



# ***Ethics by Design***

## ***Safeguarding Data Subject Rights***

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# Charter of Fundamental Rights of the European Union

Article 7

## Respect for private and family life

Everyone has the right to respect for his or her private and family life, home and communications.

Article 8

## Protection of personal data

1. Everyone has the right to the protection of personal data concerning him or her.
2. Such data must be processed fairly for specified purposes and on the basis of the consent of the person concerned or some other legitimate basis laid down by law. Everyone has the right of access to data which has been collected concerning him or her, and the right to have it rectified.
3. Compliance with these rules shall be subject to control by an independent authority.

# Why Ethics?

*'The protection of natural persons in relation to the processing of personal data is a fundamental right.'*

## Treaty on the Functioning of the European Union

Article 16

(ex Article 286 TEC)

1. Everyone has the right to the protection of personal data concerning them.

*'From my perspective, ethics comes before, during and after the law..'*

*Choose Humanity: Putting Dignity back into Digital*  
*Giovanni Buttarelli*



**DEBATING ETHICS:**  
DIGNITY AND RESPECT IN DATA DRIVEN LIFE





## ***Ethics and Data Processing under GDPR***

*'Personal data shall be processed lawfully, fairly and in transparent manner in relation to the data subject' (art. 5 (1) a GDPR)*



# Fairness of Data Processing

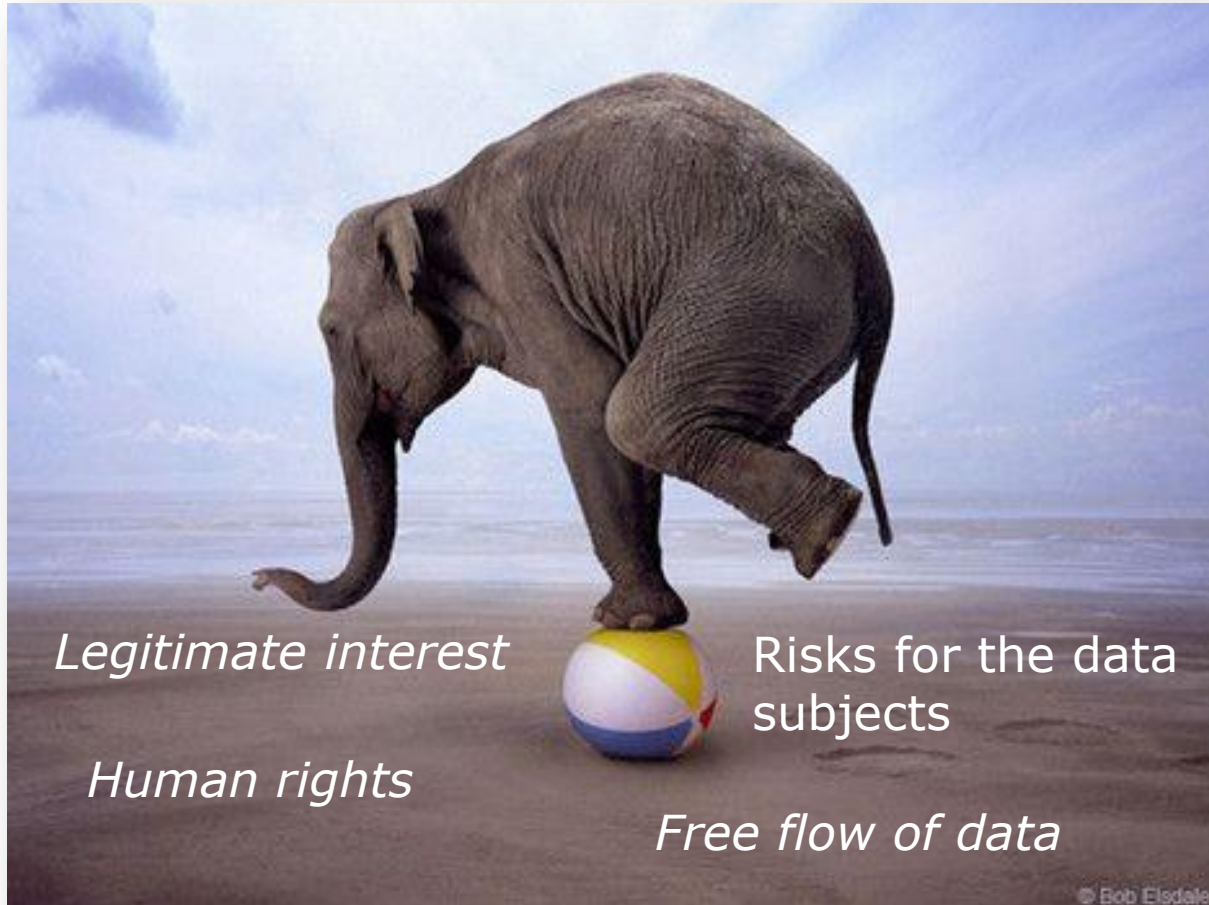
*Data must be processed in a way which :*

- *Ensures highest degree of autonomy of the data subjects;*
- *Enables interactions with the controller;*
- *Is in line with the expectations of the data subjects and is truthful;*
- *It is non-discriminatory;*
- *Does not exploit the vulnerabilities or the needs of the data subjects;*
- *Is not misleading...*



***ETHICAL by default***

# ***Balancing Act***



*Legitimate interest*

*Human rights*

Risks for the data subjects

*Free flow of data*



European  
Commission



## Balancing and Protecting

### ***What should be taken into account and when?***

- *The nature, scope, context and purposes of the processing;*
- *Risks of varying likelihood and severity for the rights and freedoms of natural persons;*
- *Both at the time of the determination of the means for processing and at the time of the processing itself.*



## Potential ethics risks

- *Discrimination;*
- *Stigmatisation;*
- *Exposing identity and sensitive data (privacy breach);*
- *Security/safety risks for the data subjects;*
- *Reputational risk and loss of position within occupational and other settings;*
- *Harms to the interests and wellbeing on the research participants, third parties and the community;*
- *Misuse of data.*





# Which Safeguards are Appropriate?

- *Address the technological, legal and ethics risks related to the data processing;*
- *Are **dynamic** in their nature and **responsive** to the evolving science;*
- ***Embedded** by design and by default in the data processing operations;*
- *Designed to **effectively** implement data protection principles;*
- *Ensure the respect of principle of data minimisation;*



## Appropriate Safeguards

*The protection of the rights and freedoms of natural persons requires that **appropriate technical and organisational measures** are set in place, such as:*

- ***minimising** the processing of personal data,*
- ***pseudonymisation;***
- *ensuring **transparency** with regard to the functions and processing of personal data;*
- *enabling the data subject to **monitor** the data processing;*
- *enabling the controller to create and improve **security** features. (recital 78 GDPR)*



## Appropriate Safeguards (some examples)

*Technical measures such as:*

- *Hashing, encryption;*
- *Access and authentication management;*
- *Secure storage, backup/log's;*
- *Network/communication security (transmission control);*
- *Use of privacy enhancing tools/systems;*





## Appropriate Safeguards (some examples)



*Organisational measures such as:*

- *Systematic data minimisation and data mapping and risk assessment reviews’;*
- *Clear and comprehensive data protection policies;*
- *Training of staff;*
- *Data protection advise and privacy embedded in the company’s culture;*
- *Legal safeguards for employees involved in high risk processing (confidentiality clauses).*



## Appropriate Safeguards

*Require the deployment of robust and adaptive **governance framework**, which is:*

- *able to address the possible risks for the data subjects;*
- *ensure effective compliance with data protection principles; and*
- *is able to demonstrate it.*

# Ethics by Design and by Default

*It is not enough to have rules on lawfulness, proper use of consent and legitimate interest paired with accountability under GDPR...*

*....we need articulate ethical framework which will also enable us to define the future we want to live in*

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***Thank you for your attention!***