### EDITORIAL INTRODUCTION

# The Sixth Geneva Conference and Person-centered Health Research

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#### Introduction

The articulation of science and humanism has been from the outset one of the keystones of our programmatic initiative on person centered medicine [1]. This involves the notion that the scientific method is what gives science its foundations and at the same time represents one of the principal strategies and tools to understand, formulate and intervene in crucial and paramount human concerns and activities such as health. A scientific approach to health and health care, from the perspective of person centered medicine, involves not only attending to organs and diseases (preferential topics in much of contemporary medicine [2]), but more broadly to the whole field of human health, including ill health and positive health [3], within which organs and diseases are inscribed.

The variety of domains involved in person-centered medicine include illness and wellness, disability and functioning, resilience and resources, plus experiences and values in health and contributors to health and wellbeing [4].

Such complexity needs be approached systematically [5] and its frame addressed [6]. This is even more

compelling given that the complexity and nonlinearity of health systems is being increasingly recognized [7].

As the above concerns were being widely acknowledged and formulated, the International College of Person-centered Medicine decided to designate personcentered health research as the main theme of its Sixth Geneva Conference. Such main theme informed the development and proceedings of the 6th Geneva Conference and the preparation of its 2013 Geneva Declaration. Next, we will highlight the development, structure and principal aspects of the 6th Geneva Conference and the papers emerging from such event and those coming from other quarters that compose this issue of the International Journal of Person Centered Medicine.

# The Sixth Geneva Conference

The Geneva Conferences on Person-centered Medicine have been held annually [8-12] always in total or in part at the Geneva University Hospital and in part since its third edition at the World Health Organization Headquarters. Starting with the Fifth Geneva Conference, a *Geneva*  *Declaration* focused on the conference's main theme has been issued and widely distributed [13]. From the Geneva Conferences process emerged an International Network [14], now International College of Person-centered Medicine [15].

The latest, sixth edition of the Geneva Conference on Person-centered Medicine was held on April 27 - May 1, 2013.

The conference took place at the Marcel Jenny Auditorium and auxiliary halls of the Geneva University Hospital and at the Headquarters of the World Health Organization. The Sixth Geneva Conference on Personcentered Medicine was organized by the International College of Person-centered Medicine (ICPCM) in collaboration with the World Medical Association (WMA), the World Health Organization (WHO), the International Alliance of Patients' Organizations (IAPO), the International Council of Nurses ICN), the International Federation of Social Workers (IFSW), the International Pharmaceutical Federation (FIP), the World Organization of Family Doctors (Wonca), the World Federation for Mental Health (WFMH), the World Federation of Neurology (WFN), the Council for International Organizations of Medical Sciences (CIOMS), the International College of Surgeon's (ICS), the International Federation of Gynecology and Obstetrics (FIGO), the Medical Women's International Association (MWIA), the International Federation of Ageing (IFA), the World Association for Sexual Health (WAS), the European Federation of Associations of Families of People with Mental Illness (EUFAMI), the World Federation for Medical Education (WFME), the International Association of Medical Colleges (IAOMC), the Paul Tournier Association, the World Association for Dynamic Psychiatry (WADP), the European Association for Communication in Health Care (EACH), L'Observatoire Francophone de Medecine de la Personne, the WHO Collaborating Center at Imperial College London, the International Francophone Psychiatric Federation (ALFAPSY), the French Psychiatric Association, the International Federation of Medical Students' Associations (IFMSA), the Zagreb University Medical School, the University of Gothenburg Centre for Person Centred Care, the George Washington University Institute on Spirituality and Health, the Peruvian University Cayetano Heredia, the University Francisco de Vitoria (Madrid), the Universite de Bretagne Occidentale (Brest, France), the Medical University of Plovdiv (Bulgaria), the Belgrade University Institute of Mental Health, and the University of Buckingham, with the auspices of the Geneva University Medical School and Hospital. In total, a record number of 35 major institutions were formally involved in the organization of this event.

Under the overall theme of Person-centered Health Research, the Sixth Geneva Conference on Personcentered Medicine encompassed a number of Thematic Symposia on Person-centered Health Research, other Symposia, Interactive Workshops, and Brief Oral Presentations offered to clinicians and scholars in medicine and other health fields as well as other interested individuals. Additionally, institutional work meetings were held prior to the core conference involving guiding principles for person-centered clinical care, personcentered diagnosis, and special institutional projects.

# Initial work meetings for the institutional construction of person-centered medicine

These work meetings focused first on the meaning, purpose and general strategies of ICPCM Workgroups for the construction of person-centered medicine, followed by brief updates on the status and plans of the participating workgroups.

This in turn was followed by break-out parallel small group meetings on the main projects. One of these was the ICPCM Project on Guiding Principles for Person-centered Clinical Care. This involved reviewing the work in this area conducted prior to this Geneva Conference and then outlining the main components of the person-centered clinical care guidelines using as one of the main references the elements of the evolving Person-centered Care Index. Another small group parallel meeting worked on the further development of the ICPCM Person-centered Diagnostic Projects The work in this session focused on preparing a Person-centered Integrative Diagnosis (PID) practical guide based on the PID theoretical model. A third small group parallel meeting dealt with the further development of the Partnership and Team Approach Project with the participation of stakeholder and communication research representatives.

A second plenary session offered an opportunity to hear reports from the progress made at the small group parallel sessions. The pre-conference work meetings also allowed an early and informal presentation and discussion of the 2013 Geneva Declaration on Person-centered Health Research, an initiative intending to extend the public impact of the Conference concerning its main theme.

A face-to-face meeting of the outgoing ICPCM Board approved procedures for the evaluation of the Conference, reviewed and approved new organizational and individual member applications, finalized the agenda of the General Assembly, and discussed a draft of the Geneva Declaration on Person-centered Health Research.

#### Meeting of the Editorial Board of the International Journal of Person Centered Medicine with the Board of the International College

Meeting participants heard a report from the ICPCM Board accepting the resignation of the then editor in chief of the IJPCM related to his discrepancies with the Journal contractual bases. The Board took steps to ensure the continuity of the Journal's publication in close coordination with the publisher, the head of the University of Buckingham Press. One step was appointing Juan Mezzich, who had been deputy editor, as the new editor in chief. Another step in response to Medline's earlier deferral of indexation was preparation of an appeal letter emphasizing a strengthening of ethical standards and procedures. The members of the Editorial Board present unanimously supported these steps and offered whatever help was needed.

#### **ICPCM General Assembly**

The 2013 General Assembly of the International College of Person Centered Medicine was attended by a substantial number of its organizational and individual members as well as other participants in the Sixth Geneva Conference. First, a summary of the work of the ICPCM in the preceding year and an evolving draft of the Geneva Declaration on Person Centered Health Research were presented. Then, an institutional action plan was outlined and accepted by the Assembly, as follows: a) Planning and conduction of the ICPCM First International Congress in Zagreb, b) Organization of the 7th Geneva Conference on Person-centered Medicine, c) Continuing publication of the International Journal of Person Centered Medicine and exploration of new publication ventures, and d) Continued development of ICPCM Workgroups and Projects.

A major Assembly item was institutional elections. The process started with an elections announcement in January based on ICPCM By-Laws, followed by nominations received from organizational and individual members, and the listing of candidates on the elections ballot. To run the voting, the Assembly elected a threemember Voting Coordination Group (VCG), which oversaw secret voting, counted the votes, and announced the results. Elected as President was James Appleyard (former WMA president, London); as Secretary General and CEO, Juan Mezzich (New York), and as Board Directors, Michel Botbol (former WPA officer, Brest, France), Tesfamicael Ghebrehiwet (former officer of the International Council of Nurses, Alberta, Canada), Joanna Groves (CEO of the International Alliance of Patients' Organizations, London), Ihsan Salloum (former WPA officer, Miami), and Sandra Van Dulmen (Permanent Secretary of the European Association for Communication in Health Care, Nijmegen, the Netherlands). The elected Board members present were recognized and congratulated by the General Assembly. A Conference Dinner organized by the Paul Tournier Association followed.

#### **Core Conference**

The Core Conference was opened on April 29 by Prof. Panteleimon Giannakopoulos, Vice-Dean of the Geneva University Medical School and Dr. Hernan Montenegro, *WHO Department for Health Systems Governance and Policy*. They were joined in the presidium by the members of the Board of Directors of the International College of Person Centered Medicine.

The first scientific session of the Core Conference was a presentation on the **construction of the 2013 Geneva Declaration on Person-centered Health Research**. The Declaration <u>rises</u> from the need for more research in Person-Centered Medicine (PCM), as well as for making general health research more person-centered. It identified ten priority research areas as follows: 1) Conceptual,

terminological, and ontological issues, 2) Studying the complexity of health, including illness and wellness, disability and functioning, resilience and resources, plus experiences of health and contributors to health, 3) Clinical communication, 4) Exploring and validating personcentered diagnostic models, 5) Person-centered care and interventions, 6) People-centered care and related public health research, 7) Research on person-centered education and training, 8) Knowledge-base development and dissemination through the International Journal of Person-9) Centered Medicine and other publications, Organization, evaluation and upgrading of conferences and congresses, and 10) Further development of an internet-based information platform.

The first Thematic Symposium of the Conference focused on **Innovative Person-centered Concepts Research**. It started with a penetrating examination of the basic science underpinnings of empathy. The importance of conceptual bridging and knowledge transfer for the further development of complex PCM was discussed next, particularly concerning the need for integrating sectors and stakeholders. It concluded with an analysis of the distinction between two frequently confused and conflated terms: personalized medicine (a reductionist biological approach) and person-centered medicine and care (a holistic scientific and humanistic perspective).

A second Thematic Symposium dealt with Personcentered Diagnostic and Treatment Planning Research. Building on the evolving construction by the ICPCM of a person-centered integrative diagnostic model and guide to provide the informational basis for person-centered clinical care, a first presentation outlined mixed statistical models encompassing qualitative and quantitative approaches to account for narrative and dimensional data in diagnostic research. This was followed by a report on exploring illness meaning and experience with various medical specialties as part of person-centered clinical assessment at McGill University. Completing the set was the presentation of a developing interactive curriculum on person-centered treatment planning by the California Institute for Mental Health, which seeks to integrate the use of specific assessment instruments with personcentered planning practices.

A third Thematic Symposium covered Personcentered Clinical Communication. An initial presentation reviewed international communication research projects within the framework of the European Association on Communication in Health Care. A second one pointedly examined the value of affective clinical communication, an emerging critical component of a process central to person-centered care. This was followed by a report on how knowledge and attitudes towards palliative care on the part of Croatian psychology, medicine, social work, nursing and theology students affect substantially clinical communication processes. A final presentation reviewed research on communication among health professionals, patients and carers, as promoted by the European Association of Families of People with Mental Illness. It illustrated how work between clinicians and carers can moderate emotional burden in the family.

A fourth Thematic Symposium touched on Personcentered Treatment Research. The presentation of an Eastern Mediterranean survey on perceptions of person centered care among patients and family doctors initiated this session. Among physicians, regularity in continuing medical education sessions were significant factors for preferring the person care model; while educational status was associated with interest on person centered care among patients. A historical review of treatment research in pediatrics has documented children's vulnerability to unethical experimentation. There are still gaps across the world in ethics and regulatory guidance in this field. A third presentation examined research on the team approach to health care using multiple dimensions of patient outcomes, cost savings, and patient's and provider's satisfaction. Factors that appear to inhibit or facilitate teamwork were also discussed. Rounding up the symposium, an examination was presented on the vicissitudes of translating research findings into clinical practice and policies.

A fifth Thematic Symposium had as subject **Personcentered Prevention and Health Promotion Research**. Noted at the outset was that, while a research database in general prevention is growing, a person-centered perspective here offers both opportunities for enhancement as well as challenges given the complexity and depth such perspective involves. Some of these challenges were illustrated through a World Medical Association survey of its national member associations on immunization policies and practices and the underlying social and behavioral factors. Complementing all this, the crucial role of self transcendence for promoting health and well-being was analyzed and discussed.

A sixth Thematic Symposium looked at Personcentered Research on Non-communicable Diseases and Mental Health. It was noted that research on chronic comorbidities poses significant challenges to diagnostic assessment and its impact on treatment choices, responses and outcomes. The relevance of the Person-centered Integrative Diagnosis (PID) model to research on chronic comorbidities was then discussed. This was followed by a WHO review of mental health research, from macro level governance to person-focused service delivery. Data from three international initiatives, engaging 750 participants, illustrated specific patient and family-centered care needs, and barriers to the provision of integrated care. A New York program aimed at offering child- and family-centered care for allergies was then described along with data on the program's successes and challenges.

A seventh Thematic Symposium examined **Person**centered Conceptualization and Metrics Research. An initial paper from Australia questioned if normality, abnormality and mental illness are three separate and distinct concepts with clear boundaries or parts of a person centered dimensional continuum along which human beings may move across time and lifespan. This was followed by a progress report from an ongoing ICPCM research project aimed at the systematic conceptualization and measurement of person-centered medicine. This has initially yielded eight broad conceptual categories from which a prototype person-centered care index has emerged. Efforts to refine this index in terms of wording, scaling, and correlational structure and to validate it in terms of applicability, reliability and content validity were outlined. An additional presentation from the above mentioned ICPCM project outlined the prospects of factor analytic methods and\_item response theory to refine quantification of person-centered care.

An eighth Thematic Symposium reviewed Research on Health Narratives. Examined first were narratives in family medicine in the United States, including writings by residents and self-reflective pieces by family physicians. These exercises and their sharing with colleagues were suggested to be highly promising for the professional development of empathetic and fully competent physicians. Presented next was a biographical outline by a British pediatrician of his personal and professional life journey and his efforts to develop a person-centered approach to child care. Finally, a presentation on narratives in mental health, examined their value as a gate to patients' conscious and unconscious feelings and representations, as well as French experience using narrative empathy as contrasted to mirror empathy to access the other person's subjectivity.

A ninth Thematic Symposium discussed Person- and People-centered Services and Policies Research. It started with a WHO presentation on research supporting health policy development and eventually practice, particularly in search for universal health coverage and people-centered care [16]. It emphasized the importance of context, of "how to", of stakeholders. It offered a "concept of people-centered care as that focused and organized around the health needs and expectations of people and communities rather than on diseases", and summarized examples of people-centered health systems development in Brazil and Togo. An ensuing presentation from Australia on person-centered health services research examined the value of bridging and knowledge transfer for advancing this new perspective in health services research. Next, a research report from Sweden suggested the value of a holistic and person-centered approach to bridge health and healthcare inequities in a globalizing and ageing society. Finally, a report from the Czech Republic discussed the current extremely detailed and formalized documentation required from nurses and the challenges this imposes for person centered medicine.

A tenth Thematic Symposium covered Personcentered Health Education Research. A report from the UK on medical academic training discussed approaches to ensure the continuity between undergraduate and postgraduate training and to focus such training on the person's circumstances and wishes, delivering care with high competency and safety. A presentation from the International Association of Medical Colleges outlined research on medical curriculum standards and evaluation that aims at recognizing the importance of personal factors in the local community. A paper from a Texas medical school argued that knowledge and wisdom upon which medical practice is based does not issue from a single source, but from a multiplicity of perspectives as predicated by person centered medicine. Ending this symposium, a presentation from Spain reported on an innovative curricular journey on ethics and professionalism and its impact on medical students' attitudes.

A Special Session on Country and Region Studies in Person-centered Health Care included presentations from several continents. One from the Americas, reported on efforts in the United States to make health care systems more person-centered, illustrating them with the Patient Centered Primary Care Collaborative (PCPCC) engaging business, insurance, government, and the health care community seeking to transform healthcare into a primarycare based, person-centered system. Another, from Europe, described a university based multidisciplinary research center in Sweden aimed at implementing and evaluating person-centered care, and illustrated it with work on chronic heart failure and irritable bowel syndrome. A third, from Africa, proposed desirable objects of observation for measuring person centered medicine. It used conceptual bases derived from South African insights. A final one from Asia, submitted and published among the conference abstracts but not delivered because of travel problems, discussed new approaches to measure quality of human dimensions of health care in Thailand, which revealed that family practices outside hospital contexts were significantly more patient-centred, cheaper, and less inclined to over-medicalization.

A Workshop from the United States and Canada on **Person-centered Approach to Treatment Measurement and Evaluation** focused on the value of the Drug Use Screening Inventory for the comprehensive assessment of adolescents addicted to substances. It also elaborated on the usefulness of psychometrically validated screens and on web-based procedures to support relevant research and service delivery.

Another Workshop outlined initial efforts for **developing a new person-centered and evidence-based regional medical school in Texas** through presentations from its dean and several department heads. It described the historical antecedents of these efforts, a particular set of domains for inquiry and action, the prospects for a medical student's journey towards person-centered care, and the essential skills proposed for physicians in the pursuit of person centered medicine.

A third Workshop, from Berlin, Munich, and Paris dealt with **Research on Treatment Consequences of Positive Health Oriented Care**. It started with an overview of research on positive mental health, attending to patients' subjective experiences and healthy aspects in the midst of mental illness. It also delved into the value of resource orientation in inpatient psychotherapy. An outcome study of inpatient dynamic psychiatry in a Munich hospital highlighted the value of comprehensive assessment encompassing both ill health and positive health to document positive therapeutic results. A formal discussion from an international perspective and active engagement of the audience completed the workshop.

A first Oral Presentations Session encompassed several brief papers on topics ranging from politics and research agenda, clinical communication, palliative medicine, impact of organizational culture, empowering value of entrepreneurial work, and qualitative research for person centered medicine. A second Oral Presentations Session touched on patients' narratives, engaging patients as partners in health care, person-centered care for coronary heart disease, training providers for personcentered maternal and new born health care, and how to elicit patients' perspectives on their illness and health care expectations.

A Special Session on Ethical Standards for Personcentered Health Research was carried out with presentations from major global health institutions. A revision of the World Medical Association's Helsinki Declaration was discussed first. This universally recognized Declaration involves ethical principles for medical research involving human subjects, and is undergoing a revision to refine its consideration of placebo issues and vulnerable populations. Next, the Council of International Organizations for Medical Sciences highlighted the protection of the person as central in its International Ethical Guidelines. Third, a person-centered analysis was presented of the World Psychiatric Association's Madrid Declaration on ethical guidelines for the practice of psychiatry. It was pointed out that the Madrid Declaration is person-centered par excellence, and that it contains a number of provisions that are prominently person-centered such as those promoting autonomy, confidentiality, empowerment, partnership, and respect for dignity. The final presentation from the World Health Organization's Ethics Department dealt with WHO perspectives on strengthening research ethics review systems [17]. These systems focus on protecting the rights of potential research participants, optimizing benefits for persons, promoting active participation in decision making processes, and access to transparent information. It concluded that the ethical conduct of research requires it to be person centered.

A Special Session on the Development of the WHO Strategy on High Quality People-centered and Integrated Care to Achieve Universal Health Coverage [18] took place at WHO headquarters with the participation of invited representatives of major ICPCM collaborating organizations (ICPCM, World Medical Association, International Council of Nurses, International Alliance of Patients' Organizations, International Pharmaceutical Federation, World Federation for Mental Health, International Francophone Psychiatric Federation, International Association of Medical Colleges, World Association for Dynamic Psychiatry, European Association for Communication in Health Care, American Academy of Family Physicians, International Federation of Gynecology and Obstetrics, Paul Tournier Association, German Dynamic Psychiatry Association, European Federation of Associations of Families of Persons with Mental Illness, International Federation of Medical Students' Associations, Zagreb University, Gothenburg University, University of Sydney, Texas A&M University, Mount Sinai School of Medicine, and University of Pretoria) as well as a number of scholars and officers of several WHO departments (Figure 1). The outline of the emerging WHO strategy highlighting people-centered and integrated care and the ensuing debate with the enthuseiastic participation of organizations' representatives and

Partial view of participants in the Special Session on WHO Strategies Development, standing at the entrance of the WHO main building, May 1, 2013.



individual scholars energized all towards further collaboration.

# Colophon

The Closing Session offered an opportunity to reflect on the success of the Sixth Geneva Conference, with its record number of collaborating organizations and high level scientific presentations. The General Assembly elected a new Board harmonizing renewal and stability, the 2013 Geneva Declaration on Person-centered Health Research was adopted, plans for the continuity and enhancement of the International Journal of Person Centered Medicine were set out, and the organization of the First International Congress of Person Centered Medicine in November 2013 and of the Seventh Geneva Conference in April 2014 were advanced.

The day after the Conference, the new ICPCM secretary general held meetings with key WHO officers (Oleg Chestnov, Assistant Director General for Non Communicable Diseases; Taghi Yasamy, Medical Officer, Department of Mental Health; and Hernan Montenegro, Medical Officer, Health Systems) to explore collaboration on our next events and on the WHO strategies related to person- and people-centered care.

An Evaluation Survey of the Sixth Geneva Conference was carried out by mail shortly after the conference. It yielded a number of recommendations for enhancing future events and suggested that the conference achieved outstanding overall quality through high level scientific presentations and discussions in a friendly atmosphere conducive to interdisciplinary and international networking.

# **Concluding Remarks**

The present issue of the International Journal of Person Centered Medicine largely contains selected papers emerging from the Sixth Geneva Conference. They were upgraded by their authors for submission to the Journal and then they were independently peer reviewed.

Following this editorial introduction, the 2013 Geneva Declaration on Person-centered Health Research coming from the Geneva Conference and finalized by the ICPCM Board is presented. It is accompanied by a paper describing the background, structure and priorities of this Geneva Declaration, authored by the drafting group and a collaborating consultation group.

Presented next and central to person centered medicine perspectives is an article proposing that people create health, as effective health promotion is a creative process. The role of narratives in clinical practice is cogently argued in the paper that follows. Key dimensions of contextualized care are delineated in an article focused on family medicine. The role and achievements of general prevention research is discussed and connected to person centered medicine. Research evidence is then reviewed on the effectiveness of the team approach in health care. What follows is a discussion of a person-centered clinical communication tool integrating illness meaning and experience. The next paper presents a child- and familycentered initiative to enhance, manage and promote well being and resilience in a pediatrics clinical program. The last paper from the Sixth Geneva Conference published in this issue presents training for person-centered maternal and newborn health care in Burkina Faso.

The two general articles that follow include first a paper where research on the hermeneutics of suffering is reviewed as a scholarly enterprise. A study on the broad characteristics of chronically traumatized women and their implications for person-centered care is then presented.

Announcements of two upcoming person-centered medicine events complete this issue.

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