Data Driven Life

EDPS workshop in cooperation with the EAG

18 May 2017
European Parliament, Room A3G-3

#DataDrivenLife

Dear colleague,

I am delighted that you could take part in today's Data Drive Life workshop which we are hosting together with the Ethics Advisory Group.Your contribution to today's meeting will be invaluable to the international debate we have launched on the ethical dimension of data protection in the digital era.

A significant hallmark of the digital revolution that is taking place, is that data infuses every aspect of society and private life. Our lives are being documented and even determined by the digital traces we leave behind together with the inferences organisations and algorithms make about that data. The massive collection of information allows private and public entities to predict our behaviour, score our reputations or nudge us to act. What are the positive and negative consequences of these data-driven changes for society as a whole and for our ability to pursue our own life choices?

Our aim when organising this workshop was to bring together speakers from a variety of academic and practical perspectives. What would enrich the discussions even more is you giving voice to your thoughts, perspectives and ideas.

The Ethics Advisory Group will publish a first Interim Report in 2017. Today's workshop is a unique opportunity for you as well as other speakers and participants to contribute to this report. Your attendance at this workshop is important to us, your intervention even more so. I encourage you to take part fully.

Here's to some lively exchanges today!

Welcome speeches

Giovanni Buttarelli
European Data Protection Supervisor

Giovanni Buttarelli is the European Data Protection Supervisor. Prior to his appointment in December 2014, he served as Assistant Supervisor (January 2009-December 2014). Before joining the EDPS, he was Secretary General at the Italian Data Protection Authority from 1997-2009. As a Cassation judge in the Italian judiciary, he has long been involved in many initiatives and committees on data protection and related issues at international level.

Prof. J. Peter Burgess
Chair of the Ethics Advisory Group

J. Peter Burgess holds the chair in the Geopolitics of Risk at the Ecole Normale Supérieure, Paris, is Professor at the Centre for Advanced Security Theory (CAST) of the University of Copenhagen, and member of Interdisciplinary Research Group on Law, Science, Technology and Society Studies (LSTS) of the Vrije Universiteit Brussel. Trained in engineering, literary studies, political science and philosophy, his research and writing focus mainly on the theory and ethics of security and insecurity.

Moderator and Concluding remarks

Prof. Luciano Floridi
Professor of Philosophy and Ethics of Information and Director of Research of the Digital Ethics Lab, Oxford Internet Institute, University of Oxford

Luciano Floridi is Professor of Philosophy and Ethics of Information and Director of Research of the Digital Ethics Lab, Oxford Internet Institute, University of Oxford. He is also Faculty Fellow and Chair of the Data Ethics Group of The Alan Turing Institute. The philosophy and ethics of information have been the focus of his research for a long time, and are the subject of his numerous publications, including The Fourth Revolution: How the Infosphere is Reshaping Human Reality (Oxford University Press, 2014), winner of the J. Ong Award.

PANEL 1

Ethics, health and medical research:
epidemiology, genetics and rare diseases

Dr. Anne Cambon Thomsen
Emeritus Research Director CNRS, Joint Unit of Epidemiology and Public Health, Inserm and University of Toulouse

Anne Cambon-Thomsen, MD and immunogeneticist, with degrees in biology, medical statistics and health ethics, is Emeritus Research Director in CNRS (French national centre for scientific research) in Toulouse, France. She works presently in a joint research Unit on epidemiology and public health at Inserm (National Institute for Health and Medical Research) and University Toulouse III Paul Sabatier where she created a societal platform on "genetics and society" in Toulouse. Her most recent researches address the societal aspects of biotechnology, the implications of genomics for public health, especially issues pertaining to biobanks and to complex disease genetics. She has experience in national and European ethics bodies and expert groups. She has been co-director of BBMRI-ERIC (Biobanking and BioMolecular resources Research Infrastructure) Common Service ELSI (Ethical, Legal and Societal issues). She has recently been appointed as a member of the EGE (European Group on Ethics in Science and New Technologies) of the European Commission and is Chair of the Deontology and ethics committee of the French National Cancer Institute (INCa). She is the Champion of the EuroScience Open Forum (ESOF) for its 8th edition, 9-14 July 2018 in Toulouse.

Prof. Effy Vayena
Professor of Health Policy and Ethics, University of Zurich

Effy Vayena is Swiss National Science Professor of Health Policy at the University of Zurich, where she leads the Health Ethics and Policy Lab. From 2000-2007 she was a technical officer at the World Health Organization (WHO), working on ethical and policy issues relating to health research ethics and reproductive technologies. She is a consultant to WHO, a faculty associate at the Berkman Klein Center for Internet & Society, Harvard Law School, and visiting faculty at the Harvard Center for Bioethics, Harvard Medical School. She is also a member of the Swiss Academy of Medical Sciences, and a member of the Leopoldina Academy's standing committee on digital society. Her current research focus is on ethical and policy questions in personalized medicine and digital health. She is particularly interested in the issues of ethical oversight of research uses of big data, ethical uses of big data for global health, as well as the ethics of citizen science. She has published widely in major journals in medicine, public health, health policy and ethics.

Moderator: **Giovanni Buttarelli**

PANEL 2

Humanitarian intelligence:
disaster response and risk management

Romain Bircher
Deputy Director of Communication and Information Management, International Committee of the Red Cross (ICRC), Geneva

Romain Bircher is Deputy Director of Communication and Information Management at the International Committee of the Red Cross (ICRC) in Geneva. He currently oversees the Divisions in charge of managing information and providing ICT services to support ICRC staff and partners in delivering humanitarian services.

From 1989 to 2000, Romain Bircher has worked for the ICRC in Afghanistan, Iraq, Iran, South Africa, Sri Lanka, Croatia and Israel to protect and assist prisoners and civilians affected by situations of violence. Once based at the ICRC Headquarters in Geneva, he has advised ICRC delegations on the protection of POWs and detainees held in the Horn of Africa, in Middle East and by the American authorities following 9/11. He has also led a specialized unit in charge of restoring family links and clarifying the fate of missing persons.

From 2010 to 2015, he led the Protection Data Unit to reinforce the management of data and improve the use of information technologies for protection and restoring family links. He notably oversaw the development of an ICRC website to restore family links: http://familylinks.icrc.org , as well as two new case management systems for the ICRC, and its key partners, the Red Cross and Red Crescent National Societies.

He holds a degree in political science, as well as certificates on information management, technology management, and data protection.

Prof. Dr. ZWITTER Andrej
Head of Political Science Department, University of Groningen

Andrej Zwitter holds the NGIZ Chair of International Relations and Ethics at the Faculty of Law, the University of Groningen. He is a senior fellow at Canterbury Christ Church, University, UK. Andrej Zwitter's current research foci include ethics in international politics and law, Big Data ethics, state of emergency politics, as well as law and politics of humanitarian action. He recently published the Monograph "Humanitarian Intelligence - A Practitioner's Guide to Crisis Analysis and Project Design".

Moderator: **Peter J. Burgess**

PANEL 3

Money, money, money:
Ethics in the financial sector

Elena Alfaro Martinez
Head of Data & Open innovation, BBVA

Elena Alfaro is the Global Head of Data & Open Innovation in BBVA Group, which functions include the generation of machine learning algorithms that constitute the intelligence behind BBVA's digital products, as well as the transformation of BBVA's skills and culture into a data-driven organization. She also leads the Group´s efforts to make the most of Open Innovation, both for the Bank and for our partners in the external ecosystem. Before that, Elena was the CEO of BBVA Data & Analytics, the Group's Center for Excellence in Data Science and Advanced Analytics, position that she held during 3 years. Before joining BBVA, Elena worked at Ericsson, playing an important role in telecommunications development in EMEA and LATAM, and broadening afterwards her experience as an expert in innovation. Regarding her background: Elena has a BA in Economics & Business Administration by the Universities of Sunderland (UK) and Universidad Autónoma (Madrid), and a Master in Intangibles Analysis and Management. She has taken part in the program "40-under-40 Young European Leaders" in 2013 edition.

Cécile Wendling
Head of Foresight, AXA Group

Cécile Wendling is head of foresight at AXA. She is working on the future of insurance, with current focus on responsible AI, ethics of algorithm, open data, smart cities, etc. Cécile Wendling has a PhD on sociology of risks. Her field of research includes topics such as crisis management, tools to anticipate risks, & foresight methods.

Aurélie Pols
Data Governance and Privacy Engineer at Mind Your Privacy

Aurélie Polsis an economist/econometrist and statistician by education and has been involved in the analysis of data from the very beginning of this activity. She is an important actor in the field of "digital data". She runs her own consulting business in Spain after selling her own first start-up company a few years ago.

Moderator

PANEL 4

Democracy:
ethics & elections

Paul-Olivier Dehaye
Co-founder PersonalData.IO

Dehaye is a research mathematician, who is also interested in the potential and dangers in the use of personal data. Working as an amateur investigative researcher, he has broken several stories on data protection issues. He is now working on a startup, PersonalData.IO, focused on giving back control to citizens over their personal data, through easy exercise of their rights and protection of their fundamental freedoms.

Young Mie Kim
Associate Professor, University of Wisconsin-Madison, USA

Kim is an Associate Professor at the University of Wisconsin-Madison, USA. Kim's program of research examines the role data and information technology play in political communication. Her recent research project investigates how political campaigns use data and advanced computing techniques to "microtarget" voters and what it means for democracy. Her research appeared flagship journals including Journal of Politics, Communication Research, Journal of Communication, among others. Kim was the Microsoft Visiting Professor of the Center for Information Technology at Princeton University, USA (2015-2016); and a Visiting Fellow at the Oxford Internet Institute, University of Oxford, UK (2011).

Antoinette Rouvroy
Research Associate at the Fund for Scientific Research (FNRS), University of Namur

Antoinette Rouvroy is a Belgian academic with a PhD in Legal sciences from Florence. She has worked as an academic in York, Montreal and, currently, Namur. Her academic origin is in law, which served as her starting point for the analysis of the philosophical, legal and ethical issues of decision-making processes in a developing information society.

Moderator

PANEL 5

Ethical smart cities

Prof. Dr. Dirk Helbing
Professor of Computational Social Science

Dirk Helbing is Professor of Computational Social Science at the Department of Humanities, Social and Political Sciences and affiliate of the Computer Science Department at ETH Zurich. He earned a PhD in physics and was Managing Director of the Institute of Transport & Economics at Dresden University of Technology in Germany. He is internationally known for his work on pedestrian crowds, vehicle traffic, and agent-based models of social systems. Furthermore, he coordinates the FuturICT Initiative (http://www.futurict.eu), which focuses on the understanding of techno-socio-economic systems, using smart data. His work is documented in hundreds of scientific articles, keynote lectures and media reports worldwide. Helbing is an elected member of the prestigious German Academy of Sciences "Leopoldina" and worked for the World Economic Forum's Global Agenda Council on Complex Systems. He is also co-founder of the Physics of Socio-Economic Systems Division of the German Physical Society and of ETH Zurich's Risk Center. In January 2014 Prof. Helbing received a honorary PhD from Delft University of Technology (TU Delft). Since June 2016 he is affiliate professor at the faculty of Technology, Policy and Management at TU Delft, where he leads the PhD school in "Engineering Social Technologies for a Responsible Digital Future".

Prof. Dino Pedreschi
Professor of Computer Science, University of Pisa - and SoBigData.eu

Dino Pedreschi is a professor of Computer Science at the University of Pisa, and a pioneering scientist in data science and big data analytics and their impact on society - human mobility, social networks, data ethics and privacy. Since 1994, he co-leads the Pisa KDD Lab - Knowledge Discovery and Data Mining Laboratory http://kdd.isti.cnr.it, a joint research initiative of the University of Pisa and the Information Science and Technology Institute of the Italian National Research Council, one of the earliest research labs centered on data mining. Dino is a founder of SoBigData.eu, the H2020 Research Infrastructure on Social Mining and Big Data Analytics http://www.sobigdata.eu, and of the master degree targeted at the education of inter-disciplinary data scientists, started in 2002. Dino received a Google Research Award for his research on privacy-preserving data mining.

Prof. Jeroen Van Den Hoven
Professor of Ethics and Technology, Delft University of Technology

Jeroen van den Hoven is University Professor and Professor of Ethics and Technology at Delft University of Technology. He has written extensively on ethical aspects of information technology. He is Founding Editor in Chief of the Journal Ethics and Information Technology, since 1999. In 2009, he won the World Technology Award for Ethics as well as the IFIP prize for ICT and Society for his work in Ethics and ICT. Jeroen van den Hoven was founder, and until 2016 Programme Chair, of the Dutch Research Council on Responsible Innovation. He chaired the EU expert group on Repsonsible Research and Innovation (RRI) and he is member of the European Group on Ethics (EGE) of the European Commission.

Moderator

AGENDA

8h15-9h00   Welcome, registration

9h00-9h30   Introductory speeches: Giovanni Buttarelli (EDPS) and Peter Burgess (EAG Chair)

9h30-10h30   Panel 1: Ethics, health and medical research: epidemiology, genetics and rare diseases
Moderator: Giovanni Buttarelli

Speakers:

(1) Emeritus Research Director CNRS, Joint Unit of Epidemiology and Public Health, Inserm and University of Toulouse

(2) Prof. Effy Vayena, Professor of Health Policy, University of Zurich

10h30-11h00   Coffee break

11h00-12h00   Panel 2: Humanitarian intelligence: disaster response and risk management
Moderator: Peter Burgess

Speakers:

(1) Romain Bircher, Deputy Director of Communication and Information Management, CICR

(2) Prof. Dr. Andrej Zwitter, Political Science Department, University of Groningen

12h00-13h00   Panel 3: Money, money, money: Ethics in the financial sector
Moderator: Aurélie Pols

Speakers:

(1) Elena Alfaro Martinez, Head of Data & Open Innovation BBVA

(2) Cecile Wendling, Head of Foresight, AXA

13h00-14h15   Walking lunch

14h15-15h15   Panel 4: Democracy: ethics & elections
                      Moderator: Antoinette Rouvroy

Speakers:

(1) Paul-Olivier Dehaye, co-founder PersonalData.IO

(2) Young Mie Kim, Associate Professor, University of Wisconsin-Madison

15h15-15h30   Coffee break

15h30-16h30   Panel 5: Ethical smart cities
                      Moderator: Jeroen van den Hoven

Speakers:

(1) Prof. Dr. Dirk Helbing, Professor of Computational Social Science at ETH Zürich, Zurich, Switzerland

(2) Prof. Dino Pedreschi, professor of Computer Science at the University of Pisa - and SoBigData.eu

16h30-17h00   Concluding remarks from Luciano Floridi

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