

August 25, Monday, 2025

Global Research Ethics and Meaningful Patient and Public Involvement: Consensus Development (Online, Zoom meeting)

Organized by:

The Brazilian Society of Bioethics (SBB)

Japanese Institute for Public Engagement (Ji4pe)

Supported by:

**Japanese Association for Philosophical and Ethical Researches in Medicine
(JAPERM)**

The Japanese Association of Pharmaceutical Medicine (JAPhMed)

**International Federation of Associations of Pharmaceutical Physicians and
Pharmaceutical Medicine (IFAPP)**

Cooperation:

Clinical Evaluation

Center for Bioethics Policy Study

Clinical Research Risk Management Study Group

[Leaflet](#)

[Video](#)

[**A Statement for Global Research Ethics and Meaningful Engagement**](#) [\(draft as of Aug 21, 2025\)](#)

●Welcome Remarks from Organizers

- **Elda Coelho Azevedo Bussinguer**, J.D. PhD (Bioethics). Full Professor at the Faculty of Law of Vitória (FDV), Brazil; President of the Brazilian Society of Bioethics Dirceu Greco (see above)
- **Kyoko Imamura**, President, the Japanese Institute for Public Engagement (Ji4pe), Japan; Former president, IFAPP

●Speakers/commentators from Japan

- **Patient representative: Hiroto Kai, Yoshiko Saito, Toshie Murakami, Akemi Kuge, Noriko Kishi, Eiko Uchisa**, Bioethics Working Group, Japanese Institute for Public Engagement (Ji4pe)

[**“Meaningful” Engagement toward Global Research Ethics: Patient Public Declaration of Research Ethics**](#)

- **Masanori Okuse**, Japanese Association for Public Awareness of Psoriasis
[**“What Does “Meaningful” Engagement Mean To Patients?”**](#)
- **Nobutaka Yagi**, President, YORIAILab; Nippon Boehringer Ingelheim
[**“What is the “Meaningful” engagement?”**](#)

●Speakers/commentators from Brazil

- **Laís Alves de Souza Bonilha**, PhD (Local Health Development). Associate Professor at the

Federal University of Mato Grosso do Sul, Brazil; Coordinator of the CONEP (Brazilian National Commission on Ethics in Research)

“CNS/CONEP’s coordination involving patient/participants groups”

- **Dirceu Greco**, M.D., Ph.D., Professor Emeritus of Infectious Diseases and Bioethics at the School of Medicine, Federal University of Minas Gerais, Brazil; Past President of the Brazilian Society of Bioethics, Member of the UNESCO International Bioethics Committee; Associate Member of the World Medical Association

“Global Research Ethics Directives: Proposal for (Response to) a Patient Public Declaration on Research Ethics”

- **Regina Bueno**, lawyer, Director, Aganim (Association for LGBT Rights) and co-organizer of INPP Juju Barbosa (Research participants Institute "Juju Barbosa"), Brazil

“Meaningful engagement of research participants in the promotion of human rights”

- **Egmar Longo Hull**, PhD, Physiotherapist, Federal University of Rio Grande do Norte, Brazil

“Experience with meaningful participant involvement in research”

● **University and medical students’ perspective**

- **Toby Pepperrell**, MD, PhD student, National Committee for Universities Allied for Essential Medicines (UAEM) Netherlands, Europe (under consideration)

“Meaningful” engagement of university and medical students for strengthening transparency and access in research ethics and environmental health”

● **Perspectives of Pharmaceutical Medicine**

- **Kotone Matsuyama**, BPharm, National Center for Child Health and Development; Professor, Nippon Medical School; President-Elect, IFAPP

“Pharmaceutical Medicine as co-creation with patients and the public”

- **Varvara Baroutsou**, M.D., Ph.D., Immediate Past President of IFAPP; CIOMS Executive Committee Member; Consultant in Internal Medicine and in Pharmaceutical Medicine, Athens, Greece

“Ethics of Pharmaceutical Medicine in a New World Order”

● **Summary and opening of discussion**

- **Chieko Kurihara**, BA, Specially-appointed Professor, Kanagawa Dental University; Editor-in-Chief, Clinical Evaluation

“Summary of views and future initiative for consensus development”