

Three Sequential Meetings Consensus for Global Research Ethics and Meaningful Engagement

Preliminary web conference, 8:30-11:30 AM in Brazil/8:30-11:30 PM in Japan;
1:30-4:30PM CET, August 25, Monday, 2025 (30 min free talk after closing)

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)

*Registration from next page;
Detail of each event: in following pages*

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); Juju Barbosa

Cooperation: Clinical Evaluation; Center for Bioethics Policy Study; Clinical Research Risk Management Study Group Registration is needed; Free of Charge for meeting

2. September 13, Saturday, 2025 3:00-5:00PM in Japan

HOTEL MYSTAYS Ochanomizu Conference Center & Zoom (Hybrid, online/in-person)

<https://iconia.co.jp/en-us/hotel-mystays-ochanomizu-conference-center-tokyo>

Global Research Ethics and Meaningful Patient and Public Involvement:
Consensus Development: Part 2

Preparation for Declaration for Global Research Ethics and Meaningful Engagement

Registration is needed; Free of Charge for meeting

(After conference session with speakers)

*Due to the time frame, registration
only for access to video is welcome.*

3. September 15, Monday, 2025 2:50-4:30PM in Japan (In-person Only)

Japanese Association for Philosophical and Ethical Researches in Medicine (JAPERM)
Second International Conference 2025

Transformation of the global research ethics: the 2024 revision of the
Declaration of Helsinki to promote patient engagement and dynamic
consideration on vulnerability

Registration with JAPERM is required separately.

In-person in Yokohama, Japan (After conference session with speakers)

4. September 16. Tuesday (or later), 2025 (Tentative)

Issue of the Statement for Global Research Ethics and Meaningful Engagement
(tentative) Published and announced by e-mail to summon signatories

In advance of the 2nd International Symposium of the Japanese Association for Philosophical and Ethical Researches in Medicine (JAPERM) on 15 September 2025, an online symposium will be held on 25 August co-organised by the Brazilian Society for Bioethics (SBB) and the Japanese Institute for Public Engagement (Ji4pe) to support consensus development for “Global Research Ethics” based on Patient Public Declaration of Research Ethics originated by patient and public group, and Meaningful Engagement, included in the 2024 version of the World Medical Association’s Declaration of Helsinki. All interested parties are welcome. We appreciate your opinions and participation in building consensus. The outcome of the 25 August online symposium, where patients, public and professionals will give presentations, which will be bridged to the hybrid (online & in-person in Tokyo) meeting on 13 September with Prof. Dirceu Greco (Immediate-past President of the SBB) and Dr. Varvara Baroutsou (Immediate-Past President of the IFAPP) broadcasted worldwide. In addition, it will be further discussed on 15 September at JAPERM symposium in Yokohama, and a Statement for Global Research Ethics and Meaningful Engagement is expected to be published on or after September 16, calling for signatories, to be addressed to relevant international organisations.

* Language: English, See detail for each event. Registration free for online sessions.

Registration to some of the three events and submission of your opinions:

<https://forms.gle/8MZq1DayWcjRV2M97>

Related references

Helsinki Statement

http://cont.o.oo7.jp/52pop/HelsinkiStatement_18Oct24_final.pdf

Patient Public Declaration of Research Ethics

<http://cont.o.oo7.jp/52pop/W28-W39.pdf>

Preliminary preparation for the Statement for Global Research Ethics Norm

http://cont.o.oo7.jp/53_2/global_research_ethics.pdf

(Next version will be uploaded before August 25 meeting)

2025 年 9 月 15 日に開催される日本医学哲学倫理学会第 2 回国際大会に先立ち、8 月 25 日に「患者市民発の国際研究倫理規範」・ヘルシンキ宣言 2024 年改訂で新たに入った「意義ある参画」に向けた提言を支援するブラジル生命倫理学会と医療基盤開発研究所 (Ji4pe) の共催でオンライン開催し、続いて 9 月 13 日に来日中の国際製薬医学会前会長 Dr. Varvara Baroutsou、ブラジル生命倫理学会前会長 Prof. Dirceu Greco とともにハイブリッド開催 (オンライン+現地・東京)、9 月 15 日に両氏を招いて日本医学哲学倫理学会企画シンポジウム (横浜) を行った上、翌 16 日以降に国際研究倫理規範に向けた提言を関連する国際機関を含め世界に発信する企画です。コンセンサス形成に向けて関心ある皆様の参加を心より歓迎します。招聘講師との貴重な交流の機会にぜひご参加ください。★登録必須・無料。講師との交流会有料。使用言語英語。詳細は以下リーフレット参照。

**Preliminary web conference, 8:30-11:30 AM in Brazil/8:30-11:30 PM in Japan;
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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**

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”

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Global Research Ethics and Meaningful Patient and Public Involvement:

Consensus Development: Part 2

Preparation for Declaration for Global Research Ethics and Meaningful Engagement

Registration is needed; Free of Charge for the meeting

(After conference session with speakers)

Registration only for receiving access link to video session is possible, due to time zone issue.

Among the speakers in the session of August 25, the following speakers will participate in-person session.

- **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
- **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
- **Kotone Matsuyama**, BPharm, National Center for Child Health and Development; Professor, Nippon Medical School; President-Elect, IFAPP
- **Chieko Kurihara**, BA, Specially-appointed Professor, Kanagawa Dental University; Editor-in-Chief, Clinical Evaluation
- **Takeo Saio**, MD, Fuji Toranomon Orthopedic Hospital

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Second International Conference 2025
Transformation of the global research ethics: the 2024 revision of the Declaration of Helsinki to promote patient engagement and dynamic consideration on vulnerability
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In-person in Yokohama, Japan (After conference session with speakers)

In the 2024 revision of the Declaration of Helsinki, a new concept in its history of 60 years, a comprehensible recommendation of meaningful engagement of patient, research participants and their community at all the stage of research has come to be included. This is based on the recognition of the context of various structural inequities in research settings where equitable distribution of benefits, risks and burdens should be carefully considered. In addition, vulnerability was re-considered as its fixed or contextual and dynamic natures and careful promotion of inclusion comes to be recommended, with strategic planning of sharing of the benefits resulting from research. This symposium will discuss such transformation of the research ethics principles, inviting global leaders engaged in the revision process of the Declaration for expanding our new horizon of research ethics.

Organizers :

Chieko Kurihara, Kanagawa Dental University

Takeo Saio, Fuji Toranomon Orthopedic Hospital

Speakers:

Chieko Kurihara, Kanagawa Dental University

Takeo Saio, Fuji Toranomon Orthopedic Hospital

Varvara Baroutsou

Immediate Past President, International Federation of Associations of Pharmaceutical Physicians and Pharmaceutical Medicine (IFAPP), The Netherland

Dirceu Greco

Professor Emeritus of Infectious Diseases and Bioethics, School of Medicine, Federal University of Minas Gerais, Brazil

Special comments:

Kotone Matsuyama

National Center for Child Health and Development; Nippon Medical School

President-Elect, IFAPP

Yoshiko Saito

Bioethics Working Group, the Japanese Institute for Public Engagement (Ji4pe)

Discussion

* This session is produced by the National Center for Child Health and Development