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Background, Structure and Priorities of the 2013 Geneva Declaration on Person-centered Health Research

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Abstract

Declarations are relevant tools to frame new areas in health care, to raise awareness and to facilitate knowledge-to-action. The International College on Person Centered Medicine (ICPCM) is seeking to extend the impact of the ICPCM Conference Series by producing a declaration on every main topic. The aim of this paper is to describe the development of the 2013 Geneva Declaration on Person-centered Health Research and to provide additional information on the research priority areas identified during this iterative process. There is a need for more PCM research and for the incorporation of the PCM approach into general health research. Main areas of research focus include: Conceptual, terminological, and ontological issues; research to enhance the empirical evidence of PCM main components such as PCM informed clinical communication; PCM-based diagnostic models; person-centered care and interventions; and people-centered care, research on training and curriculum development. Dissemination and implementation of PCM knowledge-base is integral to Person-centered Health Research and shall engage currently available scientific and translational dissemination tools such journals, events and eHealth.

Keywords

Geneva Conference; Geneva Declaration; Person Centered Medicine; Person Centered Health; Research

Introduction

During the last decade a series of new models of health have transformed our understanding of the concept of health and of the implementation of health care systems. These models

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include, among others, person-centered medicine (PCM) and person-centered diagnosis and care [1,2,3], integrated care [4], the chronic care model (CCM) [5], and bridging and knowledge transfer [6]. These new models of ‘collaborative health’ are closely connected to each other, are characterized by their holistic, multidisciplinary and relational nature, and recognize health and healthcare as a dynamic and complex system.

Person-centered Health involves complex structures and high-dimensional interactions among multiple factors, where the meaning of the measurements becomes crucial for proper interpretation, and where phenomena are very difficult to model under classical approaches. The complexity and nonlinearity of health systems have been recently acknowledged by the World Health Organisation [7]. This recognition has major implications to data-analysis, too often based on techniques and procedures designed for linear phenomena, which should not be applied to systems characterised by non-linearity, self-organisation and constant change, fragmented but highly interconnected, history-dependent and counterintuitive. In order to analyse and to understand complex systems, prior expert knowledge should be incorporated into the analysis itself. Generalizing classical data analysis methods to be guided by prior expert knowledge permits a better modelling of these phenomena and improves the quality of the results. Taking the prior expert knowledge into account is not necessarily related to a loss of scientific rigour, since, from the beginnings of the artificial Intelligence developments in the mid 1950’s, there are strictly rigorous frameworks, based on logical paradigms, to handle expert knowledge in a formal and automatized manner. As an example, the ‘Expert-based Collaborative Analysis’ (EbCA) [8] completes classical data analysis with prior expert knowledge as a mean to extract relevant knowledge in complex health domains and shows how explicit and tacit or implicit expert knowledge are critical to guide the scientific analysis of very complex decisional problems such as those found in health system research.

Framing analysis is the first step of the EbCA process and other methods that incorporate prior expert knowledge in the analysis of complex phenomena. Until very recently health research has paid very little attention to framing tools which have been regarded as irrelevant or as ‘evidence’ within the classical Evidence-based Medicine framework [9].

Declarations, together with Bills and Guides are relevant to frame crucial areas in health care [10], to raise awareness and to facilitate transfer of knowledge across the different stakeholders involved in health care. A major example of the usability and impact of these tools is provided by the Declaration of Helsinki on Medical Research issued by the World Medical Association in 1964 and its successive revisions [11].

The International College of Person Centered Medicine (ICPCM) has launched a long term strategy to generate a Person-Centered Medicine (PCM) “knowledge-base” (a repository that provides a means for information to be collected, organized, shared, searched and utilized, and machine-readable). Within this strategy, the ICPCM Conference Series have included the following main themes: Conceptual Explorations (2008), From Concepts to Practice (2009), Collaboration across Specialties, Disciplines & Programs (2010), Articulating Person-centered Clinical Medicine & People-centered Public Health (2011), and Chronic Diseases: Person- & People-centered Perspectives (2012). The Geneva

Declarations emerged from the institutional interest to extend the impact of the ICPCM Conference Series around their main topics. The first declaration started in 2012 with the adoption and release of the Declaration on Person-centered Care for Chronic Diseases [12,13].

The crucial role of research and of building the broader possible bases of solid evidence for PCM had been recognized early on by the ICPCM. In 2012, and in consonance with priorities of other sponsoring organizations, such as the WHO, the ICPCM decided it was timely to dedicate the 2013 Geneva conference to this topic. The aim of this paper is to describe the development of the 2013 Geneva Declaration on Person-centered Health Research and to provide additional information on the research priority areas identified during this iterative process.

Method

In December 2012, a team of 6 experts was created to prepare a draft based on iterative discussions by mail exchange and 4 teleconferences. The resulting draft was also sent to other ICPCM experts and the ICPCM board for feedback. The draft of the Declaration on Person-centered Health Research was presented and discussed with members of the ICPCM workgroups in April 2013, and comments were incorporated to the final draft which was discussed with participants at the 6th Geneva Conference ICPCM General Assembly, and, after approval, it was presented at the closing session on May 1st 2013. The declaration has been structured in four sections: Introduction and aim, principles, priority lines and areas, and action plan and call for action.

Results and discussion

This declaration emerged from the need for more research in Person-Centered Health (PCH), as well as to make general health research more person-centered. It follows the previous definition agreed on by the IPCM and highlights the holistic, multidisciplinary and relational character of PCM across all levels of health care, from individual interventions to general health policy. The principles of the declaration are based on the extensive conceptual review of PCM previously made by the ICPCM [1,14,15]. Within this framework PCM articulates science and humanism for a bio-psycho-socio-cultural understanding of health and for the undertaking of health care actions from individual interventions to people's health to general health policy, guided by the ethical principle of respect for the autonomy, dignity and responsibility of each person.

The group has identified 10 priority areas in PCM research:

- 1) **Conceptual, terminological, and ontological issues:** The development of a knowledge-base and the generation of evidence that can be transferred and applied in different settings require common conceptual frameworks, terms and taxonomy. For example it is relevant to provide a 'synset' (set of synonyms and semantically related terms) [16] of the key concepts in this field and the conceptual map or the formal relationship across these terms to enhance scientific communication. Under the umbrella term of 'Person-Centered Health'

it is necessary to set up the definitions and boundaries of ‘Person-Centered Medicine’, ‘Person-Centered Care’, ‘Person-Centered Planning’, ‘People-Centered Care’, and also the links with ‘Personalised Medicine’ [17]. It is also important to set up an internationally agreed glossary of terms and consensus-based guides to develop research that can be effectively compared across settings, territories and cultures. Finally the relationship of PCM and the partnership approach in medicine [14] should be established with other fields of collaborative health such as integrative medicine, integrated care, chronic care, bridging and knowledge transfer. A comprehensive approach should encourage analysis from different perspectives including philosophy of science, biological, psychological, social, and cultural approaches. International comparisons should be encouraged [18].

- 2) **Evidence on the main components of PCM:** It is important to generate more evidence on the different domains of PCM taking into account the complexity approach [19]. These domains include illness and wellness, disability and functioning, resilience and resources, plus experiences of health and contributors to health and wellbeing in PCM [1]. In particular, the development of well-being can be characterized in terms of the non-linear dynamic interaction among plasticity, virtue, and functioning as the “motor of well-being” [20,21]. Within this context the experiences of health such as suffering, meaning and understanding of illness, contentment, fulfilment and flourishing constitute a core element of PCM that deserve special attention. Developmental and life course perspectives should also be studied within the context of PCM (e.g. mental capital approach) [22] with special attention to gender and age groups (children and elderly population) and to other vulnerable groups [23,24]. The standardization of international assessment procedures and instruments of the main components of PCM should be encouraged [25]. Spirituality is another area that requires further research and closer attention within the PCM framework [26,27]. Finally, a translational approach should be adopted in the integrative study of these domains linking person-centered research to genomics, neurosciences and epigenetics, as well as to social, environmental, economics and policy research [28,29].
- 3) **Clinical communication:** Doctor-patient relationship (or carer/provider-consumer communication) constitutes a key element of PCM. This relationship represents the fundamental matrix for the whole of care [30]. It should encompass empathic listening, comprehensive diagnosis beyond symptom checklists, appreciation for symbolic meaning, non-verbal communication, engagement and information exchange and transfer, as therapeutic partnership and to advance the process and outcome of care. Within this context, well as greater proficiency in establishing communication and using it to develop effective topics that require special attention are integrative/translational research in PCM communication, shared decision making [31], the impact of health information technologies, and the roles of patients and health professionals in relation to empowerment and new models of care [32,33].

International guidelines for person-centered research on clinical communication are emerging [34].

- 4) **PCM diagnostic models.** This includes the development, validation and comparison of the usability of PCM diagnostic models, guides and assessment instruments. For example the Person-centered Integrative Diagnosis (PID) model [1] not only identifies and classifies illnesses, disabilities and related problems but also assesses positive health [21]. It also includes a comprehensive evaluation of biological, psychological and social contextual factors contributing to health. This model is also unique as it includes a narrative component to complement each domain considered. It further includes in a narrative format domains on the experience of and values relevant to ill and positive health. The PID intends to serve as effective informational base for understanding the clinical situation and planning for care collaboratively among clinicians, patients and families [1,35,36]. Other models, while not as comprehensive and balanced on including the totality of health as the PID include the ‘pragmatic model’ which describes the behaviours shown by persons with mental disorders as the base for diagnosis and intervention in mental health [37]. Other contextualized models also include the International Classification of Primary Care (ICPC-2). This classification system allows for simple linkage between reason for encounter, diagnosis and intervention, taking into account the complex relationship between biological, psychological, mental and social problems and their temporal variations [38,39].
- 5) **Person-centered care and interventions:** The International Alliance of Patients’ Organizations have defined five principles of patient-centered healthcare: Respect, choice and empowerment, patient involvement in health policy, access and support, and information [40]. A better understanding of individual person-centered care (PCC) and interventions for health promotion, prevention, treatment and rehabilitation is required, including aspects related to empowerment of patients and their families, and care issues such as usability, efficacy and effectiveness, efficiency, appropriateness, equity, parity and quality of interventions following the PCM care models [41]. The international standardization of instruments for assessing the different facets of PCC and the development of indicators of individual interventions on PCC deserve special attention. Furthermore, PCM research calls for patient active partnership and engagement in the research endeavour from identifying priority areas and research questions to study design and choice of meaningful outcomes to dissemination of results and practical implementation of research findings.
- 6) **People-centered care:** More research is needed on indicators of people-centered care (PCC) [40] as well as on health system analysis and policy that are conducive for people-centered care and planning at all levels of care (community, regional, country and international levels) [12,14]. Particular topics that should be mentioned are patient involvement in health policy, links between PCC and integrated care to develop and to implement person-centered integrated

care systems, PCC in vulnerable population groups, and use of new methods of system analysis in PCC.

- 7) **Research in training and curriculum development** is also required, as training and education are key contributors to the development and implementation of PCM. The 2006 World Health Report documented the severe shortages of health professionals around the globe and their poor fit to health service delivery needs, including training on person-centredness, as well as limitations in opportunities for health professional students of different disciplines to learn together and interact adequately during their training [12].

Finally, three priority areas related to the development of the PCM knowledge-base and its scientific dissemination have been identified:

- 8) **Scientific publications** such as the *International Journal of Person-Centered Medicine* and other relevant publications and the systematic analysis of the corresponding literature [42].
- 9) **Organization of scientific events** such as the Geneva conference series and congresses on PCM for the generation, presentation and discussion of new knowledge and to promote productive networking, bridging and interaction among scholars and other health stakeholders [43].
- 10) **Developing eTools** such as an internet-based informational platform and substructures to support PCM activities and research, such as workgroup efforts and inter-institutional and scholarly collaboration [44,45].

The action plan includes a formal commitment of the ICPCM to undertake and/or to continue its activities on these priority areas. The call for action is addressed to similarly-minded scholarly societies, professional associations and educational institutions, governmental and inter-governmental organizations to collaborate effectively on research aimed at enhancing person- and people-centered health and quality of life across the world.

Conclusions

ICPCM has identified specific PCM research and the incorporation of the PCM approach to general health research as key priorities in collaborative health within a complexity perspective. Main areas of research include: Conceptual, terminological, and ontological issues, evidence on the main components of PCM, clinical communication, PCM diagnostic models, person-centered care and interventions, people-centered care and services, research on training and curriculum development and advancing the PCM knowledge-base and its scientific dissemination through journals, events and eHealth tools.

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