Personal Data Masking the Public Good in the GDPR

An Excursion into Personal Privacy and Private Goods

Unicamp Permanent Forum
Permanent Forum Roadmap: Ethics in the collection and use of data
Who owns the data? And How can the Data be explored?
Session: Data and Privacy in Europe
The GDPR's Limitations and Consequences
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The Vantage Point

- EU GCP Dir/Reg and Paediatric Regulation
- Chair WG, *Guidelines and Recommendations for European Ethics Committees* (Brussels 1995/7)
- Past member UNAIDS ERC
- Chair, WHO WGs on Guidelines for Ethics Committees & DSMBs
- Co-founder, FERCAP & SIDCER
- CIOMS Member
- Past Member, WHO GCP & ICTRP Committees
- Past Member, EORTC IRB; Chair, INCTR EC
- Member, EWG, European Academy of Paediatrics
- Co-founder, European Network for Research on Alternating Hemiplegia (ENRAH)
- EUROSOCAP, ENCCA, nEUroped, RESPECT, EBC

Current Activities

- Established in 2000 ‘PREP - Preparedness Planning for Clinical Research During Public Health Emergencies’ in response to the SARS-CoV-2 pandemic
- Ambassador for Ethics and Law, European Open Science Cloud (EOSC) Future
- Chairman, EOSC Future / RDA Artificial Intelligence and Data Visitation Working Group (RDA AIDV-WG) & Member, COVID-19 Legal & Ethics Sub-Working Group
- Chairman, International Data Policy Committee (IDPC) & Member, Executive Committee, International Committee on Data (CODATA), International Science Council (ISC)
- Member, Regulatory and Ethics Work Stream (REWS), Global Alliance for Genomics and Health (GA4GH)
- Research Data Publishing Ethics Working Group, FORCE11 & The Committee on Publication Ethics (COPE)
- Co-founder, Ukraine Clinical Research Support Initiative (UCRSI)
- Member of the Data Stewardship Working Group, Virus Outbreak Data Network (VODAN) GO-FAIR

Our Two Questions

1. Who owns the data?
2. How can the Data be explored?

Credits: NASA, ESA, CSA, and STScI

→ What role should ethics play in the collection and use of data? in responding to these two questions?

Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation) (Text with EEA relevance)

27 April 2016 (4 May 2016) → 25 May 2018

The aim of the General Data Protection Regulation:

‘[1] to reinforce data protection rights of individuals,

[2] facilitate the free flow of personal data in the digital single market and

[3] reduce administrative burden.’

Participants from the European Commission

- *Directorate-General for Justice and Consumers
- Directorate-General for Research and Innovation
- Directorate-General for Health and Food Safety

Integrity & Privacy
‘Human Subject’ → ‘Data Subject’

- ‘including research on identifiable human material and data’ (WMA Declaration of Helsinki, 2000-2013)
- ‘identifiable data and biological materials’ (WMA Declaration of Taipei, 2016)
- ‘personal data’ means any information relating to an identified or identifiable natural person (‘data subject’) (EU GDPR, 27 April 2016 (4 May 2016) → 25 May 2018)
- ‘Human subject means a living individual about whom an investigator . . . Obtains, uses, studies, analyzes, or generates identifiable private information or identifiable biospecimens’ (US Common Rule, July 2018)

Data Subject

‘personal data’ means any information relating to an identified or identifiable natural person (‘data subject’); an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person;

GDPR Article 5

Principles relating to processing of personal data

1. Personal data shall be:

(a) processed lawfully, fairly and in a transparent manner in relation to the data subject (‘lawfulness, fairness and transparency’);

(b) collected for specified, explicit and legitimate purposes and not further processed in a manner that is incompatible with those purposes; further processing for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes shall, in accordance with Article 89(1), not be considered to be incompatible with the initial purposes (‘purpose limitation’) [‘broad consent’];

EU Data Governance

- Law: EU & Member State
  (Third Country Regulations)
- European Data Protection Board (EDPB) [previously, Article 29 Working Party]
- European Data Protection Supervisor (EDPS)
- National Data Protection Agency(ies) (NDAs)
- Data Controller
- Data Processor
- Data Protection Officer
- Data Recipient

→ Data Subject

Lawful Bases to Process Data (A)

Must be for a specific purpose and necessary. Lawful basis dependent on context.

1. The data subject has given consent to the processing of his or her personal data for one or more specific purposes
2. Processing is necessary for the performance of a contract to which the data subject is party
3. A legal obligation to which the controller is subject
4. To protect the vital interests of the data subject or of another natural person

Lawful Bases to Process Data (B)

5. The performance of a task carried out in the public interest or in the exercise of official authority vested in the controller
6. The purposes of the legitimate interests pursued by the controller or by a third party, except where such interests are overridden by the interests or fundamental rights and freedoms of the data subject which require protection of personal data, in particular where the data subject is a child

Goods

- Private goods: ‘A private good is a product that must be purchased to be consumed, and consumption by one individual prevents another individual from consuming it.’

- Public goods: ‘Public goods are commodities or services that benefit all members of society, and which are often provided for free through public taxation. Public goods are the opposite of private goods, which are inherently scarce and are paid for separately by individuals.

Some Questions

- Is consent ‘fit-for-purpose’ in collection and processing?
- Are citizens & patients well-informed on the processing of their data and the potential utility to which their data may contribute?
- Could we move from a consent-based approach data processing to a social contract-based approach?