Foreword

Promoting patients’ participation and engagement for a more and more effective, efficient and sustainable healthcare offer.

This goal is crucial from various perspectives and it’s also attracting the interest of several healthcare professionals and political-economical decision makers who are in charge in welfare systems. The interest of scientific research is growing as well, challenged by an issue, which is certainly socially relevant, but still needs roots both at the theoretical and empirical level.

The research program Horizon 2020, recently launched by the European Commission, is a good example – surely not the only one – of this trend: the section of this program dedicated to the societal challenges frames health as the main committing topic at the European level and claims for the activations of research guidelines oriented towards an integrated and sustainable and citizen-centered care and to the active participation of people in health promotion, prevention and care, even with the aid of new technologies.

With the contribute of a conspicuous number of experts from different scientific fields, the book deals with this task in a straightforward way, by achieving a double result: a) setting the current “state of the art”; b) suggesting future lines for research aimed at developing the topic both at the theoretical and pragmatic level.

I will let the Reader deepen the book’s content. Here I would just suggest some considerations which may help in better linking its various contributes with each other, within a dynamic retrospective and prospective vision.

1. The research on Patients’ Engagement and Participation in Health (PEPH) appears the outcome of a path started long time ago and reached today this theoretical and pragmatic elaboration. Its beginnings may be retrieved in the paradigmatic turn promoted by Engel at the end of the ’70 with the proposal of a bio-psycho-social approach in healthcare, in substitution of the dominant medical model previously elaborated by Parsons. From this new approach and on the basis of the numerous drivers of change (i.e. cultural, organizational, political…) that were actual in occidental societies, in the 80’ and 90’ many considerations started to be made in order to innovate the healthcare vision from both a theoretical and a pragmatic point of view.

On the one hand, the humanization movement in medicine developed the topic at the level of values (ethical and political) by refusing the simplified representation of patients as passive receivers of medical action and claiming for them a more active and participative role in the management of health (e.g. the elaboration of patients’ rights cards, the informed consent practice, the evaluation and measurement of patients’ satisfaction…).

On the other hand, studies on the effectiveness of medical practices led to recognize the patient’s role as a determinant of medicine’s success. By furthering the analysis of the conditions for patients’
compliance and adherence to care, the patient-centered approach to medicine (able to acknowledge and value the patient’s role) was asserted as the necessary condition to assure the effectiveness of the medical actions.

Finally, the encounter between a managerial culture – coming from the business field – and the welfare systems highlighted that the efficiency of such systems should be a priority issue. Answering uniquely in medical terms to the increasing and various needs of healthcare appears impossible; the activation of patients and of their social networks is a precious resource in order to maintain a balanced relationship between healthcare demand and offer and also in order to promote healthcare sustainability.

These three pathways can be easily considered as the historical roots of PEPH. Indeed, from the early 2000’s, the PEPH perspective has progressively asserted itself as an approach that may offer an integrated and coherent answer to the needs of healthcare humanization, effectiveness in prevention/promotion/care, sustainability and efficiency of healthcare systems.

2. During the last two decades much has been done. Nonetheless, much still needs to be done. We may consider PEPH as a research agenda that is today testing its own ability to generate good research and good practices. Which conditions might better sustain the virtuous development of this research agenda? The necessity to overcome the partiality of previous approaches and to deal with the complexity and multiple facets of the phenomenon suggests two prior advices for future research on PEPH.

First, a stronger link among different scientific disciplines involved in the study on PEPH (i.e. theoretical and empirical disciplines, life and human: philosophy, medicine, psychology, sociology, technological sciences, linguistics, economics, communication sciences, management and organization sciences …) is required. Certainly, this is not an easy goal to be achieved! In other words, a transdisciplinary perspective is warranted to embrace a “messy” comparative mode (i.e. not linear, hybrid, reflexive, heterogeneous…) based on the principle of “transformative contamination” (crossbreeding) among various scientific disciplines.

Second, it is crucial to promote a more interactive dialogue among the various actors involved in the management of this topic. Both the field of scientific research and the “extra-scientific” fields (i.e. politics, business, public opinion) can fully contribute to orient the realization of PEPH in the social contexts. The “extra-scientific” fields are indeed not only destined to receive the operative outcomes of scientific research, but they also orient such research in terms of thematic priorities and development. From this perspective, it should be underlined that concepts such as trans-sectoriality and co-authorship are more and more adopted in the literature in order to highlight the deep and generative link between science and social worlds.

In sum, trans-disciplinarity and trans-sectoriality appear to be two crucial challenges which the research on PEPH is asked to face in order to avoid the risk of being a mere suggestive and fascinating (maybe mainstream and fashionable) topic, with a poor scientific and pragmatic impact. These two challenges have been clearly dealt with in the development of this volume and they are well represented by the thematic variety of the diverse contributes.

Procedamus igitur!

A. Claudio Bosio
Catholic University of the Sacred Heart of Milan, Italy