

EULAC PerMed Technical Workshop

Ethical, Legal and Social Aspects
Related to Personalised Medicine



NOVEMBER 17-18, 2020

PROGRAMME OVERVIEW

Objective of the workshop: To exchange insights on key ethical, legal and social issues in personalised medicine (PM) research and implementation in Europe and in Latin America and the Caribbean (LAC) and identify recommendations for future bi-regional collaborations in the field of PM.

Target audience: The research and clinical care community that directly works with PM. This can be investigators, PhD students, project managers, clinicians and paramedical personnel. It can also include policy makers, representatives of ethics committees, funding bodies and other regulatory bodies who regulate PM research or policies on PM in the health systems.

To connect to the workshop:

Day 1: <https://global.gotomeeting.com/join/291551821>

(If joining via phone Access Code: 291-551-821)

Day 2: <https://global.gotomeeting.com/join/869553685>

(If joining via phone Access Code: 380-990-845)

DAY 1

November 17th, 15:30-19:20 CET

15:30 – 15:40

OPENING REMARKS

Esther Rodríguez, EULAC PerMed Coordination, ISCIII. Spain

15:40 – 16:15

KEYNOTE LECTURE: INTRODUCTION TO ETHICAL, SOCIAL AND LEGAL ASPECTS OF PERSONALISED MEDICINE – RESEARCH & CLINICAL FRAMEWORKS

Carmen Ayuso, Chief of Clinical Genetics Dept. and Scientific Director of the Health Research Institute Fundación Jimenez Diaz (IIS-FJD, UAM), Madrid

Session 1

Chair: Dr. Sergio Rego

16.15 – 16.55

INFORMED CONSENT AND LIABILITY – EU AND LAC EXPERIENCES

Claude Vergès – Professor of Medical Ethics and Bioethics and president of the Bioethics Committee of the University of Panama

Sophie Rybczak – Lawyer, international expert in data protection law

16.55 – 17.05

Q&A

17.05 – 17.20

BREAK

Session 2

Chair: Dr. Florencia Tevy

17.20 – 18.20

PRIVACY AND CONFIDENTIALITY IN CLINICAL CARE

Eva Winkler – Professor for Translational Medical Ethics heading the program “Ethics and Patient Oriented Care in Oncology” at the National Center of Tumor Diseases, Heidelberg

Isabel Cornejo – Professor of Civil Law and Philosophical Foundations of Law, Universidad Autónoma of Chile

Fruzsina Molnár-Gábor – Research group leader at the Heidelberg Academy of Sciences and Humanities and senior lecturer at the Faculty of Law, University of Heidelberg

Session 3

Chair: Dr. Sergio Rego

18.20– 19.00

EQUAL ACCESS TO PERSONALISED CARE

Alberto Lecaros – Director of the Bioethics and Law Observatory, Universidad del Desarrollo, Chile

Encarna Guillen – President of the Spanish Association of Human Genetics. Member of the Bioethics Committee of Spain

19.00 – 19.20

QUESTIONS AND DISCUSSION

Moderated by Sergio Rego and Florencia Tevy

DAY 2

November 18th, 15:30-18:45 CET

15.30 – 15.35

WELCOME

15.35 – 15.40

INTRODUCING ERA PERMED JTC 2021

Maria Josè Ruiz Alvarez, JTC2021 Secretariat, It-MoH, Italy

Session 4

Chair: Dr. Monika Frenzel

15.40 – 16.20

ACCESS TO EXISTING DATA IN RESEARCH

Ricardo Armisen – Professor in Center for Genetics and Genomics, Institute of Science and Innovation in Medicine (ICIM)

Luca Marelli – Senior Research Fellow, Centre for Sociological Research (CeSO), KU Leuven, Belgium

Session 5

Chair: Dr. Claude Vergès

16.20 – 17.00

HOW TO TRANSLATE PM FROM RESEARCH TO CLINICAL CARE – ETHICAL, SOCIAL AND REGULATORY CONSIDERATIONS

Danilo Doneda – Professor at Brazilian Institute of Public Law. Nominated counselor by the Chamber of Deputies to the National Data Protection Council

Y. Michael Barilan – Physician and Associate Professor of medical education, School of Medicine, Tel Aviv University

17.00 – 17.10

Q&A FOR SESSIONS 4 AND 5

Moderated by Monika Frenzel and Claude Vergès

17.10 – 17.30

BREAK

Session 6

Chair: Dr. Delia Sánchez

17.30 – 18.10

ETHICAL, SOCIAL AND LEGAL ASPECTS RELATED TO MULTINATIONAL COLLABORATIONS IN CLINICAL RESEARCH

Vasiliki Rahimzadeh - Postdoctoral Fellow, Stanford Center for Biomedical Ethics, Stanford University

Mev Dominguez - Oncologist. Cancer genomics researcher at Oslo University Hospital and administrator of the Lynch Syndrome Prospective DB

18.10 – 18.30

QUESTIONS AND DISCUSSION

Moderated by Delia Sánchez

18.30 – 18.45

SUMMARY AND CLOSING REMARKS

Esther Rodríguez, EULAC PerMed Coordination, ISCIII. Spain



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