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

Blaženka Divjak
Minister of Science and Education of the Republic of Croatia

16.30 - 16.50 **Andrea Renda**
Ethical Guidelines for Trustworthy Artificial Intelligence:
Between Ethical Purpose and Cutting-Edge Technical Robustness

16.50 - 17.10 **Andrzej Rys**
Key Challenges and Opportunities for Uptake of Big Data
in HealthCare

17.10 - 17.30 **Rain Laane**
Making a Big Data Work for Patients at the National Scale:
A Case of Estonia

17.30 - 17.45 **Coffee Break**

17.45 - 18.05 **Matthias Mann**
Cutting Edge Research in Biotechnologies:
Who Should Have Control Over Your Biological Data?

18.05 - 18.25 **Jason Bobe**
Participant-Centered Research Design and "Equal Access"
Data Sharing Practices: How Far We've Come?

18.25 - 18.45 **Michael Chou**
Non-anonymous Approach to Creating Public Genome and Health
Data: What Was Learned from Personal Genome Project?

18.45 - 19.05 **Mildred Z. Solomon**
Scientific Data and Disbelief in Science

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,
Michael Chou, Mildred Z. Solomon, Rain Laane**

DAY TWO: SUNDAY, May 19, 2019.

BIG DATA INDUSTRY AND THE IDEA OF EQUAL ACCESS

9.15 - 9.35   **Lorenzo Pengo**
Digital Transformation in HealthCare: Health for All & Data for All?

9.35 - 9.55   **Effy Vayena**
The Social Impact of Data Science: New Values for Guidance

9.55 - 10.15   **Tin Oreskovic**
Predictive Medicine and Ethics of Data Science:
The Case of Measles Vaccination

10.35 - 10.55   **Edward Cronan**
The right to science in the age of medical data: an inevitable
conflict with the law of intellectual property?

10.55 - 11.15   **Coffee Break**

PEOPLE'S SCIENCE, CIVIL SOCIETY, AND LEGAL ENVIRONMENT FOR DATA SCIENCE

11.15 - 11.35   **Christine Mitchell**
What is and Should be the Status and Normative Weight of
Public Engagement with Science?

11.35 - 11.55   **Sebastian Porsdam Mann**
How to Resolve the Tension Between the Medical Duties of
Confidentiality and Beneficence?

11.55 - 12.15   **Maiko Mori Watanabe**
What is the Responsibility of Physicians with Data in Social
Inequality?

12.15 - 12.35   **Valerie Bradley**
Evidence-Based Policy-Making: The Case of Mental Disabilities

12.35 - 12.55   **Roberto Andorno**
Big Brain Data and the Right to Mental Privacy

12.55 - 13.15   **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**

BIG DATA AND BIG RESPONSIBILITIES: PROFESSIONAL ASSOCIATIONS, PARLIAMENTS, GOVERNMENTS AND INTERNATIONAL ORGANIZATIONS

15.30 - 15.50 **Dorjan Marušič**
Developing Person-Centered Standards for Data Management in HealthCare Services: What Has Been Done Throughout the World?

15.50 - 16.10 **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

16.10 - 16.30 **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

16.30 - 16.50 **Luigi Bertinato**
How to Ensure Transparency and Equal Access to Data at the National HealthCare System Level

16.50 - 17.10 **Ivan Pristaš**
Big Data, Big Opportunities and Big Challenges for the Public Health Institutes

17.10 - 17.30 **Closing Remarks**
Christine Mitchell