

# Data Trustees and Data Donation

Position by Wikimedia's Free Knowledge Advocacy Group

The European Strategy for data is today, along with the European Green Deal, a key policy field for the economic and social future of the EU. We have moved beyond the point where information technology plays a niche part of our daily lives and our businesses. Instead, most social activities now are based at least partially on data technology. Having access to information and being able to reuse it is a fundamental prerequisite for education, business, democratic activity and research nowadays.

## **Can citizens make data available for the public good?**

As part of the conversation how more data can be made available for use for the public good the global discourse in general and the European Commission's consultation on a "European Strategy for Data" in particular pose the question whether it is easy enough for citizens to give access or "donate" their (personal) data for the public good. **So are there sufficient tools and mechanisms to do so legally?**

## **Three real world examples**

The German **Robert Koch Institut** asked citizens to share data from activity trackers with the scientists in order to better research correlations between sleep, pulse, heart rate and COVID-19. As of 14.04.2020 more than 300.000 citizens had done so over a dedicated application or website (<https://www.corona-datenspende.de/>).

The citizen science project **Quantfied Flu** (<https://quantifiedflu.org/>) by the non-profit Open Humans Foundation asks citizens to share data from activity trackers during the days they were sick and report symptoms. The goal is to research whether wearables warn us when we're getting sick.

The cooperative project **Midata** (<https://www.midata.coop/en/home/>) serves as data trustee for health data. It's a nonprofit, with a cooperative governance structure, based on the Swiss legal framework. But they help set up similar structures in other countries and they were founded by well respected researchers.

## **Can users share their data for the public good?**

The three examples above go to demonstrate that citizens sharing their data for the public good (in these cases health research) is **already being a practice in the real world**. Data is being "donated" to public health institutes, non-for-profits and collaboratives across industries, bolstering efforts to create innovative public services.

## **Are such data "donations" legal?**

It might be an open question whether or not such practices are completely covered by EU law. We would appreciate a legal assessment by the European Commission and the European Data Protection Board (EDPB). Legislative action might be necessary depending on the results of such a study. Wikimedia would be willing to collaborate on this.

## **What do we want to achieve?**

Apart from the legality of such data sharing practices, we also need to answer the question what social change we would like to achieve by “data donations for the public good”?

At the strategic level, we propose to pursue three main goals:

### **1) Recognise the importance of the public sphere in pursuing public good goals**

Extraction of data for economic value might be important to business, but exclusivity it is not always the most sustainable and efficient way to pursue overarching public good goals. The tendencies toward monopolisation and data silos that parts of the information technology economy have demonstrated over the past decade must serve as a warning light. We believe Europe and the world would benefit from places (protocols, portals, platforms, institutions, organisations) that handle sharing and reuse of data and whose operational logic follows wider social, rather than solely economic goals.

### **2) Data governance should increase user trust**

As the examples above demonstrate, citizens seem willing to play a part in pursuing public good goals by sharing their data. For this model to be scalable and sustainable, however, we must ensure that trust in the projects handling the data does not erode. We are open to what the best public policy tool is to achieve such lasting user trust. It might include voluntary labels, guidelines that spell out concrete practices or hard legislation defining who, how and when can process citizen data for the public good (much like charities must fulfill certain criteria in order to receive and keep their legal status).

### **3) Respect privacy**

The EU is the global leader in privacy legislation and despite initial reluctance we see many aspects of the GDPR being followed by businesses and legislators worldwide. Both for this and for the fact that privacy is directly related to user trust we need to ensure that any data governance models we come up with are fully compatible with the highest data protection standards Europe has to offer.

### **4) Improve data portability**

Data donations rely to a large extent on the possibility to move citizen data from data silos to the new trusted spaces and institutions. GDPR grants this rights, but so far the technical infrastructure has been lacking. If supported by adequate education, understanding of GDPR rights and easy-to-use tools, data portability will strengthen the donations considerably. We think that these improvements are crucial for trust to emerge.

## **Potential criteria for a data trustees**

Based on the above, we have attempted to gather a list a of criteria:

- Data handling must be as standardised as possible, using open formats
- Reuse of data should be possible using open data standards
- Fully transparent organisations

- Privacy and user choice -> the data donor should know exactly what their data is being used for at each point

### **No new IP rights on data**

We would like to emphasize that any new copyright or new sui generis rights on data or databases would be extremely undesirable and contrary to the public good goals we would like to achieve.

### **Contact:**

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