



Brussels | November 14

BEYOND PRIVACY

Learning Data Ethics

EUROPEAN BIG DATA COMMUNITY
FORUM 2019

Supported by



Beyond Privacy: Learning Data Ethics **European Big Data Community Forum 2019**

14 November 2019, Solvay Library, Brussels

Event Report

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1. Introduction

The Beyond Privacy: Learning Data Ethics – European Big Data Community Forum 2019 was held on November 14, 2019 at the Solvay Library in Brussels.

The event, supported by the [Big Data Value PPP](#), was organised by five EU-funded H2020 research projects active in the Big Data field and focused on Privacy-Preserving Technologies, transparency and legal compliance: [e-SIDES](#), [MyHealthMyData](#), [SODA](#), [SPECIAL](#), [WeNet](#).

By bringing together the community active in Big Data research, policy and industry, the event aimed at driving forward the discussion on how best to deal with ethical challenges in Big Data, also in view of the rise of Artificial Intelligence. The occasion was particularly relevant in order to present the most recent discussions and practical guidelines about ethical principles, thus raising attendees awareness around Data Ethics and the research work currently undergoing in this field.

The day was structured along two main sessions. The morning session, titled “Towards Value-centric Big Data”, was dedicated to high level keynote speakers, panel discussions and presentations involving representatives from organisations active in the legal, technical and civil society fields. The session also featured presentations from the five EU-funded research projects hosting the event, which provided an overview of the main outputs produced throughout their duration.

The afternoon session, titled “Lessons learned from research and technology for a human-centred Big Data” hosted two parallel breakout sessions dealing with legal and ethical issues in Big Data and focused on the presentation of the research material and tools currently available to the community to explore and tackle these challenges. The breakout sessions called for interaction and attendees’ active contribution to the discussion, which was supported through online voting and Q&A sessions.

During the day the audience was further engaged through the support of a graphic animator providing a live visual summary of the key take-aways.

This report describes the event and presents the highlights and key findings stemming from the discussion. It includes links to the presentations, relevant papers and guidelines presented during the day, as well as pictures and visual summaries of the sessions.



1.1 Agenda

09.00 Registration and welcome coffee

Morning Session: Towards value-centric Big Data

Chair: Richard Stevens, e-SIDES Coordinator, IDC

10.00 Opening session Richard Stevens, e-SIDES Coordinator, IDC

10.15 Welcome Keynote Dr Malte Beyer-Katzenberger, Unit G1 – Data policy & innovation, Directorate General for Communication Networks, Content and Technology of the European Commission

10.30 Keynote Dr Christiane Wendehorst, President - European Law Institute, co-chair of the German Data Ethics Committee

Extracting the value of data: How the research and industry community can best move forward to balance privacy and fairness

Chair: Gabriella Cattaneo, e-SIDES

10.45 Panel

- Marina Da Bormida, Ethics Expert and Lawyer
- Maryant Fernandez Perez, Senior Digital Policy Officer, BEUC - The European Consumer Organisation
- Diego Naranjo, Head of Policy, EDRI - European Digital Rights
- Moira Patterson, Global Affairs Program Director, IEEE

11:30 *Coffee break*

Chair: Richard Stevens, e-SIDES

11.45 Projects panel

- *Privacy-preserving technologies in a data-driven society* (Daniel Bachlechner, e-SIDES)
- *Progressing practical privacy-preserving big data analytics* (Paul Koster, SODA)
- *Enhancing transparency in the big data and AI landscape* (Sabrina Kirrane, SPECIAL)
- *Diversity and Privacy: Opportunities and Challenges* (Laura Schelenz, WeNet)
- *A GDPR-compliant blockchain-based system with advanced privacy-preserving solutions* (Edwin Morley-Fletcher, MyHealthMyData)

13.00 *Networking Lunch*



Afternoon Session: Lessons learned from research and technology for a human-centered Big Data

Chair: Rigo Wenning, SPECIAL & Mosaicrown

14:00 Afternoon Session Introduction
Rigo Wenning, SPECIAL & Mosaicrown

Technology and Data Protection Law – how can software engineering support legal compliance?

(Chair: Eva Schlehahn, SPECIAL):

- Data Privacy Vocabularies to fulfil GDPR Transparency & Compliance Checking requirements (Eva Schlehahn, SPECIAL)
- Anonymisation of personal data leads to the inapplicability of the GDPR – Myth or Reality? (Anna Zsófia Horváth, SODA)
- Why have we preferred to opt for sharing synthetic data and for computation “bringing the algorithms to the data” (Edwin Morley-Fletcher, MyHealthMyData)

14:10 Breakout sessions

Human centric big data governance: responsible ways to innovate privacy preserving technologies

(Chair: Karolina La Fors, e-SIDES):

- e-SIDES lessons for the responsible innovation of privacy-preserving technologies in the era of AI (Karolina La Fors, e-SIDES)
- Data for Diversity-Aware Technology: Some Ethical Considerations (Laura Schelenz, WeNet)
- BDVA TF6.SG4 paper: Data Protection in the era of Artificial Intelligence (Charlotte van Oirsouw, BDVe)

16.00 Wrap up of the breakout sessions
Rigo Wenning, SPECIAL & Mosaicrown

16.30 Closing remarks
Richard Stevens, e-SIDES Coordinator, IDC



2. Morning session: Towards Value-centric Big Data

2.1. Welcome Keynote: Towards a more ethical Data Economy?



Towards a more ethical Data Economy?

Dr Malte Beyer-Katzenberger, Unit G1 – Data policy & innovation, Directorate General for Communication Networks, Content and Technology of the European Commission

[Download the presentation](#)

The Beyond Privacy: Learning Data Ethics - European Big Data Community Forum 2019 kicked-off with a Welcome Keynote from Dr Malte Beyer-Katzenberger (Unit G1 – Data policy & innovation, Directorate General for Communication Networks, Content and Technology of the European Commission) discussing the European course towards a more ethical Data Economy from a policy perspective. During the speech particular emphasis was placed on how access to data and data sharing are increasingly gaining importance in the EU path towards the development of a competitive, secure, inclusive and ethical Data Economy. Control and access to data are in fact expected to be the next challenge at European level for the next two years: between fully closed data and fully open data there are shades of shared data on which the European community is currently working on also in terms of future funding initiatives. As a matter of fact, the European Commission, together with the Member States, intends to support the creation of common European data spaces to make data sharing across borders seamless, while ensuring full compliance with the General Data Protection Regulation.



«The EU needs to go further in developing a competitive, secure, inclusive and ethical digital economy with world-class connectivity. Special emphasis should be placed on **access to, sharing of and use of data**, on data security and on Artificial Intelligence, in an environment of trust.»

(conclusions of 21/22 March 2019 the European Council)



2.2. Keynote: Opinion of the German Data Ethics Commission

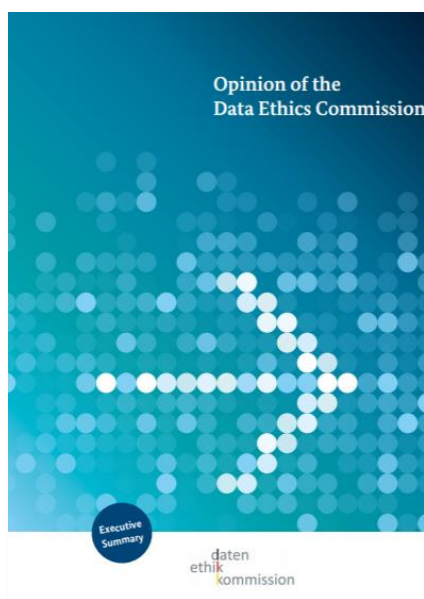


Opinion of the German Data Ethics Commission

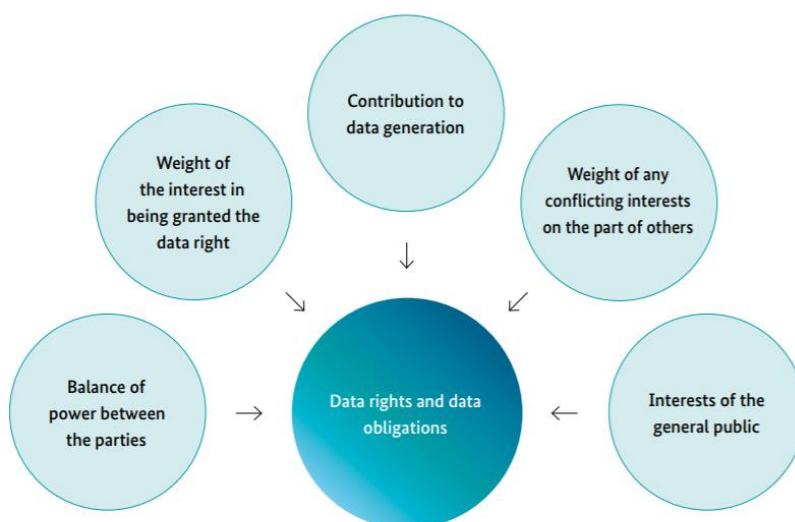
Prof Dr Christiane Wendehorst, President - European Law Institute, co-chair of the German Data Ethics Commission

[Download the presentation](#)

The second Keynote of the day given by Prof Dr Christiane Wendehorst (President - European Law Institute and co-chair of the German Data Ethics Commission) focused on the presentation of the work carried out by the German Data Ethics Commission established in 2018 with the mission to develop, within one year, an ethical and regulatory framework for data, algorithm-based decision-making (ADM) and AI. In particular, the speech focused on the Opinion the Commission presented on October 23, 2019 to the German Federal Government. The document includes ethical guidelines and 75 concrete recommendations for dealing with data and algorithmic systems with the aim to strengthen European values such as freedom and democracy, protect individual rights and promote social cohesion and prosperity in the digital age.



[Download the Executive Summary](#)



«Ethics, law and democracy must serve as a **shaping force for change**, both in the broader sense and more specifically in the field of technology. To achieve this goal, interdisciplinary discourse in politics and society is required, and care must be taken to ensure that any rules and regulations adopted are open enough to retain their regulatory clout and their ability to adapt, even in the face of fast-paced changes to technologies and business models»

Opinion of the German Data Ethics Commission, October 2019

2.3. Panel: Extracting the value of data - How the research and industry community can best move forward

The two Keynote speeches were followed by a panel discussion chaired by Gabriella Cattaneo (Associate Vice President – IDC4EU European Government Consulting at IDC and e-SIDES project member) involving representatives from organisations active in the legal, technical and civil society fields:

- Marina Da Bormida, Ethics Expert and Lawyer
- Maryant Fernandez Perez, Senior Digital Policy Officer, BEUC - The European Consumer Organisation
- Diego Naranjo, Head of Policy, EDRi - European Digital Rights
- Moira Patterson, Global Affairs Program Director, IEEE

The panelists presented their different viewpoints around the theme “extracting the value of data”, discussing how the research and industry community can best move forward to balance privacy and fairness.

Each panel speaker also highlighted any relevant publicly available papers or guidelines in their field complementing the information presented during the day or offering further insights. References and direct links to the documents have been provided in the following pages.





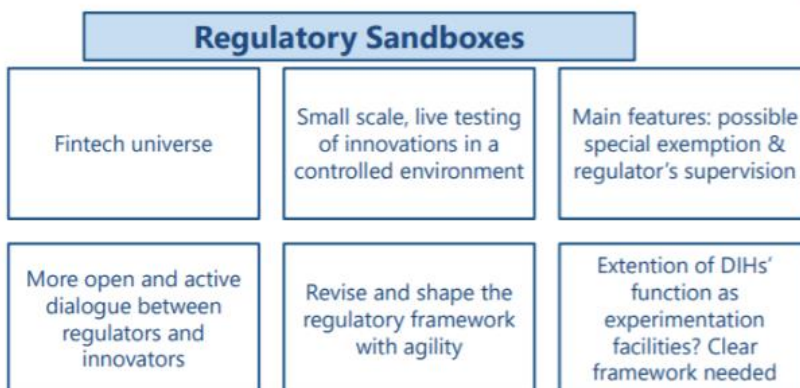
Operationalizing Data Ethics:

Which barriers, opportunities and facilitating factors for SMEs?

Marina Da Bormida, R&I Lawyer and Ethics Expert

[Download the presentation](#)

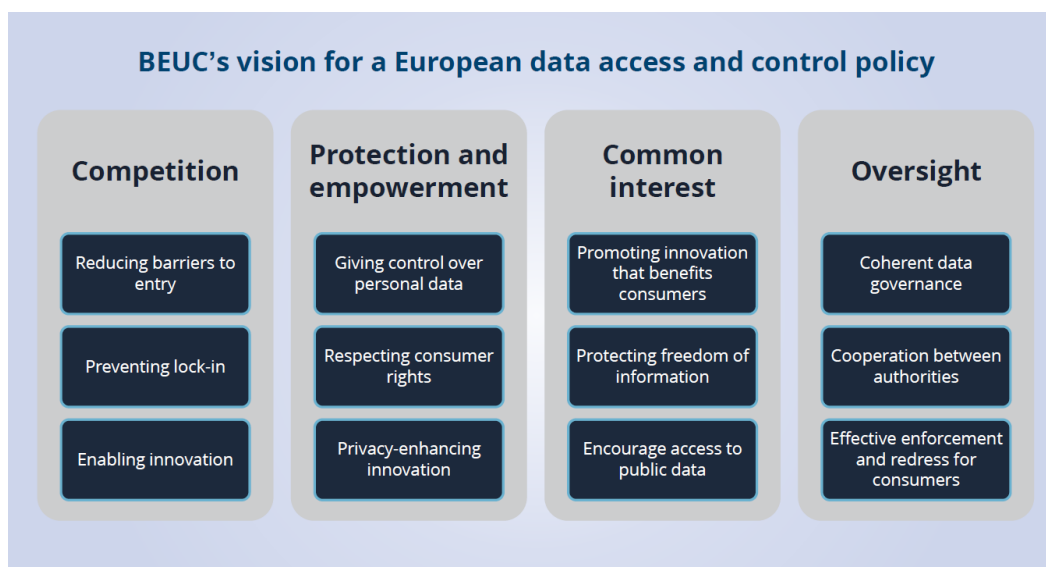
The way forward...reflecting on facilitating measures/ 1



Consumer-friendly EU policies on Artificial Intelligence and the Data Economy

Maryant Fernández Perez, Senior Digital Policy Officer, BEUC – The European Consumer Organisation

[Download the presentation](#)





Find more - BEUC's position papers:

On AI and algorithm decision-making:

[AI Rights for Consumers](#)

[Automated Decision Making and Artificial Intelligence - A Consumer Perspective](#)

On data access and control:

[Access to Consumers Data in the Digital Economy](#)



Protecting Digital Freedom

Diego Naranjo, Head of Policy, EDRI – European Digital Rights

In his presentation, Naranjo underlined the essential elements needing to be taken into account in order to balance privacy and fairness while extracting the value of data:

1. Legal consent
2. Data minimization (future of AI)
3. GDPR: not for preventing but to ensure the correct use of data
4. AI: before regulating on AI we might want to be sure not to overregulate on AI
5. Ethical use of algorithms



IEEE SA - Advancing Technology for the Benefit of Humanity

Moira Patterson, Global Affairs Program Director, IEEE

[Download the presentation](#)

IEEE ACTIVITIES IN A/IS AND ETHICS

Our Work: Putting principles into practice



Community

- 3000 members from all continents
- 40% women
- Participation & endorsement by industry
- Recognition by governments & international organizations



Ethically Aligned Design

- Provides guidance for standards, certification, regulation, & serves as a reference for the work of policymakers, industry members, technologists, & educators



"EAD For" Series

- Business
- Artists
- Health
- Parenting
- Advertising



Standards

- Nearly 30 AI/AS standards projects in development of which 15 are ethically oriented
- Included in the ethically oriented standards is IEEE P7000, which establishes a process model by which engineers & technologists can address ethical considerations



Certification

- Criteria and process for Certification / marks addressing:
 - Transparency in A/IS
 - Accountability in A/IS
 - Algorithmic Bias in A/IS



Education and learning

- AI & Ethics in Design Business Course
- EAD University Consortium
- Engagement and collaboration with governments, municipalities and intergovernmental fora (EU, EC, CoE, OECD, UN orgs, NYC, Vienna, Espoo, ...)



BEYOND PRIVACY



Learning DATA ETHICS

PANEL



EXTRACTING VALUE FROM DATA

KEY note
WE ARE NAVIGATING THE RIGHT DIRECTION

MACHINE LEARNING
SHARED DATA RISES SHARED SPACES

2021 FUNDING PROGRAM

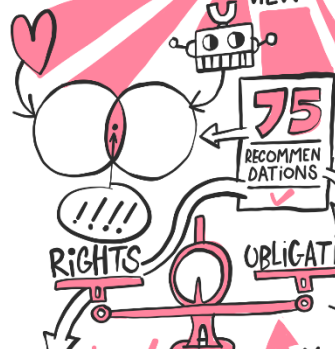
HIGH Level GROUP

ETHICS

KEY note

DATA ETHICS

HOLISTIC VIEW



NO PRIVATE OWNERSHIP OF DATA

DUTY TO SHARE HEALTH PRIVATE DATA

PUBLIC OPEN USE OF PUBLIC DATA

TRANSPARENCY



TRUST IS GOOD!
CONTROL IS BETTER!

DATA

- 1. COMPETITION
- 2. SAFETY
- 3. COMMON INTEREST

- AI RIGHTS:**
- TRANSPARENCY
 - ACCOUNTABILITY
 - FAIRNESS
 - NON-DISCRIMINATION
 - SAFETY
 - JUSTICE
 - RELIABILITY

GDPR

RIGHTS

CERTIFICATION

IEEESA



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2.4. Projects Panel

The second panel held during the morning session was dedicated to the presentation of the five EU-funded research projects hosting the European Big Data Community Forum 2019: [e-SIDES](#), [MyHealthMyData](#), [SODA](#), [SPECIAL](#), [WeNet](#). The panel, chaired by Richard Stevens (Consulting Director at IDC4EU – European Government Consulting, IDC and e-SIDES Project Coordinator), focused on the discussion of the projects objectives and main achievements in the research fields of privacy, data protection, ethics and legal compliance.



About the project

Data-driven innovation is deeply transforming society and the economy. Although there are potentially enormous economic and social benefits this innovation also brings new challenges for individual and collective privacy, security, as well as democracy and participation. The main objective of the CSA e-SIDES has been to complement the research on privacy-preserving Big Data technologies, by analysing, mapping and clearly identifying the main societal and ethical challenges emerging from the adoption of Big Data technologies, conforming to the principles of responsible research and innovation; setting up and organising a sustainable dialogue between industry, research and social actors, as well as networking with the main Research and Innovation Actions and Large Scale Pilots and other framework programme projects interested in these issues.



Privacy-preserving technologies in a data-driven society

Daniel Bachlechner, Fraunhofer & e-SIDES

[Download the presentation](#)





About the project

More and more data is being generated, and analysing this data drives knowledge and value creation across society. Unlocking this potential requires sharing of (often personal) data between organisations, but this meets unwillingness from data subjects and data controllers alike. Hence, techniques that protect personal information for data access, processing, and analysis are needed. To address this, the SODA project has aimed to enable practical privacy-preserving analytics of information from multiple data assets using multi-party computation (MPC) techniques. For this data does not need to be shared, only made available for encrypted processing. The main technological challenge has been to make MPC scale to Big Data, by embedding MPC into a comprehensive privacy approach, demonstrated in an ICT-14.b and a healthcare use case.



Progressing Practical Privacy-Preserving Big Data Analytics

Paul Koster, Philips research & SODA

[Download the presentation](#)



About the project

The SPECIAL project aims to address the contradiction between Big Data innovation and privacy-aware data protection by proposing a technical solution that makes both of these goals realistic. To this end it has developed technology that: (i) supports the acquisition of user consent at collection time and the recording of both data and metadata (consent, policies, event data, context) according to legislative and user-specified policies; (ii) caters for privacy-aware, secure workflows that include usage/access control, transparency and compliance verification; (iii) demonstrates robustness in terms of performance, scalability and security all of which are necessary to support privacy preserving innovation in Big Data environments; and (iv) provides a dashboard with feedback and control features that make privacy in Big Data comprehensible and manageable for data subjects, controllers, and processors. SPECIAL thus aims to allow citizens and organisations to share more data, while guaranteeing data protection compliance, enabling both trust and the creation of valuable new insights from shared data.



Enhancing Transparency in the Big Data and AI Landscape

Sabrina Kirrane, Vienna University of Economics and Business & SPECIAL

[Download the presentation](#)





About the project

Diversity permeates our everyday life and covers many dimensions, such as competence, culture, gender or economic across humans and social relations. Technology has evolved to a point where humans from diverse backgrounds, cultures, and experiences have an unprecedented ability to connect with each other. Yet technology does not in-and-by-itself provide support for developing and maintaining the social relationships that transcend geographical and cultural backgrounds. WeNet addresses this gap by providing a diversity-aware, machine-mediated paradigm of social relations. The goal is connecting people that can support each other, and the key is leveraging their diversity. The WeNet paradigm includes a family of computational diversity-aware models supporting human interaction. Learning models construct diversity profiles based on people's past behaviour and interactions. A diversity-aware search builds upon these profiles to connect the "right" people together. To support people's interactions, a diversity alignment mechanism lifts communication barrier to ensure that messages between humans are interpreted correctly, and a diversity-aware incentive mechanism generates incentives to motivate people to support each other.



Diversity and Privacy: Opportunities and Challenges

The project WeNet – The Internet of Us

Laura Schelenz, International Center for Ethics in the Sciences and Humanities, Tübingen & WeNet

[Download the presentation](#)



About the project

Issues of data subjects' privacy and data security represent a crucial challenge in the biomedical sector more than in other industries. The current IT landscape in this field shows a myriad of isolated, locally hosted patient data repositories, managed by clinical centres and other organisations, which are subject to frequent and massive data breaches. Patients are disenfranchised in this process, and are not able to have a clear understanding of who uses their personal information and for what purposes. This makes it the ideal field to build and test new models of privacy and data protection, and the technologies that encode them. MyHealthMyData (MHMD) has aimed at changing the existing scenario by introducing a distributed, peer-to-peer architecture, based on Blockchain and Personal Data Accounts.



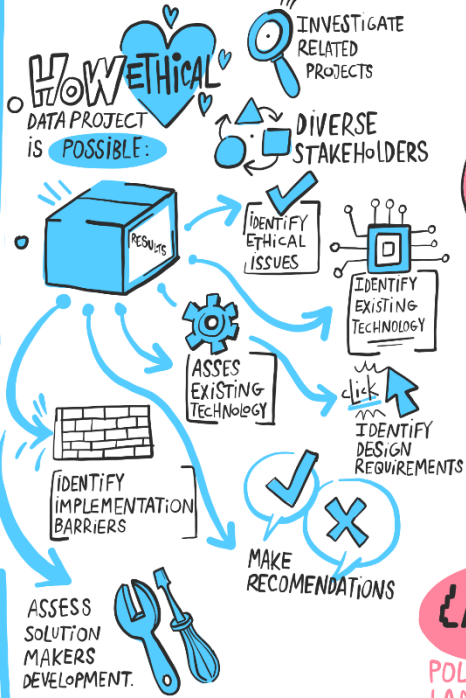
A GDPR-compliant blockchain-based system with advanced privacy-preserving solutions

Edwin Morley-Fletcher, Lynkeus & MyHealthMyData

[Download the presentation](#)



PROJECTS PANEL



WORLDWIDE PARTNERS
MULTIDISCIPLINARY APPROACH

TRANSPARENCY

TECHNICS
STUDENTS
SCIENTIST

DIVERSE NETWORK



consent

G.D.P.R.



LANGUAGE

POLICY LANGUAGES

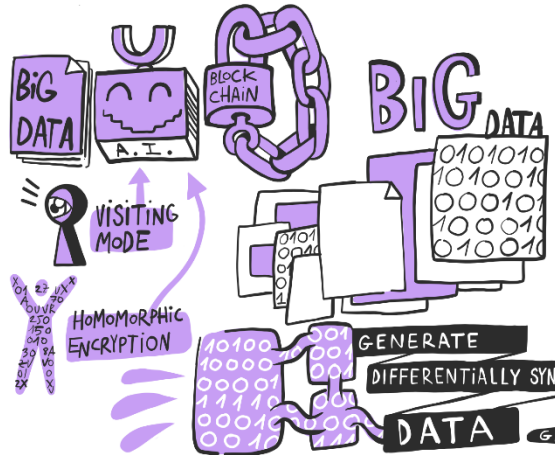
CHALLENGES:

STANDARDIZATION

AI. COGNITIVE LIMITATIONS

ENSURING WELL BEHAVING IS CRUCIAL

EMBRACE DECENTRALIZATION & ITS COMPLICATIONS



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3. Afternoon Session: Lessons learned from research and technology for a human-centered Big Data

The afternoon session focused on the presentation of the lessons learned from research and technology for a human-centered Big Data. It hosted two parallel breakout sessions calling for interaction and attendees' active contribution to the discussion.

The breakout sessions were moderated by facilitators from the projects team, asking questions to the participants and facilitating the group discussion. Inputs from the participants were collected through online polls and visually summarised by the graphic facilitator on two wallboards presented to the plenary audience during the wrap-up session.

3.1. Breakout session: Technology and Data Protection Law – how can software engineering support legal compliance?

This breakout session, chaired by Eva Schlehahn from the Independent Centre for Privacy Protection Schleswig-Holstein & SPECIAL, involved representatives from the SPECIAL, SODA and MyHealthMyData projects with the aim to explore privacy, transparency and compliance issues from a legal perspective, with a specific focus on GDPR requirements.



Data Privacy Vocabularies to fulfil GDPR Transparency & Compliance Checking requirements

Eva Schlehahn, Independent Centre for Privacy Protection Schleswig-Holstein & SPECIAL

[Download the presentation](#)



Anonymisation of personal data leads to inapplicability of the GDPR – Myth or Reality?

Anna Zsófia Horváth, University of Göttingen & SODA

[Download the presentation](#)



Why have we preferred to opt for sharing synthetic data and for computation “bringing the algorithms to the data”

Edwin Morley-Fletcher, Lynkeus & MyHealthMyData

[Download the presentation](#)





TECHNOLOGY & DATA PROTECTION LAW

How can SOFTWARE ENGINEERING SUPPORT LEGAL COMPLIANCE.

← IMPORTANCE →

• MORE TRANSPARENCY
6

• AUDIENCE IS DOUBTFUL
1

• LOGS OF DATA
10

• TAXONOMY

• DATA HANDLING POLICIES
6

• BIG DATA & PRIVACY ARE NOT MUTUALLY EXCLUSIVE

✓ AGREE 14

✓ PARTIALLY AGREE

✗ DISAGREE

• GREY ZONE: PERSONAL / NOT PERSONAL WOULD BE PRACTICAL?

• DIFFICULT!

• IMPORTANT NOT TO MIX UP

• ANONYMIZATION

• ENCRYPTION

• VISITING MODE APPROACH?

• SYNTHETIC DATA CAN BE MADE ANONYMOUS?
- THIS HAS TO BE PROVED

• WHAT IS DIFFERENTIAL PRIVACY?

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3.2. Breakout session: Human-centric Big Data governance – responsible ways to innovate privacy-preserving technologies

This breakout session, chaired by Dr Karolina La Fors from eLaw - Leiden University & e-SIDES, involved representatives from the e-SIDES, WeNet and BDVe projects with the aim to explore human-centric Big Data governance. In particular, the session focused on responsible innovation of Privacy-Preserving Technologies, diversity-aware technologies and ethical challenges in Big Data.



The occasion was also particularly relevant to announce the publication of a new paper by the [BDVA](#):

Timan, T. & Z. Á. Mann (eds) (2019) "Data protection in the era of Artificial Intelligence. Trends, existing solutions and recommendations for Privacy-Preserving Technologies", October 2019. BDVA

[Download the paper](#)



e-SIDES lessons for the responsible innovation of privacy-preserving technologies in the era of AI

Karolina La Fors, eLaw - Leiden University & e-SIDES

[Download the presentation](#)



Data for Diversity Aware Technology: Ethical Considerations

Laura Schelenz, International Center for Ethics in the Sciences and Humanities, Tübingen & WeNet

[Download the presentation](#)



Data Protection in the era of Artificial Intelligence

Charlotte van Oirsouw, TNO & BDVe

[Download the presentation](#)



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HUMAN-CENTRIC BIG DATA GOVERNANCE

RESPONSIBLE WAYS TO INNOVATE PRIVACY PRESERVING TECHNOLOGIES


ARE PRIVACY-PRESERVING TECHNOLOGIES USED IN YOUR PRACTICE?

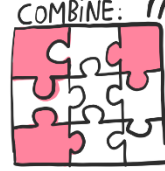

WHAT COULD INCENTIVATE PUBLIC PRESERVING TECHNOLOGIES

 ANY DATA PROTECTION
• MARKET ORIENTED SANCTIONS
• EXCLUSION FROM ECOSYSTEM
• ETHICS IN EDUCATION
• ENFORCEMENT


• POSITIVE & NEGATIVE DISCRIMINATION


FITNESS FOR A.I.


OVERSIGHT BODIES

COMBINE:

• LEGISLATION NEEDED
• LEGISLATION WE HAVE
• HARM-MINDING APPROACH


• DIVERSITY AWARE TECHNOLOGY




NO PRIVACY PROBLEMS FOR MILLENNIALS


• REGULATORY SANDBOXES


• CONTEXTUAL VS GENERIC


INTERNATIONALIZATION PRACTICES


Q&A
ANSWERS
QUESTIONS

 PREMIUM SERVICES
VS
 PRIVACY

GDPR VS CONSENT


AI AS A RESCUE TOOL

4. Wrap-up

During the plenary wrap-up session chaired by Richard Stevens (Consulting Director at IDC4EU – European Government Consulting, IDC and e-SIDES Project Coordinator) the moderators of the parallel break-out sessions were invited on stage to present the key outcomes from the discussion and the results of the online polls.



Break-out sessions key Take-aways

Eva Schlehahn, Independent Centre for Privacy Protection Schleswig-Holstein & SPECIAL
Karolina La Fors, eLaw - Leiden University & e-SIDES

[Download](#)



The audience was also presented with the wallboards realised by the graphic facilitators and featuring the visual summaries of the day, which guided the wrap-up by the moderators as well as the closing remarks.

All the presentations, including links to the papers and guidelines presented during the day, are available at: <https://e-sides.eu/resources>

If you would like to contact any presenter with questions, please write us at the following email address: info@e-sides.eu

We look forward to keeping the dialogue going and working with you on this topic in the future

