**Putting patients first? Reflections concerning “Consensus Framework for Ethical Collaboration”**

The “Consensus Framework for Ethical Collaboration between Patients’ Organizations, Healthcare Professionals and Pharmaceutical Industry” 1 was signed by five global healthcare organizations in January 2014. They are the International Alliance of Patients’ Organizations (IAPO), the World Medical Association (WMA), the International Council of Nurses (ICN), the International Pharmaceutical Federation (FIP), and the International Federation of Pharmaceutical Manufacturers and Associations (IFPMA). The framework is based on the following principles: (1) put patients first, (2) support ethical research and innovation, (3) ensure independence and ethical conduct, and (4) promote transparency and accountability.1 Given that the document is intended to support high-quality patient care, some reflections about these principles can be offered**:**

(1) The framework needs to improve the recognition of global health inequity and strongly confront “structural violence.”2 Partnerships between these organizations are appreciated for improving healthcare access, especially for the most neglected diseases, which requires the establishment of a fair international pharmaceutical policy.3 Health equity needs to be a priority if such organizations are seeking to achieve “optimal care for all.” Otherwise, it will only put patients from developed countries first.

(2) To support ethical research and innovation, the voice of patients needs to be heard. The WMA’s Declaration of Helsinki was lately updated. Between 2012 and 2013, four conferences were held in favor of it. The IFPMA spoke at two meetings. Neither the IAPO nor other patients’ organizations spoke at those conferences.4 However, the IAPO commented on the WMA’s public consultation. But we strongly believe that listening to the voice of the patient is something to be improved.

(3) “Ensure independence and ethical conduct” as an overarching principle is appreciated. But the framework needs to be stricter. There are limits on gifts, and the modest refreshments and meals are appreciated, but what about the “ghost management”? 5 “What policies might restrain the effects of industry sponsorship?” 5

(4) Transparency and accountability are appropriate. Requirements to register clinical trials and publish negative research data, for example, are in proportion to the public interest. However, this principle is not clear, that is, what compensation is “proportionate with the services provided”?

Congratulations to the five organizations for attempting to put patients first. But as the framework is a living document, the next step is to clarify the indistinct assertions, that is, what exactly is “inappropriate influence”? What is “appropriate care”? What is the “legitimate scientific purpose”?

We assume that this new framework can be a social justice instrument. Otherwise, it may be just a rhetorical, if not a fallacious, framework.

Referencies

1. Consensus Framework for Ethical Collaboration between Patients’ Organisations, Healthcare Professionals and the Pharmaceutical Industry. http://www.ifpma.org/fileadmin/content/Publication/2014/Consensus\_Framework-vF.pdf (accessed Jan 29, 2014).
2. Farmer P. Pathologies of Power: Health, Human Rights, and the New War on the Poor. Berkeley: University of California Press, 2005. ISBN 978-0-520-24326-2
3. Trouiller P, Olliaro P, Torreele E, Orbinski J, Laing R, Ford N. Drug development for neglected diseases: a deficient market and a public-health policy failure. The Lancet, Volume 359, Issue 9324, Pages 2188 – 2194. DOI: 10.1016/S0140-6736(02)09096-7 (accessed Jan 22, 2014).
4. Schemper Júnior BR, Hellmann F. Controvérsias em tempos de mudança na Declaração de Helsinque e a experiência brasileira em ética em pesquisa. In: Caponi S, Verdi M, Helmann F; Brzozowski FS. Medicalização da Vida: Ética, Saúde Pública e Indústria Farmacêutica. 2ed. Curitiba: Prismas, 2013, v. 1, p. 37-66. ISBN: 978-85-8192-281-2
5. Sismondo S. How pharmaceutical industry funding affects trial outcomes: causal structures and responses. Soc Sci Med. 2008 May; 66 (9): 1909-14. doi: 10.1016/j.socscimed.2008.01.010. (accessed Jan 23, 2014).