

SPECIAL ISSUE

PATIENT AND CITIZEN EMPOWERMENT IN RECENT EU LEGAL AND POLICY INITIATIVES

Call for papers for a Special issue on: Patient and citizen empowerment in recent EU legal and policy initiatives

There is a growing Europe-wide trend towards a patient-focused approach in health research, in which concepts such as patient empowerment, engagement and involvement hold center stage. The aim is to ensure that patients' needs and priorities in healthcare and research are identified, met and are used to facilitate a proactive attitude of patients in the management of their health across various phases of their patient journey. Involvement can occur at all stages of the research and development cycle and can take various forms, such as patient advisory panels or patient representatives as members of working groups at regulatory bodies.

The importance of patient empowerment is increasingly recognized in international and EU instruments. For instance, the revised International ethical guidelines for health-related research involving humans, prepared by the Council for International Harmonization of Medical Sciences (CIOMS) contain provisions on community engagement, advising researchers, sponsors and health authorities to engage participants and communities in a meaningful way in the research and the dissemination of research results. One of the main objectives of the European Health Data Space (EHDS) regulation is to empower individuals to take control of their health data. It also puts in place provisions to mandate cooperation with patient representatives in the scope of the various new public bodies it establishes. Similar rules on cooperation with representatives of key stakeholders could be found in the new Health Technology Assessment Regulation 2021/2282.

For this Special Issue, we welcome contributions critically analyzing key legislative and policy developments in the EU and the Member States related to putting patient and citizen empowerment (or engagement/involvement) in practice in the context of, for example, but not limited to:

- Health research
- Drug development
- Medical devices
- Digital health and big data
- Health technology assessment, including pricing/reimbursement

We are looking for original research including empirical research, opinion papers, country or policy reports and case annotations as well as formats that go beyond traditional research papers, for instance creative perspectives related to the topic or interviews with a key stakeholder representative.

All contributions will be subject to double blind peer review before acceptance for publication and are required to conform to the author guidelines available at: www.lexxion.eu/ehpl-authors

The Special Issue is Guest Edited by Teodora Lalova-Spinks (Ghent University, Faculty of Medicine and Health Sciences)

Please send your contributions by **1st March 2025**
to mckernan@lexxion.eu



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