



Discussion Paper # 1

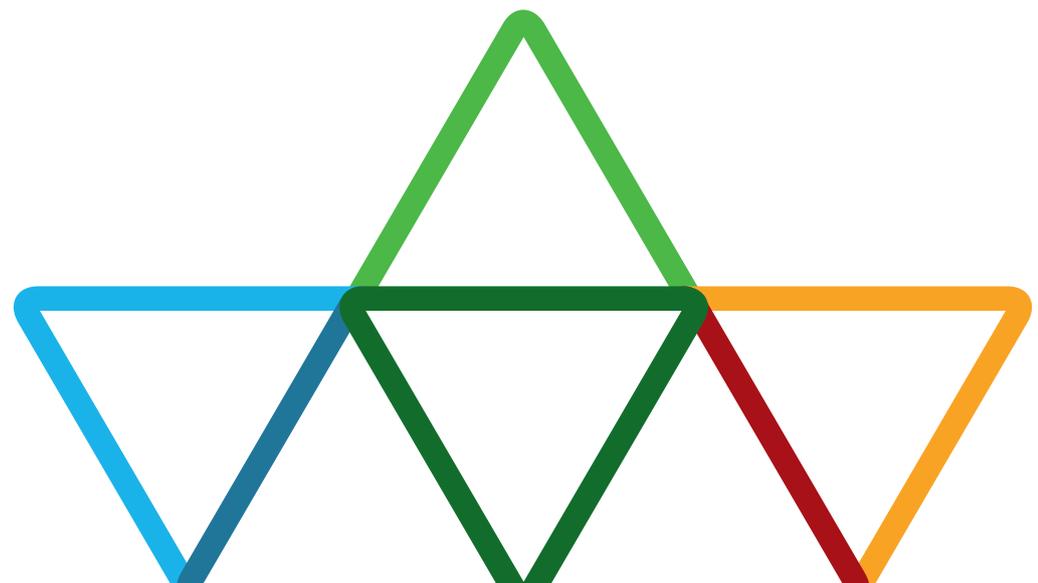
**Data altruism:**  
how the EU is screwing up  
a good idea

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## CONTENTS

<b>I. WHAT IS DATA ALTRUISM?</b> .....	<b>3</b>
<b>II. WHAT THE EU COULD HAVE DONE</b> .....	<b>4</b>
<b>III. WHAT THE EU DOES INSTEAD</b> .....	<b>5</b>
<b>IV. ANALYSIS: THE DGA'S ROCKY RELATIONSHIP TO THE GDPR ...</b>	<b>6</b>
<b>V. COLLATERAL DAMAGE</b> .....	<b>7</b>
<b>VI. CONCLUSION</b> .....	<b>7</b>

In November 2021 the European Parliament and the Council reached an agreement on a new regulation.

The Data Governance Act (DGA), among other things, contains a set of rules which intend to promote "data altruism" across the EU. The central idea of data altruism is that citizens (or companies) voluntarily provide data for the purposes of the public good.<sup>1</sup>

That data should be used for the common good is indeed a worthy ideal, but the DGA lacks the effective means of achieving it. Instead, additional registration requirements, special forms, new authorities and registers, more information and record-keeping obligations, and annual activity reports promise to deflate people's enthusiasm for altruism.

The trilogue agreement now reached on the EU Commission's November 2020 proposal is unlikely to change. The DGA will thus go down in history as a missed opportunity.

## I. WHAT IS DATA ALTRUISM?

Just as big data, pattern recognition, and machine learning often require large and diverse amounts of data, ideas on how to regulate data are manifold: these range from data ownership to data taxes, open data, data sharing obligations, data trustees, and data portability.<sup>2</sup>

<sup>1</sup> This is defined in greater nuance in Art. 2 No. 10 DGA: "data altruism" means voluntary sharing of data based on 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 or receiving a reward that goes beyond a compensation related to the costs they incur making their data available, for purposes of general interest, defined in accordance with national law where applicable, such as healthcare, combating climate change, improving mobility, facilitating the establishment of official statistics, improving public services, public policy making or scientific research purposes or improving public services in the general interest."

<sup>2</sup> The German Social Democratic Party (SPD), with the support of Justus Haucap and Viktor Mayer-Schönberger, has also previously considered the proposal of a "Daten-für-Alle-Gesetz" (= Data For All Act).

Animating the debates on data regulation is the question of how to best organize data access for the common good, rather than simply allowing data power to concentrate in the hands of a few large companies. One idea that emerges in this context is for people to voluntarily provide data for public good purposes — a practice which the EU is now trying to promote under the heading of "data altruism."

There are already examples of data altruism in practice. This includes projects such as:

**decode**: A project in which citizens of Barcelona collected data on noise, air pollution, temperature, and humidity through environmental sensors placed inside and outside their homes. These data were then made available to the general public by way of so-called "data commons." The final report, which is well worth reading, can be found [here](#).

**OpenSCHUFA**: This project by Algorithmwatch and the Open Knowledge Foundation examined the SCHUFA, Germany's largest credit enquiry agency. More than 4,000 people donated their SCHUFA self-disclosures in order to enable a check of the score determined by SCHUFA through reverse engineering.

**Corona data donation app**: This app of the Robert Koch Institute (RKI) was downloaded by 530,000 persons in Germany (as of 30.09.2021). Participants linked their fitness wristband or smartwatch and gave their consent to scientific data analysis. Measured values such as sleep patterns, heart rate, and number of steps were then transmitted to the RKI, helping scientists to better understand the spread of the coronavirus.

These examples of data donation are in a legal grey area. It is not at all clear whether and under what conditions they are permissible. Moreover, the legal requirements of the GDPR are very challenging. For both altruistic organisations and altruistic donors, these requirements can be daunting.

It is therefore useful and desirable to think about mechanisms that would promote altruism, and it is commendable that the EU has taken up the idea of data altruism. However, the chosen path of adding additional requirements via the DGA does not really promote altruism.

## II. WHAT THE EU COULD HAVE DONE

If the EU had truly wanted to facilitate processing of personal data for altruistic purposes, it could have lifted the requirements of the GDPR, which are almost impossible for many controllers to meet. Possible alternative courses of action include the following:

- **Altruism Exemption:**

With a bold stroke of the pen, the EU could have excluded the processing of personal data for altruistic purposes from the scope of the GDPR. Similar to the “household exemption” (Art. 2 (2) (c) GDPR), it could have created an “altruism exemption”, a “common good exemption”, an “NGO exemption”, or an “exemption for non-profit purposes”. This would have been a liberating move and brought the longed-for “boost”.

- **Altruism Privileges**

The EU could have – somewhat less ambitiously – favoured altruistic controllers in the balancing of interest that must be done under Art. 6 (1) (f) GDPR. According to this provision, processing of personal data is lawful if it “is necessary for 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. The EU could have given controllers a “balancing advantage” when weighing interests.

- **Further Processing**

The EU could have otherwise privileged further processing for altruistic purposes as in the case of research purposes (Art. 5 (1) (b) GDPR). The EU could have clarified the highly controversial question, which is particularly relevant to data altruism, of whether a compatibility check is sufficient in the case of further processing for a change of purpose (Art. 6 (4) GDPR) or whether there must be an additional legal ground.

- **Publicly Available Data**

The EU could have at least privileged the processing of publicly available personal data, a provision which was “forgotten” in the GDPR and now leads to unsolvable problems.

- **Accompanying Obligations**

The EU could also have provided for procedural facilitations for processing for altruistic purposes – for example, that certain information, documentation and accountability obligations be waived in the case of processing for altruistic purposes.

- **Altruistic Controller**

The EU could have created a new category of controller – the “altruistic controller” – with rights and obligations under data protection law that take into account the public benefit-oriented processing purpose.

- **Data Donation**

The EU could have – as proposed by the German Ethics Council – created a legal ground for data donations, the permissibility of which is disputed among data protection experts. It could at least have provided some legal certainty by defining “data donation”. A possible definition could be:

*“Data donation is the permanent provision of data for context-specific information-gathering processing, without any direct incentive in return and without the donating party necessarily having any influence on the concrete use in the individual case.”*

- **Consent:**

The EU could have specified the conditions for consent to data processing for altruistic purposes. But even that is now left to an implementing act to be adopted later (Art. 22 DGA).

- **Common good:**

The EU could have made the concept of the “common good” concrete. The DGA draft does not go beyond the formulation that data processing for altruistic purposes pursues objectives of “general interest [...] such as health-care, combating climate change, improving mobility, facilitating the establishment of official statistics, improving public services, public policy making or scientific research purposes or improving public services”.

To recap: Of all of the possible courses of action outlined above, the EU is pursuing none of them – and, one must unfortunately add, this was to be expected.

Why? Because the GDPR is apparently the untouchable gold standard for the EU – improvement excluded!

### III. WHAT THE EU DOES INSTEAD

Instead of reforms that would actually facilitate data altruism, the EU is doing what it seems to do best in relation to data: Establishing new procedures, demanding the creation of authorities, organising responsibilities, and coming up with application and review deadlines. These are as follows:

- **Registers**

Member States (Art. 20 (1) DGA) and the EU (Art. 15 (3) DGA) must each establish a “register of recognised data altruistic organisations”.

- **Seal of approval**

Controllers listed in this register may call themselves a “data altruism organisation recognised in the Union” (Art. 15 (3) DGA).

- **Requirements**

This requires that the data altruism organisation be a legal entity, has been established to meet objectives of general interest, operates on a not-for-profit basis, and performs its activities through a legally independent structure (Art. 16 DGA).

- **Registration obligations**

The registration application of the data altruism organisation must contain numerous details, some of which will be published in the register (Art. 17 DGA).

- **Record-keeping obligations**

The data altruism organisation must keep complete and accurate records of all persons, given the possibility of processing, the times and purposes of the data processing, and any fees charged for the data processing (Art. 18 (1) DGA).

- **Activity report**

The data altruism organisation must prepare an annual activity report with information on its activities, on the persons that were allowed to use data, on the general interest purposes pursued, on the technical means, on the results and on its sources of revenue and expenditure (Art. 18 (2) DGA).

- **Information obligations**

The data altruism organisation has additional information obligations towards the data subjects (Art. 19 DGA).

- **Rulebook**

The EU Commission shall adopt a rulebook that will lay down additional information requirements, security measures, communication roadmaps and interoperability standards (Art. 19a DGA).

#### IV. ANALYSIS: THE DGA'S ROCKY RELATIONSHIP TO THE GDPR

As summarised in the previous section, the DGA provides a mechanism for organisations to register as 'Data Altruism Organisations recognized in the EU' in order to (in principle) increase public trust in their operations. It is worth clarifying that this registration is *voluntary*, as the EU Commission recognized that a compulsory regime would pose too high an administrative burden for some organisations. Despite the Commission's intention of increasing trust and easing administrative burden, however, the analysis shows how all of this may have unintended negative consequences for data altruism in practice:

- **GDPR unaffected**

The draft regulation explicitly clarifies that the requirements relating to the processing of personal data remain unaffected (Art. 1 (2) DGA):

*“Union and national law on the protection of personal data shall apply to any personal data processed in connection with this Regulation. In particular, this Regulation shall be without prejudice to Regulation (EU) 2016/679, Regulation (EU) 2018/1725 and Directive 2002/58/EC, including the powers and competences of supervisory authorities. In the event of conflict between the provisions of this Regulation and Union or national*

*law on the protection of personal data adopted in accordance with Union law, Union or national law should prevail. This Regulation does not create a legal basis for the processing of personal data and does not alter any obligations and rights set out in Regulation (EU) 2016/679 or Directive 2002/58/EC.”*

The GDPR therefore also applies in full to data altruistic organisations.

► Therefore, an organisation that wants to process personal data for altruistic purposes must – in addition to the newly added obligations – also comply with all the obligations of the GDPR (by my count, there are 68 obligations in the GDPR alone).

- **Where is the incentive?**

One wonders why an organisation should go to the trouble of being recognised as a data altruism organisation on top of the already enormous compliance burden of the GDPR. The application for registration, the additional record-keeping obligations, the annual activity report, the additional obligations to inform the data subjects and the upcoming rulebook would cause a considerable compliance effort. To make matters worse, the altruistic organisation itself must not pursue a profit-making purpose.

► Thus, in addition to the additional effort, the organisation would not be allowed to “earn money” with the knowledge gained from its data processing, which would not necessarily be ruled out under the GDPR.

- **What about Public Trust?**

In principle, the costs of this additional compliance burden wrought by the DGA would be offset by the higher trustworthiness organisations

gain in the eyes of the public once they are formally certified as data altruism organisations. However, it seems questionable whether such a seal of approval would actually help people already sensitive to data protection overcome their scepticism about donating data.

Moreover, people who are “altruistic” enough to want to make “their” data available to a good cause should usually not need any further incentive. If the “gold standard GDPR” does not create enough trust in the processing of personal data, why should recognition as a data altruistic organisation?

#### ■ **Administrative Confusion**

Another highly problematic issue is the dual authority structure that would be created by the DGA. Compliance with data protection requirements would continue to be monitored by the respective competent data protection supervisory authorities. Compliance with the requirements of the DGA would be controlled by other authorities, which would have to be created for this purpose. A confusion of competences between data protection and DGA authorities would be pre-programmed in this arrangement. The DGA just says that the authorities have to “cooperate” (Art. 20 (3) DGA).

## V. COLLATERAL DAMAGE

The Data Governance Act is not only annoyingly bureaucratic, but first and foremost a missed opportunity to breathe life into the “Data for Good” idea.

#### ■ **Reflex Effect on GDPR**

Even worse, however, is that an even more restrictive interpretation of the GDPR is threatened via the diversions of the DGA. According to the GDPR, data processing for altruistic purposes is, of course, permissible in principle.

Since the purpose of the processing has to be taken into account in the balancing of interests test (Art. 6 (1) (f) GDPR), processing for altruistic purposes is often likely to exceed the permissibility threshold.

#### ■ **Shift in Best Practice**

Once the mechanism of the DGA are established, however, a “best practice” is likely to develop, according to which data processing for altruistic purposes would only be considered worthy of recognition under the Data Governance Act.

#### ■ **Mere GDPR compliance as a disadvantage**

Controllers who do not want to register as a “data altruism organisation” could also come under pressure. Non-registered data altruism organisations may be suspected of being less trustworthy, even though they are compliant with the “gold standard GDPR”.

► NGOs, foundations, ad hoc initiatives and other controllers would even be disadvantaged compared to non-altruistic controllers, because they would in fact be required to register additionally.

## VI. CONCLUSION

The EU dreams of a “common European data space”. Data protection is and remains the elephant in this data room. So long as the anti-processing straitjacket of the GDPR is not loosened even a little for altruistic purposes, there will be little hope for data innovations from Europe. In any case, the EU’s bureaucratic ideas threaten to stifle any altruism.

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