

# INTERNATIONAL FEDERATION OF PRIMARY CARE RESEARCH NETWORKS

UNDER THE TASK FORCE ON RESEARCH OF WONCA



# NEWSLETTER



*An international forum for Primary Care Investigators*

## CONTENTS

### FROM THE IFPCRN CHAIR

International Collaboration in PCRN.....1

### FROM THE PCRNs

Distance Interactions. Internet, an option.....2

The Maastricht Network of Affiliated and Academic Practices.....3

Canadian National Networks of Networks.....4

Middle East PCRN.....5

### MEMBER AND ORGANIZATIONAL NEWS

IFPCRN Membership Status.....6

IFPCRN Registration form.....8

and enduring link between community based FP's and a research environment which emphasizes the need to improve the interface between practice and research». This same meeting also highlighted the role of PCRN's in accomplishing this. There was also a meeting of the Brisbane International Initiative for Advanced Education in Primary Care Research. The goals of this group are to develop international collaborations to support education in primary care research using the resources from many different countries. In the U.S., as in many other countries, there is increased recognition, even at the level of our National Institutes of Health, that research in Primary Care is needed if we are to continue to improve the health of patients in our communities.

### Changes in IFPCRN Leadership.

Dr. Helen Smith, our first Vice-Chair has stepped down as she has recently assumed the position of the Chair of Primary Care at The Brighton and Sussex Medical School. I'm sure you will join me in congratulating Dr. Smith on this advancement! To fill the gap left by Dr. Smith, Dr. Gómez-Clavelina, the editor of this newsletter has kindly stepped forward to assume the Vice-Chair position. Dr. Francisco Javier Gómez-Clavelina. M.D., is Professor of Family Medicine Department of National Autonomous University of Mexico (UNAM) and also serves as President of Mexican Academy of Family Medicine Professors AC (AMPMF). He is based in Mexico City, Mexico. Thank you, Francisco!

### IFPCRN Seeks Project PI's.

Several excellent ideas for multi-national research studies have come forth, and we are continuing to seek individuals who want to develop and implement research projects within the IFPCRN. Unlike the US

## From the IFPCRN Chair

### INTERNATIONAL Support in PCRN

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### The Support For International Collaboration in Primary Care Research is Growing.

Two meetings this spring have highlighted the growing international support for primary care research networks. The first was sponsored by WONCA and was held in Kingston, Ontario, Canada in March 2003. This meeting had representatives from 36 countries. The preliminary report from this group (yet to be finalized but summarized in the most recent WONCA newsletter) emphasizes the need to develop «a strong

## From the PCRNs

### DISTANCE INTERACTIONS: INTERNET, AN OPTION.

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One of the main strategies of collaboration in the environment of investigation in Primary Health Care is the creation of investigators' nets. For the IFPCRN it has been a challenge to establish an effective net of communication that allows solving the problems of the diversity in the development and use of computer systems. From its creation in May of 2001, the Steering Committee has carried out efforts to develop a wide communication that allows the exchange of ideas, the development of working groups and lines of investigation. These efforts have resulted the creation of the IFPCRN website, the elaboration of a database that includes the members and their networks and research interests, a listserver in the website of WONCA and a Newsletter for electronic distribution every four months.

The search of a better communication within the IFPCRN led the Mexican Academy of Professors of Family Medicine AC (AMPMF) to test the use of the Internet for a conference at distance. This was done during the III National and First International Colloquy of Professors-Investigators in Family Medicine, February 24<sup>th</sup>, 2003. During 50 minutes, it was possible to establish communication of audio and video between a net of investigators and Dr. John Beasley Professor Emeritus of Madison University and Interim Chair of IFPCRN. The headquarters for communication were The Faculty of Medicine of the National Autonomous University of Mexico (UNAM) and the School of Medicine of Madison, Wisconsin, USA. Several trial-runs were necessary, as was the elaboration of a script for the conference, the participation of two translators and two technicians in computation systems. There was also prior translation of the slides that were used as backup material.



*Patricia Tellez-Girón and John W. Beasley from Madison Wisconsin, USA.*

The experience was of high impact for the 35 investigators of the AMPMF who were interested in participating in events of this type and to look for the diffusion of the results of its studies using communication systems via Internet. There are plans for a wide use of this system for the II International Colloquy on 2004. It is necessary to consider that the investment in time and financial resources was minimum. We estimate that this methodology favors a wide and direct communication on real time at low cost.

It is necessary to offer a special «thank you» to John Beasley, to Patricia Téllez Girón and to Janet Reschke for their effort to implement the necessary to transmit the Conference from Madison, Wisconsin USA. In Mexico City, the members of the staff were: Francisco J. Gómez-Clavelina, Deborah Billings, Karen Sáenz-García and Andrés Hernández-Gómez. Many thanks for your time and patience.

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**THE MAASTRICHT NETWORK OF AFFILIATED AND  
ACADEMIC PRACTICES**

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***Research in general practice***

Within the context of this Newsletter I want to start with a specific part of the research network of the department: the RNH practices. The RNH is a Research Network of general practices of the Department of General Practice.

The aim of the RNH is to establish a computerised anonymous database with patients characteristics and all relevant health problems of these patients. It has primarily been established as a sampling frame for researches.

***Morbidity in General Practice in the Netherlands.***

The role of General Practitioners (GP) is crucial in the Dutch health care system. They are the only physicians working in primary care and are therefore the first doctor a patients meets if he need medical help. The GP's occupy a "gate keeper" function what implies that, in principle, all referrals to other specialist take place via the GP. Nearly all patients in the Netherlands are registered on the list of a GP whether they are insured by sickness funds or private sickness insurance.

GP's therefore possess a wealth of information on the health situation of their patients, and on many aspects of their medical treatment. From this position the GP can do research in a not selected, general population and he can do research about aspects of health of diseases which frequently occur in the community, the general population than in a referred to a hospital , also selected population.

Much information of the GP population is stored in a non systematically way, sometimes only in hand written records but in general not easy to access for research. Therefore it is necessary to use systematically computerised records in GP to facilitate the use of this data for research purposes. The GP's in the RNH research network use such computerised health information system. Characteristics of their practice population and relevant health problems can conse-

quently be easily retrieved for their own benefit but also to use for research purposes.

We use the International Classification of Primary Care (ICPC) coding as method for registration of the health problems presented. Every time the GP meets a patient the data on the encounters and relevant other health information are systematically stored in the computer of the practice. Monthly all these data from are stored in a central computer of the University. The health problems are defined as diagnoses (CVD), patterns of complaints (chronic), risk factors (smoking), adverse effects of drugs etc.

For researchers from outside the practices (specialists from the medical faculty, other GP's) it is possible, following certain strict rules to use the data and for example to select certain categories of patients (CVD, COPD, osteoporoses) for include these patients in research projects. The database of the RNH provides also a permanently up tot date dynamic research population which can be used for different kinds of analyses as well as sampling frame for different research designs such as cross-sectional studies, retrospective cohort studies, chart review studies, RCT's.

About 60 GP's in 25 practices are participating in the RNH with a population of about 100.000 persons on the lists of these practices. Several mechanisms are set up to guarantee the quality of the data from the RHN such as peer review, development of special software for data control, ongoing refinement if instructions and guidelines and regular feed back regarding the quality of the data provided, and random checks of data provided.

***The Academic Network of General Practices.***

All above mentioned RNH practices participate as a group of special practices in a large network of "Affiliated and Academic Practices". But in this network much more and also other GP's are participating.

In this large Network of about 300 practices in the Maastricht region several other research and educational tasks are executed in close relationship with the Department. In the educational curriculum for students in our medical faculty, students visit during the four program years several times the practices of the GP's to meet real life patients. In Network of about 350 practices, the department can carry out educational programs: Practical medical education (10 weeks clerkships in General Practice) or the general practitioner specific vocational training programs (3 years course in practice).

## CANADIAN NATIONAL NETWORK OF NETWORKS

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To be an *affiliation practice* means that the practice is willing to receive one or more students on an annual basis, or to participate in a specific research project. With the special *Academic practices* every year a detailed plan of action is made which usually contains more tasks: education tasks, high standard health care



Prof Dr Jan W. van Ree, GP, PhD

development and patient care but also frequent participation in research projects. The research program and registration of health problems and diseases, in a more selected group of GP's in the academic Network, is carried out in the RNH practices, already mentioned above.

A small selection of *International Publications* in 2001 and 2002 from research projects in this Network:

- Hooi JD, Stoffers HEJH, Kester ADM, van Ree JW, Knottnerus JA. Peripheral arterial occlusive disease: prognostic value of signs, symptoms, and the ankle-brachial pressure index. *Med Decis Making* 2002;22:99-107.
- Stalenhoef PA, Diederiks JPM, Knottnerus JA, Kester ADM, Crebolder HFJM. A risk model for the prediction of recurrent falls in community-dwelling elderly: a prospective cohort study. *J Clin Epidemiol* 2002; 55(11):1088-94.
- Vroomen PCAJ, Krom MCTFM de, Wilmink JT, Kester ADM, Knottnerus JA. Diagnostic value of history and physical examination in patients suspected of lumbosacral nerve root compression. *J Neurol Neurosurg Psychiatry* 2002;72:630-634.
- Wullink M, Stoffers HEJH, Kuipers H. A primary care walking exercise program for patients with intermittent claudication. *Med Sci Sports Exerc* 2001;33(10):1629-34.
- Akker M van den, Buntinx F, Metsemakers JFM, Aa M van der, Knottnerus JA. Psycho-social patient characteristics and GP-registered chronic morbidity: a prospective study. *Journal of Psychosomatic Research* 2001(50):95-102.
- Akker M van den, Mol SSM, Metsemakers JFM. Barriers in the care for patients who have experienced a traumatic event: the perspective of general practice. *Family Practice* 2001;18:214-216.
- Bindels R, Winkens RAG, Pop P, van Wersch JWJ, Talmon J, Hasman A. Validation of a knowledge based reminder system for diagnostic test ordering in general practice. *Int J Med Inf* 2001; 64: 341-54.
- Hooi JD, Kester ADM, Stoffers HEJH, Overdijk MM, van Ree JW, Knottnerus JA. Incidence of and risk factors for asymptomatic peripheral arterial occlusive disease: a longitudinal study. *Am J Epidemiol* 2001; 153 (7): 666-72.
- Vermeer F, Limpt P van, Wild vd J, Harting J, Gorgels A, Ruland E, Ree JW van. Hypercholesterolemia in undertreated in patients with coronary artery diseases. Results of a survey in 1997 and 2000. *J Am Coll Cardiology* 2001; 37(2):238.

Seven community based family practice research networks across Canada, and the National Research System of the College of Family Physicians of Canada (NaRes), have begun collaborating on a joint initiative whose aim is to develop primary care research networks with linkages locally, regionally and nationally. The seven community based research networks involved in this initiative are located in Toronto, Vancouver, Halifax, Kingston, London, Sherbrooke and Alberta. Each network developed as an independent organization and none of them, with the exception of Thames Valley in London, receives stable infrastructure funding. The remainder have not reached full potential due to inadequate levels of support. Without adequate funding the potential research contribution that could be realized by these networks will remain unfulfilled, both locally and collectively. Funding obtained from projects carried out in the networks only provides a small, insufficient surplus. It is hoped that through a collaborative proposal the primary care research networks can obtain adequate infrastructure funding to reach their full potential.

Primary care research networks could have a significant impact on the health care system. Questions such as rurality, continuity of care, multi-morbidity, social and cultural determinants of health, the effectiveness of health care innovations in primary care, and many more, could be explored. Essentially community-based research networks form the laboratory for systematically addressing research questions in primary care. The practice population and context reflect most closely the realities facing primary care practitioners, assuring relevance and generalizability of results.

The participatory nature of the networks ensures that knowledge is readily transferred into practice. Networks also provide a setting where clinicians from multiple disciplines can collaboratively evaluate their practice. This may well improve interprofessional understanding and foster team-working in the clinical context, as well as in research. The ability to liaise with like-minded colleagues is also revitalizing and empowering.

The purpose of this collaboration is to integrate research efforts between primary care and academic groups at three levels. Locally, the community-based networks would create close liaisons between community physicians, other primary care practitioners and academic health services researchers. Community-based networks can also collaborate regionally or provincially on specific projects. At a national level, larger studies could be conducted utilizing the existing NaReS infrastructure. The integration of the NaReS with the local and inter-regional network initiatives would provide the necessary infrastructure to develop meaningful liaisons across Canada.

However, it is difficult to find stable infrastructure funding for primary care research networks. By collaborating as a group on a national initiative, we hope to be more successful in securing funding. One potential funding source is the Canadian Institutes of Health Research (CIHR). The CIHR are Canada's major federal funding agency for health research. The objective of the CIHR «is to excel, according to internationally accepted standards of scientific excellence, in the creation of new knowledge and its translation into improved health for Canadians, more effective health services and products and a strengthened health care system». Community based research networks are designed to address these objectives in the arena where the great majority of patient-health service contacts occur.



Edmonton, Alberta, Canada.

\*Maher Peggy, Drummond Neil, Gryzbowski Stephen, Vanasse Alain, White David, Burge Fred, Grava-Gubins Inese, Stewart Moira, Rosser Walter, Xhignesse Marianne.

## MIDDLE-EAST PRIMARY CARE RESEARCH NETWORK

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The idea of Middle-East Primary Care Research Network (MEPCRN) started during the last WONCA meeting in London when I attended the meeting of the International Federation of Primary Care Research Networks (IFPCRN). After communicating with a number of colleagues in the area they liked the idea to start a middle-Eastern network, and this is how we started.

There is a substantial research need in primary care in the Middle-East. Research is an essential prerequisite in developing the speciality further in the area, and in developing evidence-based practice. Areas of research field that has been neglected includes a substantial part of illness and disease presenting to health services of which the bulk is only encountered in primary care. In addition the behavioural aspects, multidisciplinary cooperation and teamwork, are among areas that traditionally has been ignored in research.

The aim of the MEPCRN is to develop family medicine research in the area, in particular to do the following:

- To build primary care research network to fulfil unmet research need.
- To do collaborative research within the area, and with other networks.
- To lobby for financial support for research in primary care from different organisations.
- To help in the development of research training programmes, and the professional development of family physicians/researchers.
- To organize conferences that deals with research in family medicine
- To establish a number of experts from a multidisciplinary background to act as advisors and mentors.
- To help in publication of research studies from the region.

- To foster collaboration between individual primary care physicians, centres and countries within the Region.
- To help in the exchange of ideas and methodologies in the area.

Membership in the MEPCRN is being developed very fast. Now includes representatives from different countries in Eastern Mediterranean region. Membership from individuals as well as from networks is being solicited at this time. Membership is free, however any potential contribution will be helpful in strengthening the network.

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### INTERNATIONAL Support in PCRN

 ... from page 1

Federation of Practice-Based Research Networks (US-FPBRN) the IFPCRN has taken on, as one of its goals, doing research. That requires, of course, an individual who is willing to be the principal investigator and who has a trial that meets our criteria for an international trial. Francisco and I (and of course the rest of our members) would very much like to hear from you with your ideas. The IFPCRN stands ready to collaborate in multi-national research in primary care.

### Practice-Based Research Networks or Primary Care Research Networks?

Are our networks Practice-Based Research Networks (PBRN) or Primary Care Research Networks (PCRN)? These two terms have come to be used more or less interchangeably. My own opinion is that «Primary Care Research Networks» is the better term, as one could have a Practice Based Research Network that is (e.g.) all oncology. These may be very useful and effective, but are certainly not related to what family doctors do on a day-to-day basis. Perhaps it would be possible to have a Primary Care Research Network that does not

involve practicing physicians, but I have considerable problem imagining a Primary Care Research Network that would NOT be practice-based. Thus it seems to me that «Primary Care Research Network» is a slightly more precise term. Nonetheless, we will probably continue to use both terms, as do our members.

## Member and Organizational News

### IFPCRN MEMBERSHIP STATUS

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### IFPCRN Membership Status

The IFPCRN membership is relatively stable with 85 members in the database and 23 countries represented. I can make the database available to any members who are interested. By way of a request, we do need somebody to help us put the data we have on our participants into a more formal «inventory» of Primary Care Research Networks around the world (many of which are not our members). Is there anybody willing to step forward to help with this task? I do think, by the way, that not only would it be of significant use to us and to the discipline, but it should also be publishable as a review paper. There is a tremendous amount of network activity around the world, and I would like WHO and other organizations to be aware of this. Any volunteers out there?

IFPCRN Newsletter will receive the scientific contributions of every IFPCRN and WONCA members, as well as comments, letters, PCRN's reports and official announcements of scientific meetings.

*Francisco J. Gómez-Clavelina*  
 Editor

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## ***This is an interactive issue!***

*You can read this Newsletter working with links.  
Links let you jump to other locations in the same document  
or to Web sites*

- ◆ *Navigate to CONTENTS section on page one (or click on the word [CONTENTS](#))*
- ◆ *Select the article that you want to read, the pointer becomes a hand with an extended finger*
- ◆ *Click on it. You could read the selected article*
- ◆ *Follow the same procedure with [go to page...](#) *  
*and with [... from page](#) *
- ◆ *Click on URLs or icons and you will access to the selected Web site using your Internet browser*



### **You're invited!**

Come join IFPCRN.

**Description:** The International Federation of Primary Care Research Networks is an organization created with the aim of making multinational projects that can be useful to improve people's health.

[\(Join now\)](#)

#### ► Check it out!

Visit IFPCRN to see what you think. If you decide to join after checking it out, please return to this e-mail to Join so your membership will automatically be approved.

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<http://groups.msn.com/IFPCRN>

***Amazing news !!!  
A New IFPCRN Web site is under construction  
and will be into WONCA Web site very soon.***



**International Federation  
of Primary Care Research Networks**  
*Organized under WONCA*  
*The World Organization of Family Doctors*  
**Membership Registration**



Type of Membership:  Individual  Network

If network membership, What is the name of that network?  
\_\_\_\_\_

What is your network role (e.g. director, executive, member)? \_\_\_\_\_

Your name \_\_\_\_\_

Degree/Title \_\_\_\_\_ Address \_\_\_\_\_

City \_\_\_\_\_ State/Province \_\_\_\_\_

Postal/Zip Code \_\_\_\_\_ Country \_\_\_\_\_

Phone \_\_\_\_\_ Fax \_\_\_\_\_

E-mail address \_\_\_\_\_

Current research interests and projects (personal and/or network projects)

\_\_\_\_\_ ( ) Personal ( ) Network

\_\_\_\_\_ ( ) Personal ( ) Network

\_\_\_\_\_ ( ) Personal ( ) Network

Please add me to the email listserver  Yes  No

Comments? \_\_\_\_\_

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Note: You can download this membership registration from IFPCRN Website