



POLICY BRIEF

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18

DATA ALTRUISM

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The concept of data altruism in the Data Governance Act	
BACKGROUND AND FIELD OF APPLICATION	<p>The Data Governance Act (DGA)¹ establishes rules to promote secure and cross-sectoral data sharing across EU Member States, reinforcing the principle that data's value lies in its use and reuse.</p> <p>Complementing the Open Data Directive, the DGA creates data governance mechanisms for protected data held by public sector bodies, such as personal data, data under intellectual property rights, or commercially/statistically confidential data. When such data is made available for reuse, public entities must implement privacy-preserving and security-enhancing tools to ensure anonymity and confidentiality. Sector-specific authorities may support these efforts by providing technical instruments that safeguard data integrity and accessibility.</p> <p>The DGA also introduces data intermediaries, that are neutral entities that facilitate trusted data sharing between holders and users. These intermediaries must comply with strict processing rules and undergo a formal notification procedure with national authorities.</p> <p>Additionally, the DGA enables data altruism, allowing individuals to voluntarily share personal data (e.g., health data) for purposes of general interest.</p>
HIGHLIGHTS	<p>The DGA establishes multiple conditions and requirements for data altruism that can be summarized as follows:</p> <ul style="list-style-type: none"> • Permitted purposes of public interest are defined by national law and include: <ul style="list-style-type: none"> ○ Healthcare ○ Public service improvement ○ Policy-making ○ Scientific research ○ Other general interest objectives • Authorization mechanisms to data reuse for data altruism purposes are: <ul style="list-style-type: none"> ○ Personal data: sharing is authorized through the consent of the data subjects. ○ Non-personal data: sharing is authorized by the permission of the data holders. • Data altruism organizations may apply for inclusion in a public national register if they: <ul style="list-style-type: none"> ○ Operate on a non-profit basis

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) OJ L 152, 3.6.2022, pp. 1–44



	<ul style="list-style-type: none"> ○ Avoid commercial relationships between data subjects/holders and data users ○ Are legally established entities pursuing general interest purposes independently from other activities ● Data altruism organizations must adhere to a rulebook issued by the European Commission, which will define: <ul style="list-style-type: none"> ○ Information requirements ○ Technical and security standards ○ Interoperability criteria ● They are also subject to transparency requirements: <ul style="list-style-type: none"> ○ Maintain records of data access activities ○ Publish annual reports detailing: Objectives, outcomes of their activities and adopted privacy safeguards ● The DGA foresees some protections for data subjects including: <ul style="list-style-type: none"> ○ Clear disclosures on data usage ○ User-friendly consent tools ● A customizable data altruism consent form will be developed to facilitate voluntary data sharing across Member States and sectors.
IMPACT	<p>The positive impact of data altruism on research and society at large is exemplified by the Corona Data Donation project (<i>Corona-Datenspende</i>)² which enabled individuals to voluntarily share personal data for public benefit even before the DGA came into force. Launched during the early stages of the COVID-19 pandemic, German researchers developed a mobile app to collect data from wearable devices (such as resting heart rate, step count, and sleep patterns) to establish a baseline for detecting fever-like symptoms. For example, a drop in physical activity combined with an elevated pulse could signal possible infection. Over 500,000 users downloaded the app, with more than 1,000 continuing its use for 2.5 years until its discontinuation.</p> <p>The voluntarily shared data was transformed into actionable insights, including real-time virus spread patterns, population health trends, and evaluations of self-testing and vaccination efficacy. Users also contributed qualitative data via surveys, enriching the dataset with behavioral and social dimensions. This information supported biomedical research, evidence-based policymaking, and improvements in public healthcare services, such as resource allocation during emergencies.</p>

² Robert Koch Institute & Research on Complex Systems of Humboldt University of Berlin, Corona Data Donation Project, available at: <https://corona-datenspende.github.io/en/>



	At date, only a few organizations are listed in the public register ³ but they will likely become more numerous, even though the incentives that they have to operate on a not for-profit base are still unclear.
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³ <https://digital-strategy.ec.europa.eu/en/policies/data-altruism-organisations>