

Virtual 3rd EULAC PerMed Summer School

“Implementing PM Research into practice: Ethical, Legal and Societal Aspects perspective “

24th- 26th November 2020

LECTURERS BIOSKETCH

1.- MARIA EUGENIA BARNETT DE ANTINORI, President of the Institutional Review Board at the Gorgas Memorial Institute for Health Studies in Panama City, Panama



Dr. Maria Eugenia Barnett is a pediatrician (M.D., University of Panama), with postgraduate studies at the Institut Suisse de Recherche Expérimentale sur le Cancer in Laussane, Switzerland, and a Fullbright Scholar with a Masters in Public Health from Tulane University, New Orleans.

Since 2012 she has been in charge of coordinating international projects and she is currently the President of the Institutional Review Board at the Gorgas Memorial Institute for Health Studies in Panama City, Panama, where she also serves as Deputy Director.”

CV: <http://www.gorgas.gob.pa/wp-content/uploads/2018/04/CV-MARIA-E.-BARNETT-DE-ANTINORI.pdf>

2.-EVA BUSTAMANTE, Director in the Chilean Collaborative Oncology Group (GOCCHI), Santiago, Chile



Dr. Bustamante, is a Biochemist from the University of Chile, PhD in Science with a mention in Physiology at the Pontificia Universidad Católica de Chile and a Master in Molecular Oncology at the Centro de Estudios Biosanitarios / CNIO, Spain.

In recent years she has specialized in research ethics issues, completing a Diploma in this matter at the Central University of Chile. She has more than 15 years of professional development with a focus on biomedical research, cancer biology, precision medicine, and bioethics.

Since 2007 she has been Head of Research and Development at the Arturo López Pérez Foundation Oncology Institute (FALP), a private non-profit institution focused on the diagnosis, treatment, research and prevention of cancer in the city of Santiago de Chile. During 2015 and until 2018 she was president of the scientific ethics committee of FALP and from 2018 to date she is the vice president. She has been principal investigator and co-investigator in more than 15 national and international projects, highlighting the PRECAMA project of the IARC, France, in which different Latin American countries participate and seeks to know the molecular and biological bases of breast cancer in the pre menopausal women. Dr. Bustamante has about 25 scientific publications, 3 book chapters and has co-directed several undergraduate and graduate theses. She is also a member of

the board of directors of the Chilean collaborative oncology group (GOCCHI), scientific advisor for the group of patients GIST Chile and collaborator of the National Cancer Forum.

3.- Helano Carioca Freitas, clinical oncology, A.C. Camargo Cancer Center (Sao Paulo, Brazil).



Dr. Freitas works at A.C. Camargo Cancer Center (Sao Paulo, Brazil). He is a Medical Oncologist with a master's in pharmacology and PhD in Oncology. Currently he sees patients with thoracic malignancies and collaborates in research projects involving precision medicine in Brazil and Latin America.

4.-MAURICIO CUELLO, Associate Professor, Service of Oncology. Manuel Quintela Hospital. UdelaR



Dr. Mauricio Cuello was born in Uruguay, and he obtained his medical degree at Universidad de la República at Montevideo. His residency was at Hospital de Clínicas Manuel Quintela, and he completed his training with a fellowship in thoracic oncology at the "Hospital German Trias i Pujol", Barcelona, Spain. Dr. Cuello has twenty years' experience in oncology with special interest in molecular epidemiology, and also quality and access to better care in cancer.

After a short passage through the pharmaceutical industry, he returned to the academy and develop the first multidisciplinary unit to lung cancer care in Uruguay.

Dr. Cuello is a member of several scientific societies, and research groups. He has also participated in the construction of treatment and diagnosis guidelines at a national and international level.

Most of his publications refer to lung cancer and quality of care, he is currently participating in studies that evaluate the impact of socioeconomic determinants of health in access to cancer care in Uruguay.

5.- PARAG CHATTERJEE, Assistant Professor, Department of Biological Engineering



University of the Republic (Universidad de la República) URUGUAY; Research Professor, National Technological University (Universidad Tecnológica Nacional) Buenos Aires, ARGENTINA

Parag Chatterjee works as an Assistant Professor at the Department of Biological Engineering at University of the Republic, Uruguay, and a Research Professor at the National Technological

University, Buenos Aires, Argentina. As a researcher of the National Research and Innovation Agency of Uruguay (ANII), he leads the development of Artificial Intelligence toward predictive risk profiling in

liver transplantation. After graduating in Computer Science from University of Calcutta in India, he is working in the transdisciplinary areas of Internet of Things and Artificial Intelligence applied to

healthcare, especially in the domain of intelligent prediction and prevention. He is a member of editorial and reviewer boards of several international journals and conferences, and has delivered talks and keynotes in 30+ conferences and events, including ExpoInternet LatinoAmérica, IoT Week Geneva and TEDx.

6.- CAMILO GARCIA DUQUE. Ruta N Corporation (Colombia)



Responsible for the design of a mechanism for the management of R&D portfolios. Design and implementation of local science, technology and innovation policies and supporting instruments. Support tasks for the establishment of the Centre for the Fourth Industrial Revolution, and networking with key national and local stakeholders.

He has experience and interest in interdisciplinary research and consulting in legal, economic, political, and societal issues related to innovation policy, sustainable development, environmental law and policy, and sustainable transitions. He has 6 years of experience as university lecturer in the field of globalization and international relations and 10 years of working experience as a consultant and public officer for several Colombian governmental and international agencies.

7.-RAMIRO EUGENIO GILARDINO, Managing Director of HE-Xperts Consulting LLC



MD, MHE, MSc, is an experienced outcomes researcher, health economics, and global health policy professional with a medical background. Over the last 10 years, he has been working in the health economics and outcomes research field having served as HEOR and market access leader for pharmaceuticals and medical devices as well as several positions in healthcare management.

Currently, he's the Managing Director of HE-Xperts Consulting LLC, a boutique consultancy providing value, access, health policy and outcomes research endpoints to support decision making in emerging settings. Previously he held several positions at ISPOR, The professional society for health economics and outcomes research.

Ramiro has previous experience in healthcare management including serving as an advisor to the Argentinean Ministry of Health and other positions such as the head of Disease Management and Medical Director in Social Security, and private payers where he oversaw the management of funds for chronic conditions, health technology incorporation, and coverage policies.

Dr. Gilardino's research interests include medical devices comparative effectiveness, health technology assessment for medical devices, pricing, stakeholder involvement, and non-traditional outcomes, including PROMS and novel elements of value. He is particularly interested in health systems sustainability within the Latin America region. He has edited a publication related to establishing health technology assessment in Latin America as well as written chapters for publications and published more than 30 articles in both indexed and non-indexed peer-reviewed journals. He continues teaching Health Economics Evaluations and Health Technology Assessment as a parttime Professor at the Universidad ISALUD in Argentina.

8.- AGATA FERRETTI, PhD candidate at the Health Ethics & Policy Lab, Department of Health Sciences and Technology, ETH Zürich



Agata Ferretti is a PhD candidate at the Health Ethics & Policy Lab, Department of Health Sciences and Technology, ETH Zürich. Agata's background is in philosophy, bioethics and health policy. During her bachelor and master, she studied at Università Statale of Milan (Italy) and KU Leuven (Belgium) where she got interested in the ethics of new medical technologies and neuroethics. Prior to joining ETH she completed a MSc degree in Global Health Policy from the London School of Economics and Political Science (UK). Her PhD, supported by the Swiss National Science Foundation, focuses on the BEHALF project, which aims to provide a framework for an ethically aligned use of big data in biomedical research and healthcare. Agata has an extensive experience in conceptual and qualitative research methods. At the Health Ethics and Policy Lab, she is working on several projects that involve collaboration with international organizations such as the OECD and the WHO. Currently, she is exploring the need for quality assurance standards, as well as for improved oversight mechanisms, to guide and monitor health-apps (e.g. COVID contact tracing apps) - from concept development to implementation. Her research interests include the ethics and governance of health-related big data, the ELSI of artificial intelligence for personalized medicine, and the use of digital health to promote global health.

9.- MAURIZIO GENUARDI, Full Professor of Medical Genetics Università Cattolica Sacro Cuore. Roma. Italy



Prof. Maurizio Genuardi is an expert in Medical Genetics and Hematology. Director, Medico Genetics Unit Fondazione Policlinico Universitario Gemelli.

He mainly deals with Oncological Genetics, hereditary tumors, BRCA Test, Lync Syndrome, Cardio Genetics, hereditary arrhythmias, Long QT Syndrome, prenatal diagnosis of genetic diseases, Fetal DNA test, interpretation of genetic tests and genetic causes of infertility .

Graduated in 1981 and specialized in 1984, he mainly deals with genetic predisposition to tumors (hereditary tumors), prenatal genetic diagnosis and counseling and rare genetic diseases.

President Elect of the Italian Society of Human Genetics and Full Professor of Medical Genetics at the Catholic University of the Sacred Heart, Prof. Genuardi is currently Director of the Institute of Medical Genetics and Head of the homonymous department at the A. Gemelli Polyclinic in Rome , where he worked in the past as an Assistant and Medical Assistant.

Author of numerous publications and member of prestigious scientific societies (SIGU, ESHG, ASHG, InSiGHT, AIFEG, HGVS, HUGO), he has participated in over 100 courses, seminars and scientific events in Italy and abroad.

10.- **CATALINA LOPEZ CORREA**, Executive Director of the Canadian COVID Genomics Network (CanCOGen)



Dr. Lopez-Correa has worked in research and innovation for more than 20 years, in 7 different countries, in the academic and private sectors. She has worked with different biotech, pharma and non for profit companies to help advance research and innovation and develop productive partnerships at the national and international level. Presently, Dr. Lopez-Correa is the Executive Director of the Canadian COVID Genomics Network (CanCOGen) at Genome Canada. Previously, she was the COO at Ruta N Medellin, driving innovation ecosystems to advance

social and economical development in Colombia and Latin America. Prior to that, Dr. Lopez-Correa was the Chief Scientific Officer (CSO) at Genome BC and before that CSO at Genome Quebec. Dr. Lopez-Correa has also held leadership positions at deCODE Genetics, and Eli Lilly and has played advisory roles at the European Commission, Innovative Medicine Initiatives and other private and public sector entities working in the application and implementation of genomics technologies. In 2013, Dr. Lopez-Correa was awarded the National Order of Merit Award in the Rank of Officer by the Republic of Colombia and in 2017 was awarded a commemorative Canada 150 medal from the Canadian Senate. Dr. Lopez-Correa holds an MD from the Universidad Pontificia Bolivariana in Colombia, an MSc in Human Genetics from Paris V University in France, a PhD in Medical Sciences from the KULeuven in Belgium, and a mini MBA from McGill University in Canada.

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11.- **GABRIELA REPETTO** Professor of Genetics at Facultad de Medicina, Clinica Alemana Universidad del Desarrollo in Santiago, Chile



Gabriela Repetto, MD received her Medical Doctor degree from P Universidad Catolica de Chile, then did a Pediatrics Residency at the University of Wisconsin-Madison and a Genetics fellowship at Children's Hospital in Boston, USA. She currently is Professor of Genetics at Facultad de Medicina, Clinica Alemana Universidad del Desarrollo in Santiago, Chile, where she created and directed the Center for Genetics and Genomics until 2018. Since then, she directs the Program for Rare Diseases, an interdisciplinary initiative in research, clinical service, education and public policy. She is the author of more than 60 peer-

reviewed publications. She was the President of the Chilean Genetics Society (2018-2020) and is a member of the steering committee of the Global Genomic Medicine Collaborative (G2MC) and the Latin American Rare Diseases Group (ERCAL)

12.- BETTINA RYLL, Melanoma Patient Network Europe, Founder. Uppsala, Sweden



Dr. Ryll holds a medical degree from the Free University of Berlin, Germany, and a PhD in Biomedical Sciences from University College London, UK. After losing her husband to Melanoma, she founded the Melanoma Patient Network Europe and developed a special interest in patient-centric clinical research, innovative trial designs and novel drug development concepts as well as pragmatic solutions on how to ensure access to innovative treatments in situations of both high unmet need as well as high uncertainty.

Between 2015 and 2018, Dr. Ryll chaired the ESMO-PAWG, the first time this position was held by a non-oncologist and was instrumental behind the development of the advocacy track at annual ESMO conferences and joined the Horizon Europe Mission Board for Cancer in 2019.

Dr. Ryll is involved in numerous initiatives promoting evidence-based advocacy. She is fascinated by the enormous potential and capacity of patient networks to both educate and support patients as well as to capture data at the primary data source, the patients themselves, to generate evidence at a granularity level non-accessible to outsiders.

13.- JAVIER SILVA VALENCIA. Instituto Nacional De Salud | Lima, Perú



Medical Doctor and Biomedical Informatician with experience in project management in health information technologies. Currently, He works on the Technical team of the General Office of Information and Systems Working on building and training in data collection software for serological tests COVID-19. Analysis and integration of health information systems, and creation of mortality data visualization panels in COVID-19

Coordinator of Digital Health and Public Health projects UNIDAD DE

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Some projects worked include a tele mentoring program for physicians in Rural Areas, Validation of Verbal Autopsy Application in rural areas (SmartVA), creation of a National Course of ICD coding, enhancing the medical certification of cause of death through an Artificial Intelligence, and design of a web application based on FHIR Standards. Health Technology Assessment Note on the use of artificial intelligence for diabetic retinopathy screening.

UNIVERSITY OF WASHINGTON | SEATTLE, WA: Field Coordinator in One Health Center

Coordinator of the activities of the research project "Evaluation of the design and usability of a Dengue vulnerability mapping tool in Peru"

TECHNICAL COMMITTEE FOR STANDARDIZATION OF HEALTH INFORMATICS | LIMA, PERÚ: Member



Virtual 3rd EULAC PerMed Summer School PM & ELSA

National committee responsible for reviewing ISOs regarding to Health Informatics and create technical norms. UNIVERSIDAD

NACIONAL MAYOR DE SAN MARCOS (UNMSM) | LIMA, PERÚ: College Professor

Courses: “Science and its Application in Health”, “Telehealth rotation for resident doctors”, “Medical Informatics”, “Introduction to Research”

14.- SELINA ZIPPONI , Privacy Compliance Manager - Fellow Istituto Italiano PrivacyFellow Istituto italiano per la privacy e la valorizzazione dei dati



Selina Zipponi graduated in law at the University of Torino and obtained a Specialization from School for Legal Professions at the University of Padua.

After graduation, she started her career as international lawyer, in an important international law firm, providing advice on privacy and data protection matters to Italian and multinational companies.

She continued her career first as privacy specialist, in the compliance and legal department of a national major company, and then as privacy manager of an important multinational company.

She has been a fellow researcher of the Italian Institute for Privacy since 2019. She is author of books and publications on data protection and privacy and she gives lectures and courses on these topics. She is a certified Data Protection Officer and she speaks Italian, English, and Spanish.