DIBSS
Dubrovnik International
Bioethics & Science School

DATA SCIENCE AND THE RIGHT TO SCIENCE

CONFERENCE PROGRAM

DAY ONE: SATURDAY, May 18, 2019.

16.00 - 16.30

OPENING OF THE CONFERENCE
Mirjana Kujundžić Tiljak
Director, Andrija Štampar School of Public Health
University of Zagreb School of Medicine

Stjepan Orešković
Chairman, Center for Research and Promotion of Best
Practice in HealthCare

Mate Car
Ministry of Health of the Republic of Croatia

16.30 - 19.15

Andrea Renda
Ethical Guidelines for Trustworthy Artificial Intelligence:
Between Ethical Purpose and Cutting-Edge Technical Robustness

Andrzej Rys
Key Challenges and Opportunities for Uptake of Big Data
in HealthCare

Rain Laane
Making a Big Data Work for Patients at the National Scale:
A Case of Estonia

Coffee Break

Matthias Mann
Cutting Edge Research in Biotechnologies:
Who Should Have Control Over Your Biological Data?

Jason Bobe
Participant-Centered Research Design and "Equal Access"
Data Sharing Practices: How Far We've Come?

Mildred Z. Solomon
Twenty-first Century Biomedical Technologies:
Building Governance, Ethics and Public Participation

19.15 - 20.00

Round-Table Discussion
Data Science - A Great Opportunity to Improve Right to Science
Chair: **Helle Porsdam & Christine Mitchell**
Participants: **Andrea Renda, Andrzej Rys, Jason Bobe, Matthias Mann,
Mildred Z. Solomon, Rain Laane**

DAY TWO: SUNDAY, May 19, 2019.

9.15 - 9.35   **BIG DATA INDUSTRY AND THE IDEA OF EQUAL ACCESS**

Lorenzo Pengo
Digital Transformation in HealthCare: Health for All & Data for All?

Effy Vayena
The Social Impact of Data Science: New Values for Guidance

Tin Oreskovic
Predictive Medicine and Ethics of Data Science:
The Case of Measles Vaccination

Edward Cronan
The right to science in the age of medical data:
an inevitable conflict with the law of intellectual property?

Coffee Break

11.15 - 11.35   **PEOPLE'S SCIENCE, CIVIL SOCIETY, AND LEGAL ENVIRONMENT FOR DATA SCIENCE**

Christine Mitchell
What is and Should be the Status and Normative Weight of
Public Engagement with Science?

Sebastian Porsdam Mann
How to Resolve the Tension Between the Medical Duties of
Confidentiality and Beneficence?

Maiko Mori Watanabe
What is the Responsibility of Physicians with Data in Social
Inequality?

Valerie Bradley
Evidence-Based Policy-Making: The Case of Mental Disabilities

Roberto Andorno
Big Brain Data and the Right to Mental Privacy

Eva Turk
Digitalization and HealthCare Education

13.15 - 13.45   **Round Table Discussion**
How to Harmonize Public and Private Interests in Big Data Management?
Chair: **Mildred Z. Solomon**
Participants: **Christine Mitchell, Eva Turk, Maiko Mori Watanabe,
Sebastian Porsdam Mann, Roberto Andorno, Valerie Bradley**

13.45 - 15.30   **Lunch Break**

15.30 - 17.30   **BIG DATA AND BIG RESPONSIBILITIES: PROFESSIONAL ASSOCIATIONS, PARLIAMENTS, GOVERNMENTS AND INTERNATIONAL ORGANIZATIONS**

Dorjan Marušič
Developing Person-Centered Standards for Data Management in HealthCare Services: What Has Been Done Throughout the World?

Boris Brkljačić
The Role of Professional Organizations in Promoting Quality Standard and Guidelines for Automated Detection of Abnormalities, Automated Quantification of Diseases, and Imaging–Genomics

Istvan Cismadia & Vesa Jormanainen
Levels and Directions to Support the Transfer and Application of Good Practices to Ease the Uptake of Innovative Usage of Data Across the HealthCare Sector in Europe

Luigi Bertinato
How to Ensure Transparency and Equal Access to Data at the National HealthCare System Level

Ivan Pristaš
Big Data, Big Opportunities and Big Challenges for the Public Health Institutes

Closing Remarks: Christine Mitchell