

Brussels Privacy Symposium

Research and the Protection of Personal Data Under the GDPR

AGENDA

14:00-14:15 (CET) – Introduction from the co-hosts

- Jules Polonetsky, FPF
- Prof. Christopher Kuner, VUB

14:15-14:45 (CET) – Opening Keynote

- Malte Breyer-Katzenberg, DG CONNECT, European Commission
- Invited Guest Speaker (TBC)

14:45-15:45 (CET) – Complex Interactions: the GDPR, Data Protection and Research

The GDPR provides safeguards and derogations relating to the processing of personal data for scientific research purposes. At the same time, the framework limits the collection of sensitive data and its sharing across organizations and national borders. In an era when EU institutions and international organizations advocate for data philanthropy and the sharing of personal data for compelling public interest grounds, legal frameworks must strike a delicate balance between public interests and individual rights. How do experts assess the interactions between scientific progress and the protection of rights under the GDPR? What have the effects of GDPR been on research in academic and corporate settings? Against the backdrop of the COVID-19 pandemic, this session explores whether GDPR has facilitated or hindered data research for healthcare purposes as well as in a broader context.

Moderator:

- Gianclaudio Malgieri, Associate Professor EDHEC Augmented Law Institute (Lille); Affiliated Researcher LSTS VUB

Speakers:

- Claire Gayrel, EDPS
- Dara Hallinan, FIZ Karlsruhe – Leibniz Institute for Information Infrastructure
- Ciara Staunton, School of Law, Middlesex University, London and Centre for Biomedicine, EURAC, Bolzano, Italy
- Henrik Junklewitz, JRC, European Commission

15:45-16:00 (CET) – Break

16:00-17:00 (CET) – Using Sensitive Data in Research to Counter (Hidden) Bias and Discrimination

Scientific research often depends on the broad collection, use, and sharing of special categories of data. In the context of COVID-19, organizations may study not only individuals' health, but also data about the geolocation, proximity, genetics, biometrics, and racial and ethnic origins of entire populations. While research often entails the processing of sensitive data, and hence presents privacy risks, it can also unearth covert bias and discrimination (for example, in the context of education, credit, housing, criminal justice and more). In this session, experts discuss the scope of the definition of sensitive data as well as the rules that should apply to the processing of sensitive data in the research arena. How can researchers ensure data based practices minimize privacy risks while at the same time not glossing over existing societal imbalances? What are the risks that methods such as differential privacy obfuscate underlying inequities? How will organizations use sensitive data to unearth and counter hidden bias and discrimination without abusing their access to such information? Where are the bounds of ethical data research in corporate environments, including healthcare, financial, advertising, and digital platforms?

Moderator:

- Gabriela Zanfir-Fortuna, Senior Counsel FPF, Affiliated Researcher LSTS VUB

Speakers:

- Elettra Ronchi, Organisation for Economic Co-operation and Development
- Paul Quinn, VUB
- Heng Xu, American University
- Knut Mager, Novartis

17:00 – 17:15 – Closing Keynote

Dr. Wojciech Wiewiórowski, European Data Protection Supervisor

In its January 2020 Preliminary Opinion on data protection and scientific research, the EDPS recommends intensifying the dialogue between DPAs and ethical review boards for a common understanding of which activities qualify as scientific research, on codes of conduct for scientific research, and on closer alignment between EU research framework programs and data protection standards. In his keynote comments, the EDPS discusses the report and reflects on the day's sessions.