

**DATA SCIENCE AND THE RIGHT TO SCIENCE:
A Common Ground for a New Ethical Framework?**

LOCATION:

Dubrovnik, Croatia

PLACE AND FACILITIES:

Interuniversity Center Dubrovnik

DATE:

May 18 and 19, 2019.

PARTICIPANTS:

Members of the Harvard Right to Science Reading Group; scientists from life, behavioral and the social sciences; ethicists, officials, and international leaders participating in cutting edge research, new regulations and the civic/public overview of legal, social, and ethical aspects of real life applications of data science.

BACKGROUND:

The future of data science not only exceeds the boundary of recent statistical theories, but is revolutionizing the current structure of academia and research paradigms. The impact of data science on the development of life sciences will continue to expand tremendously in the coming decades. The consequence is a growing capacity of research to provide insights into human biology and yield significant new understanding of human behavior. We are also facing a tremendous development and growth of data bases, creating opportunities as well as new challenges unknown to the scientific community and society at large before the age of big data. New methods of collecting and analyzing data may allow large improvements in health outcomes, among other reasons since medical therapeutic and diagnostic services offered to individual patients begin to merge the knowledge and practices of population and precision medicine.

THE PROBLEM

Contemporary systems are capable of collecting complex data in thus far unparalleled quantities - terabytes (10^{12} bytes), petabytes (10^{15} bytes) or zettabytes (10^{21}) of storage are needed, now creating the problem of how to manage the volume, velocity, variety, and veracity of the collected data. Such a complex constellation of new data and methods has created exciting opportunities for progress on old questions, as well as the prospect of opening entirely new ethical

dilemmas. The high-speed development in data science is not met with due understanding of the ethical, cultural and legal issues associated with collection, storage, sharing, and interpretation of the collected data. Privacy management gives users the option to control their data by allowing or revoking access to their data. In real world situations, personal data are at times shared or abused. The conflict is often between the desire of scientists to have access to shared resources and the desire of individual entities to profit when other entities partake of their resources. The anonymization of data must be strong and vigorous, monitored by independent bodies, legally enforced, and coherent with evolving societal values. We are now reaching the appropriate point to evaluate the first outcomes of the General Data Protection Regulation 2016/679.

THE OBJECTIVE:

Scholars from a variety of disciplines and across the globe are involved in the research of ethical dilemmas at the intersection of data science and life sciences. The organizers of the ***Data Science and Right to Science Conference*** are aiming to develop a formatted interdisciplinary dialog between social, behavioral, and life scientist coming from a variety of disciplines (biology, bioinformatics, genetic medicine and neurosciences, sociology, psychology, bioethics and philosophy) to discuss, with representatives of international organizations and governments as well as other actors, including civil society movements, research networks and corporations, the possibility of a *new framework for big data research*. An interdisciplinary dialog is needed because modern data science itself adopts techniques and theories drawn from many fields within life sciences and behavioral sciences, used together with methods from statistics, computer science, and more narrowly, machine learning.

THE METHOD

The conference will open in standard format with two keynote speeches. The first one will focus on the relation between new developments in data science (with a special focus on clinical and population based healthcare); the second one will focus on ethical dilemmas and problems of big data management. Two case studies will follow, demonstrating the opportunities and challenges of using data science. The round tables will involve researchers from universities and leading health and data industries followed by round-table discussion with participants from governments, international organizations and NGO's involved in the Open Science and Right to Science initiatives. The questions and answers from the participants will follow each session.

THE OUTCOMES:

The conference will test the possibility of systematically applying a human right to science approach as a way to protect and promote participation in science across all stages of the research, development, and technology application cycle.

The Conference will promote applying the concept of a Right to Science to the growing ethical dilemmas in data science development. A Right to Science approach will be tested as a systematic methodical response to the advanced and evolving features of big data research such as: data ownership, data privacy protection, methodological transparency and oversight across various types of big data

research. The value-related question we are asking is: what kind of big data society are we developing and how can everyone benefit from such development, while minimizing social, educational, race-based, gender-based constraints, among others.

The Conference will try to *catalyze the communication and thinking process* among the participants coming from various disciplines on *how to reach the modes of data generation, systematization, storage and utilization that would help exploit and utilize the immense potential of big data in a sustainable, confident and socially fair manner.*

The Conference will make an attempt to inform the data science departments of the international organizations such as UNESCO, UNITED NATIONS, WHO and EU on key issues discussed, arguments developed, and conclusions derived

Proceedings, presentations and research papers will be published in partnership with peer-reviewed journals that will join the discussion as co-organizers of the conference.