthier than the average GP patients with multiple chronic diseases and women are underrepresented. Pragmatic, large trials of therapies which are relevant in GP and look at the effectiveness of treatments in everyday settings and typical populations are lacking (6).

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, or safety issues. Exemplary, influential interventional and observational studies have been performed by Little (7) and Hippisley-Cox (8). Although there is some research on alternative/complementary therapy, it is often of relatively poor quality. Non-pharmacological treatment is a rare research topic. There is very little research on or accounting for co- or multi-morbidity (9-12).

Research on chronic care / disease management

Chronic care / disease management

The prevalence of chronic diseases is steadily growing, partly as a consequence of demographic ageing. It is estimated that in developed countries the major portion of a GP's working time (up to 80%) is devoted to chronic care (13). A large proportion of research on problem solving in chronic diseases is focussed on single diagnostic or therapeutic strategies, single outcomes (or even surrogate endpoints), therefore missing the complexity of primary care for chronically ill patients. However, there is a growing consensus that chronic care in general practice requires integrated, comprehensive and structured models (14, 15). This point of view is not confined to general practitioners. Therefore, many studies describe models of chronic care or structured disease management programmes that bypass the general practitioner or take "usual care" as a presumably poor comparator. Many intervention studies are designed by specialists or 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). This constitutes additional challenges for research in general practice to prove that most of these managed care models constitute new fragmentation in the system of care if they neglect the role of GP/FM in primary care. A number of reviews provide evidence for the value of GP-led primary care for chronic diseases (16-18); this research domain overlaps with ‚primary care management' and 'comprehensive care'.

Research on (shared) decision making

Decision making

A lot of studies relate GPs decisions in particular clinical situations (upper respiratory tract infection, depression care etc.) to predictors on patient or doctor/practice level, usually with a cross-sectional design. Qualitative research explores doctors' decision making processes or preferences. Qualitative methods or specific measurement tools (19) 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 were less satisfied with shared decision making than with a classical (more paternalistic) consultation style. Patients who prefer shared decision making 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 tools or aids, mostly related to specific disease related situations, for either doctors (i.e. synthesised evidence, electronic decision support) or patients (i.e. information materials). Some of these studies have an observational design (development or implementation), whereas others apply a specific tool as an intervention and compare with control groups (cf. also the chapter on educational research).

Research on quality of care

Quality of care

Quality of care related research and quality development in practice was adopted quite early by general practice researchers (20-24). The main contributions partly as controlled trials or as systematic reviews and conceptual papers, were provided initially in Europe by working groups in Maastricht and Nijmegen (NL), Manchester and Leicester (UK) and then subsequently under the umbrella of the European network organisation, EQuiP (25). The major research fields and methods of quality improvement, with respect to specific problem solving capacities, were peer review /quality circle work (26), medical audit (27-29), guideline development and dissemination (30, 31), research on implementation strategies (32, 33), patient participation (34, 35), and quality indicators /quality frameworks (i.e. the quality and outcome framework QOF in the UK)(36). A vast body of literature deals with solving specific quality problems, e.g. improving guideline adherence, improving the use of laboratory test results (37) or optimising prescribing by means of different methods such as continuing medical education, benchmarking, academic detailing, structured feedback etc. (38). Quite often, however, and particularly when performed in managed care settings, cost-effectiveness features as a primary 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 a reference standard in studies with a benchmarking approach, though they were originally intended to be decision aids. Many disease-related articles feature diabetes, depression, or stroke. A number of reports target patients, attempting to encourage them to lead a healthier lifestyle. Multidisciplinary or collaborative care is studied fairly often, as is the issue of frequent attenders. Most "quality of care" studies attempt to show the superiority of a specific intervention as compared to the default "usual care". This approach tends to shed an unfavourable light on general practice. However, the majority of empirical studies show only minor (or even no) effect, which often appears caused by insufficient concepts of improvement (e.g. solely educational interventions). Despite some important reviews (23, 30), a consistent theoretical framework on the rationale and effects of strategies in quality improvement is still lacking.

Genetics/ genomics

Research on genetics /genomics in GP/FM

Research papers on genetics /genomics in GP/FM or primary health care generally dealt with either GPs' or sometimes patients' views on genetic tests or counselling services, or interventions undertaken to increase their implementation. GPs and patients revealed mostly ambivalent feelings which appreciated the importance and possibilities of genetic medicine, but simultaneously expressed concern about its complex implications on patient management and impact on families. Intervention studies looked at the uptake of services or at attitudes, but not at patients' health outcomes. Results were inconclusive (39, 40).

Educational research

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. While most studies were not done within the context of primary care/family medicine; they are relevant to this theme as 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 and 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 with respect to behavioural change (which seems to be a central obstacle to quality improvement) (41, 42), performance and (much more rarely studied) patient outcomes, across many individual educational methods. Dissemination of material, didactic lectures, but also uncommented feedback seems to be largely ineffective (43, 44).

Interventions are somewhat more successful when they are interactive, use multiple methods and are designed for a small group of physicians from a single discipline. Multifaceted interventions aimed 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 such as physicians' current performance and barriers to change (45). Even thoughtfully designed interventions 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 or learning effects, in particular on interventions targeting practising physicians. Instrumental research on assessment methods for educational studies is needed.

Needs for further research and appropriate research methodology

Research needs and appropriate methodology

Descriptive, cross-sectional surveys and attitude studies will not add much knowledge in most countries /settings. Nevertheless, large primary care registries on a sound data basis (e.g. QRESEARCH (46) will increasingly be used for non-experimental designs (for example, epidemiology, health care research, rare events etc).

Future research should focus on

- High quality studies on primary care epidemiology, on reasons for encounter, with a longitudinal perspective, and data collected referring to episodes of care
- Clinical studies dealing with common, everyday complaints and illnesses
- Pragmatic RCTs on non-selected general practice patients and treatments which are relevant for primary care, including comparisons of dosages, established treatments and studies on when to stop treatment
- Observational and interventional research on diagnostic reasoning in (low-prevalence) primary care settings. This should start from complaints and symptoms and deal with uncertainly and complexity, using step-wise strategies, including watchful waiting, assumptive symptomatic treatment , and focus on low technology strategies
- Research on primary care patients with multi-morbidity, acute and chronic diseases at the same time. This includes research into the attitudes of patients and physicians on how to set, rank and agree on priorities or specific wishes, and to revise this ranking over time
- 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 extended follow-up periods
- 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

Comprehensive approach

Comprehensive approach

Definition of the research domain

Definition

According to the WONCA Europe definition, a comprehensive approach includes the ability to

- Manage multiple complaints and pathologies simultaneously
- Promote health and well being by applying disease prevention strategies appropriately
- Manage and coordinate health promotion, prevention, cure, care, palliation and rehabilitation

The core competency and research domain “comprehensive approach” thus includes two aspects: a focus on management of illness (managing simultaneously multiple complaints and pathologies encompassing acute as well as chronic health problems) and another on well-being and health promotion according to the biopsychosocial model. General practitioners have to manage and co-ordinate all of these aspects in a specific long term general practitioner-patient relationship.

Starfield (1) calls one of her core components “comprehensiveness”, describing it as the extent to which the healthcare provider actually recognises all the patient’s needs as they occur, and offers a range of services broad enough to meet all their common requirements.

This means that the “comprehensive approach” research domain includes studies on health promotion and prevention, diagnosis, treatment and follow-up of all diseases but also palliation. It necessitates the simultaneous consideration of (all) these different aspects of care, and requires research not linked to specific diseases, but to patient groups or to health themes in all their aspects.

Summary of findings

Summary of findings

Retrieval and appreciation of literature

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 is a very large term; primary health care and patient-centred care appear as subheadings. This results in a specificity problem with this search: Many articles were retrieved that did not have comprehensive health care as defined in the individual MeSH term, or understood in the definition of the research domain. When searching for references with the keywords ‘health services research’ and ‘comprehensive health care’, we found many articles related to community oriented care. So there is clearly overlap between the different searches. A lot of retrieved articles focused on nursing and were not relevant to family practice. These were then excluded through use of the search string ‘NOT nursing’.

Results of the literature review

Most research on medical comprehensive care is either related to care or prevention of a specific disease, very often depression/ mental health, alcohol abuse (2, 3) or cardiovascular disease, or to specific activities such as disease screening, or complex interventions (counselling (4-6), implementation of a chronic care model (7), lifestyle modification (8)). Concerning prevention and comprehensive care, there seems to be not much good research in family practice to date. Often, the setting of studies and their relevance for general practice is not clarified. This gives a very scattered view with multiple fragments of knowledge highlighting very specific situations (often without defining the setting of care well), 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, more often they were undertaken by specialists on more or less selected samples. Meta-analyses concluded that the evidence does not support an effect of stages-of-change- based interventions on levels of physical activity. With respect to quitting smoking there is only a positive trend suggesting that this approach might affect behaviour (9). Some positive evidence was found regarding fat intake at short- and long-term follow-up. Individual studies on lifestyle interventions often claim positive effects, but these are usually small and often described by surrogate or disease-specific outcome measures and cover only very limited aspects of health. In conclusion, scientific evidence does not significantly support lifestyle interventions to modify health behaviour.

Preventive primary care outreach interventions aimed at older people were associated with a reduction in mortality and increased likelihood of continuing to live in the community (10, 11).

Palliative care is also an important issue within comprehensive care. Most studies focus on management and are performed by nurse researchers. Good communication which addresses both the patient's and the family's needs is an important element of good end of life care which aims to improve the quality of life (12-14).

Many studies related to practice management and organisation were found under the heading comprehensive and primary care (15-19), however, most fell into the domain of primary care management, and were considered in that section.

There is limited material on **medical education** for a comprehensive approach (20-23). In a review of educational interventions in primary care, the authors concluded that there are only 2 articles, which met the criteria for good research in this field. One of these studies was conducted in Zambia. Almost all existing research on a comprehensive approach is either cross-sectional or prospective with relatively short follow-up times. Sustainability and long term impact on the relevant health outcome is rarely studied. There is an important lack of methodologies and outcome measures as well as longitudinal studies.

So far, there is very little evidence to support this competency as understood in the WONCA definition. The concept of a comprehensive approach in general practice is not well defined in terms that are applicable for designing research, apart from the Starfield indicator, which is, however, rarely used. We do not know how well 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.

Needs for further research

Research needs

Maybe "comprehensiveness" is an umbrella concept, which should encompass 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 themselves be the subject of 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. There is a lack of studies and thus evidence on effectiveness and efficiency of comprehensive models of care. We need a better appreciation of the comprehensive, "full-range" work of GPs, and a way to reflect this in electronic medical records and research databases. However, we still lack the specific research tools and outcome measures or indicators of comprehensiveness.

More studies need to be done reflecting on 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

Appropriate methodology

Appropriate research methodology

- Research on the specific aspects of a comprehensive approach should start with a definition of the precise aspect and research question.
- Observational studies (but not questionnaire surveys) should include the experiences, attitudes and needs of patients and doctors as this can be helpful to clarify specific aspects of a comprehensive approach.
- 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 effectiveness and sustainability.
- 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 the "usual" comprehensive general practice care should be considered, as well as its validity as a comparator – beware of generic or Hawthorne effects.

Community orientation

Definition of the research domain

According to the WONCA Europe definition, community orientation includes the ability to reconcile the health needs of individual patients and the health needs of the community in balance with available resources. Presentation of the paradigm of community oriented medicine started with work of Kark in the 1950s and 1960s (1) and received a more structured definition during the 1980s.

According to this definition, the following topics can be included in the research domain: Health needs reflecting individual health needs in the context of a person's environment, as well as community health needs, and possible conflicts between these two. It also includes the specific context-related decision making process, and cooperation with other professionals and agencies according to these health needs. These domains are overlapping with other competencies such as primary care management and comprehensive approach.

Summary of findings

Community orientation is a rather new competence. Several articles in recent decades are descriptive, explanatory opinion papers. They attempt to define the concept of community oriented primary care and describe its development (1-7). The English language concept of "community", however, includes both small entities such as a family, for example, and large communities such as a school, a city or a country. This renders the concept difficult to study and results in considerable overlap between public health and primary care research. Not unexpectedly many 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 few trials on community oriented primary care (COPC), and most of the studies lack control groups or comparators. To date, studies have focused on specific issues, diseases, screening, preventive services, often either too specific or too general, hardly any with relevant, GP related outcomes. Thus most of the current research which covers community based studies does not really utilise a community oriented approach (8-10).

Several studies addressing various clinical topics and preventive care are community/population based, but are not community orientated from a primary care point of view (11). They cover specific conditions or problems neither from a patient-centred nor a community orientated care model. Some articles are evaluating the implementation of COPC model in specific, local communities (12-13).

The COPC approach is specifically studied in the following fields: geriatric care, maternal and newborn care, psychiatric care or common conditions (such as diabetes, arthritis). The focus is generally on minority and underprivileged groups or risk factors and preventive medicine (immunisation, smoking cessation, dentistry), and (14-25). Some articles also described methods of disease management in COPC involving cooperation between PC and institutions in community, collaborative care, or GPs' referral to several community programmes (26-32). 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 a combination of qualitative and quantitative research methods (33- 43).

Regarding educational research, there are several descriptive studies on the teaching of students in which the content of educational programmes or teaching experience was described, but very few evaluated the teaching. The majority of studies were not controlled (44-51).

Research needs

Needs for future research

Further research should therefore focus on

- Developing research instruments and outcome measures reflecting different aspects of community orientation, and their convergence
- Comparing different approaches/models of primary health care in the community - regarding outcomes with respect to both individual health and community needs
- Community based care models for specific areas of clinical work such as palliative care, drug addiction programmes
- Information technologies in COPC
- Education of COPC- regarding evaluation of programs, validated instruments, with a clear methodology and adequate statistical analysis

Appropriate methodology

Appropriate research methodology

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

Holistic approach

Holistic approach

Definition

Definition of the research domain

According to the WONCA Europe definition, a holistic approach includes the ability to use a biopsychosocial model that takes into account cultural and existential dimensions.

The holistic approach can thus be defined as “caring for the whole person in the context of their values, family beliefs, family system, culture and socio-ecological situation within the larger community, and considering a range of therapies based on the evidence of their benefits and cost”. A holistic approach recognises that humans are complete, integrated beings rather than aggregates of separate organs, and that all illnesses have several dynamic components (1-3).

Another aspect of a holistic approach is the complexity issue. Individuals, organisations, social groups and society have characteristics of complex adaptive systems (4). This phenomenon is evident in clinical and general practice research. The more directly involved the patient or the health care provider is in the intervention, the more sophisticated the design of the trial has to be to take account of the influence of the individual over the outcome (5). So a better understanding of complex systems may, for example, also facilitate the interpretation of results from clinical trials and diagnostic research. Ethical issues are considered an important part of a holistic approach to health and health care.

The research domain should include studies on the effectiveness of a biopsychosocial model applied to care, complexity, cultural competency and ethics.

Summary of findings

Summary of findings

Almost all of the retrieved papers are opinion papers or non-systematic reviews (6-10). There is virtually no investigative research. The majority of the papers relate to nursing; and a considerable number to complementary medicine, a theme that seems to be associated with a holistic approach. Few articles deal with “holistic care” for various conditions, but usually the definition does not seem to follow the WONCA Europe concept. However, many of the reviews and opinion papers agree that a holistic approach is important and valuable, and that care providers and patients hold similar views on this issue. Care providers and patients across many countries seem to share a common view on holistic care, but this has not been translated into outcome measures. However, ICPC provides the possibility to code the social, as well as psychological problems, presented or dealt with which may be used as a proxy for a holistic concept. Nevertheless, daily general practice and primary care often claims to adopt a holistic approach. From a theoretical or consensus point of view, it seems that a holistic approach, including the concept of complexity, becomes ever more important as populations present with more chronic diseases. To aim for a broad concept of health and well-being, care requires both a holistic, comprehensive and person centred view of the patient. It has been postulated that a holistic approach improves patients’ satisfaction and coping, and probably their health, but the research evidence to support these assumptions is lacking.

However, some aspects of a holistic approach have been subject to research: There is a limited number of papers studying the concept of cultural competency in depth, as well as the influencing factors, obstacles in practice, measurement instruments and models of implementation (i.e. programmes focussing on cultural competency) (11-18).

There are some papers which focus on complexity, looking at barriers and facilitators for change in healthcare as complex phenomena. Such research also shows that the metaphor of ‚removing barriers to change' is of limited use in a 'complex' context of non-implementation of a certain policy or programme (19).

In conclusion, the concept of a holistic approach remains poorly defined and is very rarely a topic for research. Both a clear definition in practical terms and validated instruments to measure it are still lacking. There is almost no research on its implications or outcomes.

Research needs

Needs for further research

Future research on a holistic approach, if intended, should therefore focus on

- Clearly defining a holistic approach, or further exploring whether the holistic approach of GP is a popular myth or a reality which can be described and measured
- Exploring what kind of need is expressed in the approval of holistic care, and in demands for complementary medicine
- Possibly identifying components/aspects which can be studied and developing outcomes and instruments to measure them
- Understanding the social, cultural and environmental circumstances which may have an effect on different aspects of health
- Evaluating the effectiveness of a holistic approach, more specifically cultural competency and a biopsychosocial care model, with regard to satisfaction and relevant health outcomes
- Effective methods of training GPs to practice a holistic approach, namely cultural competency and addressing of social problems, if proven valuable

Appropriate methodology

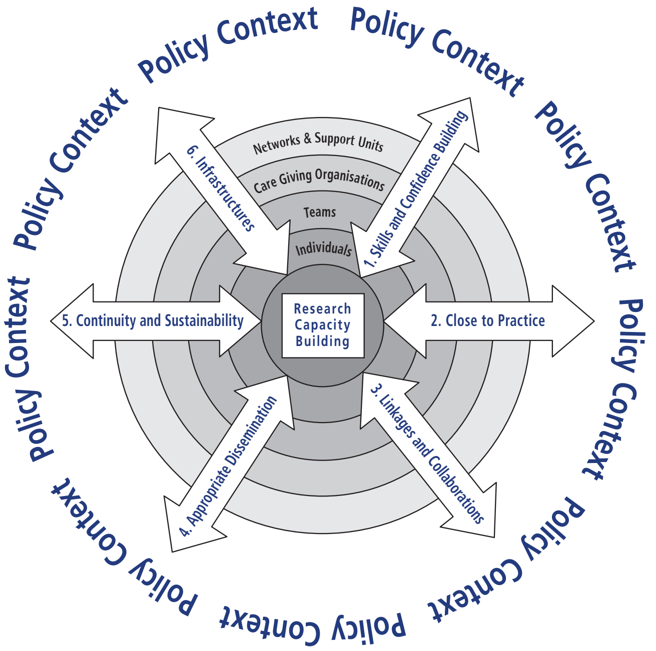
Appropriate research methodology

- Qualitative research seems to be appropriate to approach this complex, ill defined field
- Instrumental research
- Observational and later comparative studies may be needed to assess effectiveness
- Mixed-method longitudinal research is likely to provide opportunities for analysing complexity and interaction in general practice and primary care

How to start research in general practice in a country with low capacity or limited resources

The aim of this manual is 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 not to start
- What classical errors to avoid
- Understand what implications your choice has



The six principles of capacity building (Fig. 1 reprinted from (1)) are fundamental to this aspect of the Research Agenda, including the level of the research network: individual, local/ institutional, national or international. At every research level the same basic principles need to be applied but according to the situation in the country.

Identify research needs in your country and establish a list of priorities

When beginning to build research capacity, it is necessary to have an overview of the current situation in your country. This overview provides a landscape of ongoing projects and opportunities to find innovative topics and research strategies appropriate for your health care system.

To conclude you need a description of the

- Organisation of the healthcare system
- State of research in primary care in your country
- Available data on morbidity, patient population, health needs

Choose your research subject

In choosing a research subject, ask the question: what poses a problem in daily practice and what is relevant for primary care. Other factors are the topics of interest in your network. Compile a plan over a longer term with clear research aims for the research unit (local network, academic department). This means building up sustainability and continuity. The third factor concerns resources, including manpower required for the project and funding possibilities. General advice would be that research in primary care needs to should be focused on the core competences of general practice rather very general or highly specialised issues. General practice GP/FM research should be relevant, original and feasible.

Is your intended research project

Relevant for your GPs, patients, setting, country?

- Is it a primary care or general practice?
- Is it context-specific for your country?
- Where can you have the largest improvement?
- Are results of your study useful and applicable in practice, in teaching, or at a policy or health services level?

Original, not repetitive?

- Assess to what extent the research has already been done by a thorough literature search.
- Repeat studies in a local context or with a context specific research question, but do not attempt to do very general or large disease related studies

Feasible in your setting and with your resources?

- Are there possibilities to establish a research team?
- Are the necessary financial resources available?
- Is it possible to build up a network of research units (practices, health care centres)?
- Would the research plan be accepted by an ethics committee?
- Is the research topic and methodology feasible in your setting regarding the following aspects: religious, social, cultural aspects?
- Can you obtain an adequate sample size regarding the prevalence of the disease, the outcomes?

Draw up a research plan

Draw up a good research plan

To start a research project a good research protocol must be formulated with the following steps.

Formulate a clear **aim** for your study, and a precise **research question** which can be translated into an appropriate research methodology

- Define outcome parameters
- How to establish a research network? (practices, patients, support)
- Which skills are necessary?
- Which materials are needed?
- Time schedule (be realistic!)
- Funding
- Implementation strategies

Common errors in choosing the subject and drawing up a research plan

- Selecting a clinical or disease related theme which is too broad or too complex – and/or without possessing the necessary experience in this field
- Underestimating the importance of a well focused and specific topic
- Being too ambitious in choosing ‘changing the world’ intervention projects, instead of small projects at practice or local level
- Overestimating the potential of the data which can be obtained

Select the appropriate **research methodology**, making first a choice between **quantitative or qualitative methods**. Make use of validated instruments and avoid constructing your own questionnaires, if at all possible. If there are no suitable instruments or questionnaires available, employ parts of instruments or previous research and perform a pilot study or a validation procedure. RCTs and classical clinical trials are very difficult and expensive; originality can be a major issue here. Be aware that where if improving quality in practice is an aim of a research project this will demand a very complex design and is usually difficult to achieve. Small quality initiatives (audit) may improve quality of care locally, but they are rarely original as a research project. The requirements for qualitative research are the need for a good research question, the choice of an appropriate technique and a realistic analysis plan. Be aware that concepts and hypotheses resulting from qualitative research can not be generalised for the whole population.

Common errors in quantitative research

- Wrong/irrelevant/surrogate outcomes (i.e. satisfaction, attitudes instead of real behaviour, biomedical proxy measures of limited relevance)
- Wrong/invalid instruments, home grown questionnaires
- Failure to make a sample size calculation/estimate
- Intervention studies: failure to compare the different subgroups at the baseline (age and gender is not always enough)
- Neglecting selection effects, overestimating generalisability
- Neglecting other sources of biases
- Inappropriate statistics/analysis
- Overestimating your data

Common errors in qualitative research

- Poor research question
- Wrong technique (keep in mind local context)
- Inappropriate sampling
- Being too superficial
- Lack of a defined method of analysis
- Drawing quantitative conclusions from qualitative data
- Lack of abstraction, sticking with citations
- Defending a high generalisibility

Build up a research team

Build up a team

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

Networking is needed to build a good **research team**. If you are a single researcher in your own practice or health centre try to find other colleagues in your environment or the support of a college or university department. If this is not possible you can do a quality improvement project in your own practice, but this is not a ‘research project’. To build a broader research capacity, establish if possible a network with other facilities or departments at your university (statistics, social sciences, nursing, pharmacy). This gives opportunities to do research on different aspects of primary care.

Look for national and international support and try to find and consult experts. Locate people, for instance by internet, on a (inter)national level who are interested in similar topics and methodologies (networking on qualitative research exists in some countries, and certainly also for other research methodologies and topics). International networks/organisations such as EGPRN provide a good way to establish contact with such researchers.

Practical issues for organising a research network (of GPs, practices, health centres...)

- How to recruit participants? Start to make a research network of practices that is sustain able. Spend some time on it.
- Let a 'peer' GP participate in your research team. He/she may motivate other GPs to participate.
- Give participants in your research project appropriate training
- 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
- Among local medical professionals, who attend conferences (locally) as they may be more likely to be interested in research.
- Search a database or contact directory of GPs who have participated in previous projects (if possible with more information on experience, activities...)
- Be honest with the workload, but keep it feasible

Finally, strategies for recruiting research subjects (patients, GPs or other caregivers) are necessary.

Develop skills

Develop skills and attend research courses

Make an overview of the necessary research skills needed for your project, possibly with the help of an expert and plan funding if additional training is necessary. In the longer term make an effort to ensure that research skills are part of medical education both at the undergraduate level and in continuous professional development.

Possibilities to improve research skills

- Cooperate with academic departments (i.e. statisticians, sociologists, other GP/FM departments)
- Organise a research method course and invite people from abroad
- Participate in existing research courses (for example EGPRN)
- Learn from the feedback on conferences

Facilitating conditions

Think about facilitating conditions

The following factors have been shown to facilitate general practice research. Try to check if they exist and can be incorporated in your strategy:

Conditions facilitating good GP/FM research

- Registration system, good electronic patient records
- An accurate working ethics committee
- Access to (full text) scientific literature
- "Eye" clearing and resource house, overview of funding possibilities

Factors facilitating the dissemination and implementation of research results

- Journal, publication possibility for publication, dissemination, contact
- Conferences to present your research
- Scientific society/ college
- Academic representation, university departments

Conclusion and discussion

Conclusion

Our research strategy has been structured around the competencies as formulated in the European Definition of General Practice/Family Medicine (1). The various core competencies of the WONCA Europe definition of GP/FM seem to differ with regard to their evidence base. Some domains and aspects have a large body of research, whereas others are poorly covered and there is need for much more research. Within the 6 research domains, aims for further research and appropriate research methodologies have been formulated. These aims are listed in Box 1 below, and represent those topics that, to date, have been less well researched and thus provide an agenda for future GP/FM research.

Agenda for future research

Agenda for future research

Agenda for future research

- Better understanding and clearly defining each competency or domain (or components thereof).
- Developing and validating instruments and outcome measures for each competency or domain (or components thereof), taking into account their complexity and interactions.
- 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).
- 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 patient-centred approach, a comprehensive approach, a biopsychosocial care model, and community orientated healthcare (as com pared 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 data bases 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. Including data on reasons for encounter/episodes of care, as well as diagnoses, functional and quality of life outcome measures.
- Furthermore, attempting to understand how social, cultural and environmental circumstances influence health differences 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 step-wise 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 or curative and preventive aspects of care in the same patients.

The majority of 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. A considerable amount of papers were unsystematic reviews or opinion papers. Therefore, on summarising the results from the different competencies or domains, we formulated a list of recommendations for appropriate methodologies for future research in GP/FM.

Appropriate methodology

Appropriate research methodology

Appropriate research methodology

- Studies should measure relevant health outcomes or assess quality of life instead of focussing solely 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 explore what relevant health outcomes are and as a first step to develop measurement instruments.
- Randomised controlled trials (RCTs) provide high level evidence on therapy or other interventions if they are original and externally valid (with regard to selection effects and bias).
- In intervention studies, the expected added value to "usual" general practice care (and its validity as a 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 implementation of care models or educational programmes.
- Longitudinal studies are important to assess continuous, comprehensive care and sustainability of 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 explain reasons why.

In some core competencies or domains, the lack of research is particularly striking. There is very little evidence on the benefits of a comprehensive and holistic approach in GP/FM (as compared to a biomedical or specialist approach). Concerning the holistic approach there is a dichotomy between the obvious lack of research and evidence and the somewhat implicit consensus about its importance as an essential element for GP/FM. Therefore WONCA Europe should reflect and reconsider the concept and its status as a core competency.

While 'comprehensive approach' is slightly better defined, there is also an obvious lack of research and evidence. In fact, the concept seems to be broader and ranked higher than the other competencies. Indeed the MeSH-term "comprehensive health care", defined as providing the full range of personal health services for diagnosis, treatment, follow-up and rehabilitation of patients, has "primary health care" and "patient-centred care" appearing as its subheadings. Maybe 'comprehensive approach' should be abandoned as a separate core competency. In an updated version of the WONCA definition of GP/FM and the EURACT teaching educational agenda, WONCA Europe may want to reflect on the multidimensionality of the core elements of GP/FM and consider a model in which a comprehensive approach and possibly person-centeredness appear as transversal or superordinated aspects.

Discussion of the methodology

The core competencies of the European definition were used to structure the literature review and the text of the Research Agenda. In defining the research domains related to them, the 11 characteristics of the discipline were considered equally; they are covered in the document, though not in individual chapters. Nevertheless, this framework is not the only possible way to structure an agenda and it might be considered an unusual way to approach evidence. There is a considerable difference between the agenda approach based upon the European definition and the way that research develops normally. When planning research projects, topics are chosen locally with regard to local interests, specific questions and incentives. Much of the retrieved research has been conducted to answer specific, often local questions on clinical problems or aspects of organising or improving care. Accordingly, the scientific literature gives a rather scattered, patchwork picture which contrasts with the meta-view implied in the characteristics and competencies from the WONCA Europe definition, and is incomplete with regard to many of its aspects. An alternative structure, implying different literature search strategies, (based on individual research questions, for example, management of a disease, or effectiveness of a defined preventive intervention, or comparing national healthcare systems) would have given more detailed or in-depth results on the individual question. However, it would have been impossible to cover the entire field of GP/FM this way. Additionally, each chosen approach would have presupposed a certain view of the discipline, which would probably not be equally acceptable or relevant everywhere in Europe. The European definition of GP/FM is generally accepted, summarises the essentials of the discipline and thus provides a feasible and relevant framework for the Research Agenda. As intended, the Research Agenda informs on the evidence base of the European definition and consorts with the EURACT teaching agenda.

This Research Agenda is mainly based on a comprehensive literature search and a review of EGPRN research activities, and supported by international key informant surveys and workshops. For the literature review, PubMed was used as the primary search engine; other literature databases, such as Embase and ERIC were not searched systematically. This approach excluded many national GP/FM journals. However, the author team was multi-national and drew on their expertise and overview of local and grey literature. To select and appraise the literature for all domains, the authors did not use either a systematic quality appraisal checklist or a fully identical procedure. This simply was not feasible or appropriate. However, generally acknowledged criteria were applied to select and appraise research papers, as described in the abstract selection process of the EGPRN (or other conferences), peer review procedures of research journals, or critical appraisal of literature. Most searches, appraisals and summaries of the literature were reviewed and discussed several times by various members of the author team until consensus was reached.

MeSH-terms proved to be very poorly adapted to GP literature articles on taxonomic and indexing levels. Not every study declared as a RCT or meta-analysis really was one. Symptom terms were usually linked to a disease or diagnosis immediately. Many studies from GP/FM or relevant to primary care were not labelled with the MeSH terms "family practice" or "primary health care". However, many specialist-initiated studies believed to be relevant for GPs, were labelled as such while in reality they were not. Conversely, some apparently specialist studies published in specialist journals were highly relevant for GP/FM, but could not always be easily identified. Any MeSH- based search is a trade-off between a sensitive approach, yielding very large number of non-specific hits, and very sophisticated search strategies which are still not fully refined but exclude a lot of possibly relevant literature. This is particularly problematic in a research field where GP and specialist approaches overlap significantly, i.e. clinical research. For some research domains, MeSH-terms are very large and do not correlate well the WONCA Europe definition.

Discussion with regard to other literature

Discussion with regard to other literature on research in GP/FM

The European definition of GP/FM has been important in shaping the discipline, outlining its content and research domains and its role for the 21st century. However, to date, it had not been lined systematically with research evidence (2). This Research Agenda utilised the definition to provide information on the current state of the evidence and research needs related to it. The outcomes, i.e. the proposed research priorities together with appropriate methodologies for their study, should be applicable in most European countries and possibly also countries outside Europe, if aspects of research capacity are taken into account.

In 1966, Mc Whinney described the research domain of family medicine for the first time. It featured the epidemiology of illness in primary care, clinical aspects such as the evaluation of symptoms, diagnostic signs or tests and psychosocial aspects (3). In the following decades, clinical strategies and a focus on the family were added to this agenda, as well as research on educational methods, health services and policy related studies (4-8). Early in the 1990s, the importance of researching the patient's perspective in addition to the doctor's view was emphasised, as well as the relationship between the family doctor and the patient and his or her family. The family physicians' responsibility towards the community was also highlighted (9, 10).

Since 2000, several opinion articles and some research papers have contributed to the discussion. Several experts have called for a research agenda in order to clarify and prioritise research needs in GP/FM (11, 12), and to provide the specific contribution of GP/FM to medicine as a science (2), and to health services and policy (13-15).

Several articles evaluated specific or local situations. US researchers studied the position of GP/FM researchers compared to other specialties when applying for research grants (16, 17); research capacity as reflected by trainees or faculty of US family medicine departments (18, 19). The output of UK programmes to promote GP/FM research was evaluated by Carter and Kernick (20, 21). Social conditions and policy in developing countries were reviewed (22, 23), as well as research needs concerning rural practice (24).

The aims, content and expected outcomes of GP/FM research have been considered in a more general perspective by international experts in the field, i.e. during the WONCA Research Conference in Kingston, Ontario, in 2003, and its published reports (2, 11, 14, 15, 23, 25-30), as well as some subsequent articles (14, 31, 32). The historical development of research and research agendas has been reviewed (10, 30). All of these papers define infrastructural requirements and highlight the importance of GP/FM and related research for health services and health policy. They point out that the contribution of high quality GP/FM – led primary is care is essential for an effective healthcare system and that stakeholders increasingly recognise this fact. Results of GP/FM research inform policy makers on how evidence-based healthcare can be delivered in a sustainable, cost-effective and equitable way, and thus underpin social and ethical decision making in order to improve health globally. It helps to bridge the gap between fundamental biomedical or clinical research and the delivery of care to a general population, and forms a link between medical research and the humanistic sciences. In order to achieve this, funding should be adequate and directed at research projects which meet patients' needs, address conditions which contribute significantly to a populations' burden of illness, and consider factors which influence the implementation of results. International professional organisations or scientific societies have a role as clearinghouses providing databases of information, access to research instruments and in facilitating training and networking of researchers. It is generally acknowledged that GP/FM needs to increase its research capacity and several papers focus on how to achieve this, mostly at a system level (15, 27, 29, 31), or with regard to the development of networks of research practices (11, 20, 23, 28, 33). Our Research Agenda complements these papers with a framework addressing individual researchers working in low capacity environments.

Infrastructural requirements also include the reconnaissance of GP/FM by the scientific society, which is also essential when applying for funding. Representation of GP/FM themes and research journals should be improved: As our Research Agenda points out, the MeSH terminology does not reflect GP/FM contents well. Index Medicus itemising GP/FM in a summary category "medicine" instead of recognising it as an own specialty is disadvantageous (2, 11, 15, 27). Nevertheless, the output of GP/FM research has improved over the last years (34). It has also been pointed out that developing a method to measure the impact of research results on the society and policy would be extremely useful (35).

Several articles have attempted to draw up research agendas by suggesting themes that are perceived as particularly important. In fact, some so-called research agendas are in fact limited to very specific topics or areas of research, for example unexplained symptoms (36), health services in rural areas (24), primary care informatics (37), mental health (38), or choice of GP/FM as a career (39). Other review papers have a wider, more general perspective; many, including the Kingston papers, were written by renowned international experts. However, none had a systematic approach or used a predefined thematic framework. Several papers state that using a wide range of methodologies which include approaches initially developed by disciplines other than medicine, is essential for GP/FM research, and is one of its strengths (2). However, none links methodologies to research themes. The research areas and themes which were considered important can be summarized in the following categories (11- 15, 26-28):

- Clinical research on diagnosis, therapy and prevention of common diseases, with a pragmatic approach, and focussing on effectiveness rather than efficacy, reflecting the multidimensionality and diversity of primary care, and including specific strategies such as watchful waiting, or continuity of care
- Research on primary care epidemiology, including assessing the burden of illness, causes of health and illness/disease (including environmental, cultural, behavioural and psychosocial factors), long-term monitoring of the natural history of symptoms and the development of health outcomes
- Research on the influence of context factors (policy, culture, social conditions, local environments) on health, patient participation, role of relationship and communication, balancing evidence vs. patient views, development of patient oriented outcomes
- Health services research including health economy, effectiveness and equity of healthcare delivery, models of care, management skills for practice and healthcare system, quality improvement, integration of services, inter-professional cooperation
- Research into frameworks of community orientation and balancing community interests vs. individual interests
- Ethics: genomics, rationing of care, vulnerable populations, community vs. individual needs, international consensus
- Education, professional development, applying evidence to care

Most of these areas also figure in this Research Agenda (although prevention, health services research and ethics are somewhat less prominent). Additionally, it points out topics already relatively well covered and suggests more specific themes (e.g. multi-morbidity, longitudinal cohort studies, research on epidemiology based on reasons for encounter and illness episodes) and appropriate methodologies and infrastructure (e.g. the need for appropriate primary care databases and improving the quality of electronic patients records for research).

In summary, this Research Agenda provides an innovative overview and complements the ongoing discussion on GP/FM research. It is unique in its systematic approach and wide range of topics, and in looking at methodology as well as research themes.

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 beyond Europe, as no such documents exist for other WONCA regions. The Research Agenda summarises the evidence relating to the core competencies and characteristics of the WONCA Europe definition of GP/FM, and its meaning for researchers and policy makers. A GP/FM development plan for building up research in a "new" setting indicates what is of immediate importance for countries with low research capacity. Evidence gaps and research needs are pointed out to provide a basis for planning research for which there is a need and for action that may influence health and research policy, i.e. applying/lobbying for research funds. This document acknowledges and includes feedback received from many parties, organisations and international experts. However, patients and patient organisations have not been formally involved in the preparation of this paper. The authors welcome further discussion and the document is open to amendments.

Research organisations

Implications for WONCA Europe, EGPRN and other research organisations

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 purposes. Research organisations 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.

Patients

Implications for patients

Patients are not only involved as subjects of a study, but their needs should be the driving force for healthcare 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 FM/GP 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 dimensions:

- Patients' preferences and choices
- Patients' involvement (1 - 7)
- Patients' rights and ethical aspects, and matters of informed consent
- Patient organisations and their role

Ethical research and patient 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

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 care delivery, 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 this 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 biopsychosocial medicine are an important part of GP/FM research. The added value to existing knowledge should be considered carefully during planning. Existing instruments and outcome measures should be reviewed and considered, so as to be able to link and compare research. For example, within quality improvement projects, taking 'usual' care as the presumably poor comparator may not always be appropriate. Research highlighting the benefits of general practice / primary care 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 and GP/FM research across Europe could be enhanced by building sustainable networks and increasing research capacity (1,2,8,9). Across Europe, there are large regional differences with regard to 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.

Implications for journals

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 with regard to 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 an evidence-based resource for editional decisions or a publication policy.

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 with regards to specific aspects of care. 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. This Research Agenda and its suggestions for future research underline the importance of primary care to patients and on the health system level. The promotion of GP/FM research as proposed in this 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. 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).

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Appendices

Overview of search strategies

Primary care management

- "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 MeSH] 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]

Patient centeredness

"patient-centered care" [Majr MeSH] combined with

- "primary health care" [Majr MeSH] and/or "family practice" [MeSH]
- "continuity of patient care" [MeSH]

Specific problem solving skills

"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.

General, for semi-quantitative classification

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

Diagnosis

- "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" [Maj 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]

(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” [MeSH] with all subheadings AND “health services” AND (“family practice” OR “family physician”)
- combined with “quality management” [MeSH]
- “primary care” [MeSH] AND “disease management” [MeSH] AND “health services” [MeSH]
- combined with “collaborative care management”, “rehabilitation”, “patient-centred care”, “frequent attenders”, “promoting healthy life style”, “continuity of health care”

Genetics

- “genetics”[MeSH] AND “family practice“[MeSH], limits: human
- “genetics“[MeSH] AND “primary health care“[MeSH]

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])

Comprehensive approach

General for comprehensive care

- “comprehensive health care” [MeSH] AND “primary care” [MeSH] OR “family practice” [MeSH]
- “comprehensive health care“[Majr] AND ((“primary health care“[TIAB] NOT Medline [SB]) OR “primary health care“[MeSH terms] OR primary care[text word]) OR ((“family practice“[TIAB] NOT Medline[SB]) OR “family practice“[MeSH terms] OR family medicine [text word]) OR ((“family practice“[TIAB] NOT Medline[SB]) OR “family practice“[MeSH terms] OR general practice[text word]) AND Meta-Analysis[ptyp] NOT “comprehensive dental care“[MeSH]

Health promotion

- (“comprehensive health care“[MeSH] OR “primary health care“[MeSH] OR “family practice“[MeSH]) AND “health Promotion“[Majr MeSH] NOT nursing limits: meta-analysis

Prevention

- (“prevention and control“[Subheading] OR “primary prevention“[MeSH]) AND (“comprehensive health care“[MeSH] OR “primary health care“[MeSH] OR “family practice“[MeSH])

Palliative care

- “comprehensive health care“[MeSH] AND “palliative care“[MeSH]) AND (“primary health care“[MeSH] OR “physicians, family“[MeSH])

Teaching

- (“teaching“[MeSH] OR “education“[MeSH] OR “education”[Subheading] OR “teaching materials“[MeSH]) AND “comprehensive health care“[MeSH] AND “family practice“[Majr 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’.

Community orientation

As there is no explicit MeSH term for community oriented primary care, 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]) AND (“primary health care” [Majr MeSH] OR “family practice” [MeSH] NOT “public health“[MeSH])
- (“minority groups“[MeSH] AND “health services needs and demand“[MeSH] OR “community networks/utilization“) AND (“primary health care” [Majr MeSH] OR “family practice” [MeSH])
- “residence characteristics“[MeSH] AND (“primary health care” [Majr MeSH] OR “family practice” [MeSH])
- “community” AND (“family practice“[MeSH] OR “physicians, family“[MeSH]) AND “education“[Majr MeSH]

Holistic approach

- “holistic health” [Majr MeSH] AND (“primary health care” [Majr MeSH] OR “family practice” [MeSH])
- “holistic health” [Majr MeSH] AND (“primary health care” [Majr MeSH] OR “family practice” [Majr MeSH] AND “health services research” [Majr MeSH])
- “holistic health” [Majr MeSH] AND (“primary health care” [Majr MeSH] AND “education” (Subheading) AND “research” [MeSH] OR “research” [TextWord])
- “holistic health” [Majr MeSH] AND (“biomedical research” [MeSH] OR “clinical nursing research “[MeSH] AND “psychology, social” [MeSH] OR “sociology, medical” [MeSH]) AND “primary health care” [Majr MeSH]

Complexity

- “complexity“[All Fields] AND (“primary health care” [Majr MeSH] OR “family practice” [MeSH]

Cultural competency

- (“cultural competency“[MeSH] OR “culture“[MeSH]) AND (“primary health care” [Majr MeSH] OR “family practice” [MeSH])

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Discussion and conclusion

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Implications

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