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The leading role of smart ethics in the digital world

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Edited by

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To those who care about the human side beyond technology

The ETHICOMP Book series fosters an international community of scholars and technologists, including computer professionals and business professionals from industry who share their research, ideas and trends in the emerging technological society with regard to ethics. Information technologies are transforming our lives, becoming a key resource that makes our day to day activities inconceivable without their use. The degree of dependence on ICT is growing every day, making it necessary to reshape the ethical role of technology in order to balance society's 'techno-welfare' with the ethical use of technologies. Ethical paradigms should be adapted to societal needs, shifting from traditional non-technological ethical principles to ethical paradigms aligned with current challenges in the smart society.

Table of contents

The Countervailing Power Of AI DAOs Influences Value Transformation; Bitcoin (POW) vs. Ethereum (POS).....	9
Is a Brain–Machine Interface Useful for People with Disabilities? Cases of Spinal Muscular Atrophy.....	19
Securing Healthcare Databases: A Comprehensive Policy-Based Framework Integrating Relational and Blockchain Technologies	31
Privacy-Related Consumer Decision-Making: Risk Assessments by Cognitively Frugal Consumers	41
Impact of Ethical Judgment on University Professors Encouraging Students to Use AI in Academic Tasks	53
Examining the Mediating Effect of Financial Fraud Risk on Financial Education and Corporate Ethics and Intention to Use Financial Services.....	63
Ethical Challenges in AI Integration: A Comprehensive Review of Bias, Privacy, and Accountability Issues.....	75
Bringing Ethical Values into Agile Software Engineering	87
The Democratization of Outer Space: On Law, Ethics, and Technology	99
Incorporating Experiential Learning Platform Framework for an Online Graduate Class.....	111
Advocate to Increase Women in Cybersecurity	117
Ethics in Internet of Things Security: Challenges and Opportunities.....	123
How Can Best Practices of Cybersecurity Include Artificial Intelligence within Smart Cities	135
“Dark Partners”: Transparency Obligations Against Deception in Virtual Influencer Marketing	143
Cybersecurity - The Best Life Path for Everyone	155
Highlighting Ethical Dilemmas in Software Development: A Tool to Support Ethical Training and Deliberation.....	165
Addressing the AI Responsibility Gap with the ACM Code of Ethics	177
The Ethical and Legal Challenges of Data Altruism for the Scientific Research Sector.....	189
Trustworthy and Useful Tools for Mobile Phone Extraction.....	201
National Cybersecurity Strategy Action Plan for Cyber Resilience: Qualitative Data and Achievements.....	213
Privacy After Dobbs: How the Shifting U.S. Landscape Affects the Broader Debate.....	225
Use And Abuse of AI – Ethical Perspectives in the Educational Sector.....	233
An Analysis on AI Ethical Aspects from A Stakeholder’s Perspective	243
The Challenge of Co-Creation: How to Connect Technologies and Communities in An Ethical Way	255
The Pivotal Role of Interpretability in Employee Attrition Prediction and Decision-Making	265
An Integrated Ethics Framework for Embedding Values in AI	277
Arab Culture and Privacy of Social Media: A Theoretical Study.....	291

THE ETHICAL AND LEGAL CHALLENGES OF DATA ALTRUISM FOR THE SCIENTIFIC RESEARCH SECTOR

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ABSTRACT

Scientific research nowadays is increasingly data-driven and therefore a growing amount of data need to be accessible and of high quality. The data altruism mechanism, as regulated in the Data Governance Act (DGA), aims to meet this demand. This paper investigates how data altruism mechanisms apply to the scientific research sector. This mechanism, based on the voluntary release of data, raises several normative challenges. From a legal viewpoint, data altruism in the research sector entails (1) the risk of fragmentation; (2) security concerns; and (3) the duty of control on data altruism organisations. From an ethical perspective, the challenges regard (1) the very idea of altruism between ethics and infra-ethics; (2) the interplay between public interest, general interest, and common good; and (3) a concern related to the autonomy of both data subjects and data holders. Given the set of challenges, both legal and ethical, and the multiplicity of actors involved in the data altruism mechanism, the intent of the analysis is to provide an assessment on how the data altruism mechanism should be implemented at national level.

KEYWORDS: data governance act, DGA, data governance, data altruism, scientific research, general interest, public interest.

1. INTRODUCTION

Scientific research nowadays is increasingly data-driven and therefore requires a growing amount of data, which need to be accessible and of high quality. The data altruism mechanism, that results as a means to meet this demand, is regulated by the Data Governance Act (DGA, hereinafter). The DGA is a Regulation of the European Union, which is applicable from 23 September 2023¹, that aims to “foster the availability of data for use by increasing trust in data intermediaries and by strengthening data-sharing mechanisms across the EU”, as described in the explanatory memorandum accompanying the proposal for a Regulation². The DGA is a crucial part of the so-called “politics of data” (Pagallo, 2022) developed by the European Commission in 2020³ and can also be considered as complementary to the Open Data Directive (ODD, hereinafter)⁴, integrating the European framework on data sharing and reuse (Ruohonen & Mickelsson 2023). Article 3 of the DGA, which identifies the scope of application, underscores the complementarity between the DGA and the ODD by stating that the DGA provides for the reuse of certain categories of data, such as data held by the public sector that are protected on the basis of commercial confidentiality, statistical confidentiality, protection of third parties’

¹ Regulation (EU) 2022/868 of the European Parliament and of the Council of 30 May 2022 on European data governance and amending Regulation (EU) 2018/1724 (Data Governance Act), ELI: <http://data.europa.eu/eli/reg/2022/868/oj>.

² Proposal for a Regulation of the European Parliament and of the Council on European data governance (Data Governance Act), COM/2020/767 final, <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex:52020PC0767>.

³ European Commission Communication, A European strategy for data, COM/2020/66 final (2020), ELI: <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:52020DC0066>.

⁴ Directive (EU) 2019/1024 of the European Parliament and of the Council of 20 June 2019 on open data and the re-use of public sector information (recast), ELI: <http://data.europa.eu/eli/dir/2019/1024/oj>.

intellectual property rights and protection of personal data. Therefore, the DGA concerns the reuse of the public sector data excluded from the scope of the ODD (Van Eechoud, 2021, p. 376).

Data altruism is defined by the DGA under Article 2(16):

‘data altruism’ means the consent by data subjects to process personal data pertaining to them, or permissions of other data holders to allow the use of their non-personal data without seeking a reward, for purposes of general interest, such as scientific research purposes or improving public services.

This paper aims to investigate the data altruism mechanism for the scientific research sector⁵. This mechanism, based on the voluntary release of data, raises several normative challenges. From a legal viewpoint, data altruism in the research sector entails the following challenges: (1) the risk of fragmentation; (2) security concerns; and (3) the duty of control on data altruism organisations. From an ethical perspective, starting from the assumption that data altruism is a form of distributed morality (Floridi, 2020), the analysis focuses on three main ethical issues: (1) the very idea of altruism between ethics and infra-ethics; (2) the interplay between public interest, general interest, and common good; and a concern related to the autonomy of both data subjects and data holders with the scope of consent.

The analysis argues that the manifold ethical and legal challenges may jeopardize the implementation of the data altruism mechanism, *a fortiori* considering that is partially delegated to national policies. Next section provides an overview of the data altruism mechanism as designed by the European institutions, focusing on the phases of the process, conditions and actors involved. Section 3 is devoted to the investigation of the legal issues; whilst Section 4 considers the ethical aspects. The conclusions provide some recommendations that should be adopted at the national level to mitigate some drawbacks of the European mechanism of data altruism.

2. DATA ALTRUISM UNDER THE DGA

The mechanism of data altruism involves several actors: (i) the subjects of personal data; (ii) the holders of non-personal data; (iii) the data altruism organisations; (iv) the data users; and (v) the competent authority for registration.

(i) The notion of data subject is indirectly derived from the definition of personal data provided in Article 4(1) of the GDPR. The data subject is the natural person, identified or identifiable, to whom the personal data pertain.

(ii) The data holder according to the Article 2(8) of the DGA is “a legal person, including public sector bodies and international organisations, or a natural person who is not a data subject with respect to the specific data in question, which, in accordance with applicable Union or national law, has the right to grant access to or to share certain personal data or non-personal data”.

⁵ Consider that the proposal for a Regulation on the European Health Data Space (EHDS) also makes specific reference to the data altruism mechanism: Proposal for a Regulation of the European Parliament and of the Council on the European Health Data Space, COM/2022/197 final, ELI: <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex%3A52022PC0197>. The EHDS Proposal does not define the data altruism mechanism but explicitly refers to the DGA definition (Article 2(1)c of the EHDS Proposal). The Article 40 of the EHDS Proposal is then specifically dedicated to “Data altruism in health”. At the moment, the EHDS Proposal has not yet been adopted. This contribution is limited to the mechanism of data altruism as regulated in the DGA.

(iii) The data altruism organisations are legal entities, specifically registered as such, operating not for profit, independent of any profit-driven data processing activity.

(iv) The data user refers to any “natural or legal person who has lawful access to certain personal or non-personal data and has the right, including under Regulation (EU) 2016/679 in the case of personal data, to use that data for commercial or non-commercial purposes” (Article 2(9) of the DGA).

(v) The competent registration authorities are entities in charge of the data altruism organisation’s registration process, designated in every Member States.

Underlying the operations of this multiplicity of actors there are two conditions enshrined in Article 2(16) of the DGA. First, data subjects and data holders must release their data to the data altruism organisation free of charge, not in return for a reward. This condition may be interpreted as a measure to avoid the establishment of a buying and selling of personal data⁶.

The second condition is that the reuse needs to be carried out exclusively for general interest purposes. The purposes of general interest are specified in Recital 45, which states: “[S]uch purposes would include healthcare, combating climate change, improving mobility, facilitating the establishment of official statistics or improving the provision of public services. Support to scientific research, including for example technological development and demonstration, fundamental research, applied research and privately funded research, should be considered as well purposes of general interest”. The mechanism of the data altruism, based on data “voluntarily made available by individuals or companies” (Proposal DGA, Explanatory Memorandum, 2020, p. 8), may generate a considerable impact on the data management in the scientific research sector.

According to the European institutions, the data altruism mechanism hinges on an articulated process with several phases. Any entity intending to be recognised as a data altruism organisation has to undergo a registration process, and among other information, has to declare “the purposes of general interest it intends to promote when collecting data” (Article 19(4)h, DGA).

As mentioned above, the scientific research is considered an example of general interest purposes (Article 2(16) of the DGA). However, indicating scientific research as a general interest purpose is a very broad, uninformative notion that adds to the on-going debate about the information to be provided to the data subject by the data controller under Articles 13 and 14 of the General Data Protection Regulation (GDPR, hereinafter)⁷ (Hallinan, 2020, p. 8). Indeed, it is often complicated to specify the aims pursued in a specific scientific research project (Pagallo & Bassi, 2013, p. 183).

Once the requesting entity meets all the requirements laid down by the DGA, it will be included in the national register of data altruism organisations by the competent national authority or authorities, within 12 weeks from the date of application, pursuant to Article 19(5) of the DGA. The competent authority in charge of certifying an entity as a data altruism organisation is designated by each Member State and, under Article 23 of the DGA, is responsible for maintaining the national public register of such data altruism organisations.

The voluntary release of personal data by data subjects to the data altruism organisations is based on consent. The consent needs to be given in compliance with the two conditions described above, i.e.,

⁶ Recital 45 DGA specifies that “Data subjects should be able to receive compensation related only to the costs they incur when making their data available for objectives of general interest”.

⁷ 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) ELI: <http://data.europa.eu/eli/reg/2016/679/oj>.

no reward and public interest purposes. The registered data altruism organisations provide to several natural and legal persons (i.e., data users) the possibility to process the data they hold, for purposes of general interest, eventually on the basis of a fee. Each data altruism organisation is required to keep accurate records – very similar to the processing register set out in Article 30 of the GDPR – concerning a set of accurate information about the specific data processing activities, based on the data altruism consent.

In addition, any data altruism organisation, pursuant to Articles 20 and 21 of the DGA, has several reporting obligations towards data subjects and data holders. In particular, prior to any processing, entities have to meet two requirements. First, they are compelled to inform data subjects and data holders of “the objectives of general interest and, if applicable, the specified, explicit and legitimate purpose for which personal data is to be processed, and for which it permits the processing of their data by a data user” (Article 21(1)*a* of the DGA). Second, any entity must communicate “the location of and the objectives of general interest for which it permits any processing carried out in a third country, where the processing is carried out by the recognised data altruism organisation” (Article 21(1)*b* of the DGA). In this regard, it is worth noting that the corresponding article in the proposal of the Regulation (Article 19(1)*b* of the DGA Proposal) identified a general duty to communicate “any processing outside the Union”. By contrast, in the Regulation in force, the wording seemingly provides that processing in a third country may be carried out only by the data altruism organisation itself.

According to the current structure of the data altruism mechanism, the data altruism organisation is pivotal. Article 19(2) of the proposal of the DGA bestowed a proper function of control on the data altruism organisation by stating that the “entity shall also ensure that the data is not be used for other purposes than those of general interest for which it permits the processing”. The DGA currently in force is more softened than the proposal⁸. However, the central role and responsibility of the data altruism organisation in the control over data provided by data subjects and data holders persists, as does its challenging aspects, considering that the very definition of data reuse is intrinsically broad and open to many possible operations (Bassi, 2011, p. 67).

The purpose of the data altruism mechanism, as unfolded in Recital 46⁹, is the establishment of data repositories providing pools of data able to generate value serving the general interest. Pursuing this goal, which could represent a “significant step towards decentralization of the web and demopolization of data” (Van de Hoven *et al.*, 2021, p. 143), remains problematic. Next section tackles the legal challenges of implementing the data altruism mechanism.

3. THE LEGAL CHALLENGES OF DATA ALTRUISM

In light of the analysis of the data altruism mechanism under the DGA, two crucial actors clearly stand out: the European Commission and the Member States. According to Article 22 of the DGA, some fundamental clarifications are left to delegated acts of the Commission, which are currently still pending. In fact, the European Commission will play a key role in specifying certain aspects of the functioning of the data altruism mechanism, such as information requirements for the provision of consent, the technical and security requirements, the communication duties, and interoperability standards. Furthermore, data altruism is up to the discretionary powers of the Member States: They

⁸ See: Article 21(2) DGA.

⁹ “The registration of recognised data altruism organisations and use of the label ‘data altruism organisation recognised in the Union’ is expected to lead to the establishment of data repositories. Registration [...] is expected to facilitate [...] the emergence of data pools covering several Member States.”, Recital 46 DGA.

may (not 'shall') "establish national policies for data altruism", under Article 16 of the DGA (Baloup *et al.*, 2021, p. 35).

However, prior to the further intervention of delegated acts of the European Commission and national policies, a few knots need to be untangled. They can be summarised in the following issues, which are investigated below: (1) the risk of fragmentation; (2) security concerns; (3) the duty of control on data altruism organisations.

3.1. Fragmentation

The DGA Regulation poses a crucial problem. On the one hand, the aim is to encourage the sharing of data by facilitating "the emergence of data pools covering several Member States" (Recital 46 of the DGA). In doing so, the registration of the data altruism organisation "is expected to facilitate cross-border data use within the Union" (Recital 46 of the DGA). On the other hand, however, Recital 48 emphasises that the DGA "should be without prejudice to the establishment, organisation and functioning of entities that seek to engage in data altruism pursuant to national law and build on national law requirements to operate lawfully in a Member State as a not-for-profit organisation". Risks of fragmentation follows as a result, given the wide leeway left to the initiatives of the Member States.

Only time will tell whether and how the Member States will implement the data altruism mechanism. So far, not much information is available about national strategies and the topic is under-researched in the literature.

Looking at the list of national data altruism authorities currently designated under the Article 23 of the DGA, there is no common strand in the action of the different Member States¹⁰. For instance, Spain has involved four entities: the Deputy Directorate General for Digital Society, the Ministry of Economic Affairs and Digital Transformation and two Spanish authorities on Artificial Intelligence (i.e., the Directorate General for Digitization and AI and the State Secretariat for Digitization and AI). Germany has nominated only one authority, i.e., the German Federal Network Agency. Further differences regard the controllers. Lithuania designated the national data protection authority (i.e., the State Data Protection Inspectorate); the Netherlands have opted for the Authority for Consumers and Markets; Finland, the Finnish Transport and Communications Agency Traficom. If, as specified in Recital 46, the registration of an entity as a data altruism organisation is meant to be valid throughout the whole territory of the Union¹¹, mechanisms of effective communication and cooperation between such different entities will have to be put in place in order to ensure the effective success of this form of data reuse.

In the European institutions' vision, this fragmentation should be overcome through a European form of consent to data processing given by the data subjects and the data holders (Article 25 of the DGA). Considering the difficulties that the choice of the most suitable legal basis for processing personal data for scientific research purposes has generated under the GDPR (Paseri, 2023, p. 11; Hallinan *et al.*,

¹⁰ According to the Article 23(2) of the DGA "Each Member State shall notify the Commission of the identity of their competent authorities for the registration of data altruism organisations by 24 September 2023". However, currently, only 14 Member States have designated their national competent authority (the list is available here: <https://digital-strategy.ec.europa.eu/en/policies/data-altruism-organisations>). Significantly, very different institutions or authorities have been identified as data altruism competent authorities. At the moment, there is no uniformity of approach among the Member States.

¹¹ In this regard, the European Commission by means of an implementing act has provided for the design of a logo to identify such organisations unanimously throughout the whole territory of the European Union, as set out in the Article 17 of the DGA.

2023), it is fair to concede that providing a unique European consent form for data altruism requires harmonisation (Lalova-Spinks, Meszaros & Huys, 2023, p. 5; Shabani, 2021). Moreover, this approach allows for the joint collection of both the personal data acquired by consent, and non-personal data acquired by permission. However, this cannot be the only way to harmonise the approach, especially as it raises several ethical challenges concerning the choice of the legal basis of consent, which is discussed below¹².

3.2. Security

The data altruism organisation must also ensure a solid infrastructure system. The goal is the establishment of data pools in order to store, transfer, manage, and share data. This makes the security of infrastructures crucial. The centralisation of data envisages several challenges from a security viewpoint, making those holding the data both very powerful, and at the same time very vulnerable. Very powerful, because the intention is to promote “the emergence of pools of data made available on the basis of data altruism that have a sufficient size in order to enable data analytics and machine learning, including across borders in the Union” (Recital 45, DGA). Highly weak because they are more easily targeted by cyber-attacks and data breaches.

The DGA points out the relevance of security, stating that the “recognised data altruism organisation shall take measures to ensure an appropriate level of security for the storage and processing of non-personal data that it has collected based on data altruism” (Article 21(4) of the DGA). Article 21(5) of the DGA sets out a duty of communication over the data altruism organisation in case of data breaches concerning non-personal data. This provision corresponds to Article 34 of the GDPR for personal data¹³. However, the measures to be taken to ensure an appropriate level of security are not specified in the Regulation. Their definition will be provided in the so-called ‘rulebook’, pursuant to Article 22(1)*b*, which is a set of delegated acts of the European Commission, still to be issued.

Regarding the security monitoring over the data pools, the Regulation mentions one aspect that is worth emphasising. Recital 46 introduces ethical councils or boards as “oversight mechanisms”, which expressly entail “representatives from civil society”. The role of these forms of bottom-up control aims to “ensure that the data controller maintains high standards of scientific ethics and protection of fundamental rights” and turns out to be in line with the European policies promoting the involvement of the society at large in the field of scientific research, represented by the phenomenon of the so-called citizen science. This phenomenon describes “the involvement of citizens and the public at large in research projects in various guises” (Paseri, 2022, p. 531). The citizen science phenomenon, expressly mentioned and promoted in the Regulation (EU) 2021/695 establishing the Horizon Europe programme, i.e., the new framework for funding scientific research at the European level¹⁴, can also acquire a renewed role in the dynamics of data altruism by envisaging participatory forms of control and assessment of the security of data pools.

¹² See Section 4.3.

¹³ The Article 21(5) of the DGA states that “[T]he recognised data altruism organisation shall, without delay, inform data holders in the event of any unauthorised transfer, access or use of the non-personal data that it has shared”. Similarly, the Article 34(1) of the DGA set out that “[W]hen the personal data breach is likely to result in a high risk to the rights and freedoms of natural persons, the controller shall communicate the personal data breach to the data subject without undue delay”.

¹⁴ Regulation (EU) 2021/695 of the European Parliament and of the Council of 28 April 2021 establishing Horizon Europe – the Framework Programme for Research and Innovation, laying down its rules for participation and dissemination, and repealing Regulations (EU) No 1290/2013 and (EU) No 1291/2013 (Text with EEA relevance), ELI: <http://data.europa.eu/eli/reg/2021/695/oj>.

3.3. Control

Article 21 of the DGA establishes “[S]pecific requirements to safeguard rights and interests of data subjects and data holders with regard to their data”. Crucial here is the role of the data altruism organisation: This entity is in charge of ensuring compliance with the requirements of the law. For instance, the data altruism organisations are obliged to provide a range of information to data subjects and data holders about the processing of their data (e.g. the general interest objectives pursued and the location of the data or the event of a data breach) and are required to take measures to ensure security.

The wording of the DGA proposal is even more explicit and incisive stating that “[T]he entity shall also ensure that the data is not used for other purposes than those of general interest for which it permits the processing” (Article 19(2) of the DGA proposal). The softer wording used in the current text is justified by the fact that such a duty of control over the entire lifecycle of the data held by the data altruism organisation would not have been practically achievable (Veil, 2022).

However, the current Regulation maintains the central role of the data altruism organisations that are in charge of multiple requirements and tasks. Data altruism organisations must ensure that the purpose of general interest is respected. The general interest is a very broad concept *per se*, and the DGA does not provide a definition. In addition, Article 18(1)a provides that in order to qualify for registration in a public national register of recognised data altruism organisations, an entity shall “carry out data altruism activities”. Nevertheless, the DGA lacks a definition of “data altruism activities”, raising difficulties both from a practical and a legal point of view.

The design of data altruism introduced by the DGA seems to align the data altruism organisation with the role of the data controller under the GDPR. In the European Data Protection Regulation, in fact, several tasks and requirements are established for the actor that determines the *purposes* and *means* of processing of personal data, i.e., the data controller (Article 4(7) of the GDPR). In this framework, the principle of accountability (Article 5(2) of the GDPR) is a pillar of the Regulation (Pagallo *et al.*, 2019, p. 24; Durante, 2021, p. 134), as a meta-principle of the entire approach of the GDPR (Paseri, Varrette, Bouvry, 2021, p. 135; Durante & Floridi, 2022, p. 135).

In the case of the DGA, the control duties, combined with the vagueness of the framing of the role and activities, complicate the context. For this reason, it’s challenging to envision which entity would intend to undertake the registration process in order to be identified as a data altruism organisation, especially considering that this entity must “operate on a not-for-profit basis and be legally independent from any entity that operates on a for-profit basis” (Article 18c of the DGA).

After the analysis of the legal challenges of data altruism, it is now time to draw the attention to the ethical challenges.

4. THE ETHICAL CHALLENGES OF DATA ALTRUISM

From an ethical perspective, data altruism can be interpreted as an expression of distributed morality (Floridi, 2020). Distributed morality is “the macroscopic and growing phenomenon of global moral actions and non-individual responsibilities, resulting from the «invisible hand» of systemic interactions among multiagent systems (comprising several agents, not all necessarily human) at a local level” (Floridi, 2020, p. 64). In other words, “the voluntary sharing of data” (Article 2(16) of the DGA) at the basis of the data altruism mechanism represents a modular and incremental operation (Benkler, 2006) that finds its morally relevant value in aggregation (Durante, 2007, pp. 248-253). According to the data altruism mechanism, the aggregation of each individual data sharing represents a moral action being “the result of otherwise morally-neutral or at least morally-negligible [...] interactions among agents

constituting a multiagent system, which might be human, artificial, or hybrid” (Floridi, 2020, p. 65). The data altruism mechanism under the DGA results in “actions that are morally negligible in themselves”, but that “may become morally significant, if properly aggregated” (Floridi, 2020, p. 72).

Accordingly, it is crucial to focus on the forms of such aggregation, ensuring that the actions of individual data subjects or data holders are not nullified, but rather foster positive moral behaviours. Three aspects to be addressed in order to achieve proper aggregation are investigated below, decoding (1) the concept of altruism; (2) the terminological uncertainty; and (3) the individual autonomy and the scope of the consent.

4.1. The Concept of Altruism

Data altruism is not a new phenomenon. The debate about so-called ‘data donation’ (Skatova & Goulding, 2019; Prainsack, 2019; Bietz, Patrick & Bloss, 2019) or ‘data philanthropy’ (Kirkpatrick, 2013; Taddeo, 2016; Taddeo 2017; Giannopoulou, 2019) has been going on for rather some time.

These forms of data release entail two moral problems. On the one hand, they may pose a risk to the individual rights: “making personal data available while, at the same time, maximizing their accessibility and use [...] highlight a tension between individual rights and data sharing” (Taddeo, 2016, pp. 4-5). On the other hand, these forms of data sharing may lead to a threat to democracy, considering that they “can hinder democratic processes also by facilitating unduly profiling which can then provide the means for unjust discrimination” (Taddeo, 2016, p. 6).

On the contrary, there are compelling reasons for individuals to donate their data in forms of data altruism or data philanthropy, which support the moral desirability of the phenomenon. Three main reasons can be identified. First, individuals, both data subjects and data holders, may be prompted to allow their data to be processed for the benefit of scientific research activities (Pagallo, 2022, p. 74; Ienca, 2023, p. 2), taking part in the formation of the collective and common good. Second, such sharing and the resulting processing, can generate economic value, which might represent indirect forms of self-interest. Third, such forms of sharing or donation may be means to react against forms of data monopolisation (Van de Hoven *et al.*, 2021) by large private actors (Prainsack, 2019, p.10), for the benefit of a larger number of actors, both public and private.

Furthermore, Thomas Nagel proposes the interpretation of a ‘rational altruism’ that “depends on a recognition of the reality of other persons, and on the equivalent capacity to regard oneself as merely one individual among many” (Nagel, 1975, p. 3). In other words, alongside the traditional reasons such as benevolence, indirect self-interest or other subjective factors, there is also a “a motivation available when none of those are, and also operative when they are present, which has genuinely the status of a rational requirement on human conduct” (Nagel, 1975, p. 80). This introduces the interpretation of altruism not as “abject self-sacrifice, but merely a willingness to act in consideration of the interests of other persons, without the need of ulterior motives” (Nagel, 1975, p. 79). The rational altruism of Thomas Nagel is particularly suited to these forms of data release, where the act of sharing carries a limited emotional impact.

In light of the tension between the moral problems and the moral desirability of these forms of data sharing, Mariarosaria Taddeo argues that the “moral ambiguity of data philanthropy, on the one side, and its moral desirability, on the other, unveil the infraethical nature of this phenomenon” (Taddeo, 2016, p. 6). Infraethics is “the not-yet-ethical framework that can facilitate or hinder evaluations, decisions, actions, or situations, which are then moral or immoral” (Floridi, 2017, p. 392). As a result, infraethics is characterised by moral ambiguity. This “moral ambiguity of infraethics is resolved once it is combined with the *right* moral values” (Taddeo, 2016, p. 7). On this basis, Taddeo claims that the “infraethical nature of data philanthropy becomes clear when considering its moral ambiguity and its

potential to foster democratic processes, the advance of scientific knowledge, civic participation” (Taddeo, 2016, p. 7).

By decoding the concept of altruism and determining whether and how to implement the data altruism mechanism at the national level, a twofold challenge should be addressed. First, altruism is also motivated by objective and impersonal reasons and is not just embodied in sentiment. Second, it is crucial to focus on the design of the infra-ethical infrastructure, “which has to be resilient enough to be able to account for the raising of new moral values as well as for the conceptual and practical changes brought about by the information revolution” (Taddeo, 2016, p. 9).

4.2. Terminological Uncertainty

The description of the different phases of the data altruism mechanism according to the DGA, illustrates the relevance of the concept of ‘general interest’. However, the DGA doesn’t provide a definition of the concept but proposes a non-exhaustive list of purposes included in the general interest. In the phrasing of Recital 45, these objectives “would include healthcare, combating climate change, improving mobility, facilitating the development, production and dissemination of official statistics, improving the provision of public services, or public policy making. Support to scientific research should also be considered to be an objective of general interest”.

In particular, Recital 16 states that “[I]n order to facilitate and encourage the use of data held by public sector bodies for the purposes of scientific research, public sector bodies are encouraged to develop a harmonised approach and harmonised processes to make that data easily accessible for the purposes of scientific research in the public interest”. The ‘public interest’ diverges from the concept of ‘general interest’ and may trigger a considerable debate if conceived according to the GDPR. Among several stances about the interpretation of the concept of public interest, the European lawmakers seem to adopt a practical approach and “under the GDPR public interest can be described as an object worth safeguarding for the needs or interests of the Member States or the EU for the purposes of which a number of specific measures could be taken, including the rights of a data subject could be constrained” (Slokenberga, 2021, p. 23).

On top of that, the memorandum of the DGA proposal also mentions the concept of ‘common good’, defining data altruism as “data voluntarily made available by individuals or companies for the common good”. Referring to ‘general interest’, ‘public interest’ and ‘common good’ generates uncertainty, impacting on the moral problems of these forms of data sharing (Taddeo, 2016). This becomes even more apparent considering that “[M]ost conceptions of the common good define a form of practical reasoning that fits the model of solidarity” (Hussain, 2018), attributing to altruism and data altruism the nature of a morally good action, in contrast to the infra-ethical nature of the phenomenon.

This terminological uncertainty makes the mechanism very flexible. The risk, however, is that this uncertainty encourages the moral ambiguity of data altruism. Once again, therefore, the intervention of the Member States, with their discretionary powers, represents a key factor in the implementation of the data altruism mechanism.

4.3. Autonomy and Consent

Voluntary data sharing under the data altruism mechanism is based on two forms: Permission for non-personal data and consent for personal data. Permission under Article 2(6) of the DGA “means giving data users the right to the processing of non-personal data”. Whereas, as specified by Recital 50 of the DGA, consent should be understood in accordance with the provisions of the GDPR, and therefore shall be free, specific, informed, unambiguous, freely revocable and, in addition, obtained in a manner that is clear and understandable to the data subject.

Article 6 of the GDPR provides for a set of mandatory legal bases for the processing of personal data: Consent thus becomes one of the possible legal bases. The reason for this choice made by the European lawmakers in 2016 was to replace a consent-based approach that had proved to be ineffective (Solove 2012; Schermer *et al.* 2014).

In order to allow the joint acquisition of personal data through consent and of non-personal data through permission, Article 25 of the DGA introduces a “European data altruism consent form”, that will be adopted by an implementing act of the European Commission. This model “shall allow the collection of consent or permission across Member States in a uniform format” (Article 25(1) of the DGA).

The DGA emphasises the purpose of “building trust among individuals and undertakings in relation to data access, control, sharing, use and re-use” (Recital 5 of the DGA). Given this goal, two considerations stand out, one regarding the autonomy of those who share data, and the other concerning the effectiveness of the unique consent model for data altruism.

As regards matters of autonomy, the strengthening of a trusted environment demands that those who voluntarily share their data, be they natural or legal persons, are involved in the mechanism as “real interlocutors” (Durante, 2015, p. 16; Smichowski, Duch-Brown & Martens, 2021, p. 48). Making these actors capable, to some extent, of shaping the system or at least of actively participating in it is in line with the objective stated in Recital 5 of the DGA mentioned above. This inclusion is by no means easy to achieve through the provision of a unique consensus model. And this leads to the second issue. One of the factors underlying the transition from the previous Directive 95/46/EC¹⁵, based on the “notice and consent” mechanism (Sloan & Warner, 2014), to the GDPR, was the idea to overcome a model of personal data management represented by pointless check lists of activities to be implemented. Developing a European model for the uniform management of data altruism may facilitate the harmonisation of the operation and yet, raise the risk of returning to the previous approach that was intended to be overcome with the GDPR.

Admittedly, as Recital 52 of the DGA points out, such a European model should adopt “a modular approach allowing customisation for specific sectors and for different purposes”. Several scholars have stressed the benefits of this modular approach (Pagallo *et al.*, 2019). However, it would be crucial, in national implementation, to envisage further forms of interaction between data subjects, data holders, and data altruism organisations (some examples are given in Smichowski, Duch-Brown & Martens, 2021, p. 49).

5. CONCLUSIONS

Luciano Floridi, in his analysis on distributed morality in the information society, argues that a longstanding discussion exists regarding “incentives and disincentives, which represent the political and legislative side of the ethical discourse”, although much work still needs to be done to develop “technological mechanisms that work as «moral enablers»” (Floridi, 2020, p. 72) for harnessing the power of distributed morality. The mechanism of data altruism introduced by the DGA, and the data pools generated as a result, may be fruitful, if further properly implemented at the national level by the Member States.

¹⁵ Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data, ELI: <http://data.europa.eu/eli/dir/1995/46/oj>.

In order to do so, a number of conditions should be fulfilled: (i) coordination in application; (ii) security; (iii) practically feasible lifecycle data control mechanisms; (iv) agreement on the concept of altruism; (v) public interest; and, (vi) autonomy in granting consent. The risk of “misuse and moral hazard” (Floridi, 2020, p. 77) is still real. Data may be used by data users to pursue intentions that are not in line with the general interest identified by the European institutions or even to make malicious use of such data. However, the potential benefits, especially for the scientific research sector, are noteworthy. Given the set of challenges, both legal and ethical, and the manifold actors involved in the data altruism mechanism, it is worth focusing on the development of governance mechanisms able to encompass all the interests at stake.

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