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The German corona-data-donation-app as an example of the concept of data donation

BY [DANIELA SPAJČ](#) - 20 APRIL 2021

The concept of data donation receives gradually more attention as an instrument to endorse scientific research. Especially during the times of COVID-19, the need for the collection and exchange of patients' and citizens' health data is rapidly increasing. This blog post seeks to outline some important considerations accompanying the discussion on data donation. The German "corona-data-donation-app" will serve as an example to illustrate some of the concerns related to the concept of data donation.

A brief introduction

In April 2020, Germany's public health authority, the Robert-Koch-Institute, started the project on the "corona-data-donation-app" ("Corona-Datenspende-App") which aims at helping the combat against the COVID-19 pandemic. As the name of the app suggests, citizens have been asked to voluntarily "donate" their data collected through the "corona-data-donation-app". The citizens' data concerning the individual's health is retrieved from a fitness wristband or smartwatch. The app enables "data donors" to transfer this data pseudonymously without having to provide the name, while allowing researchers to allocate the data to an individual user. Pseudonymisation is a technique that de-identifies data in a manner that the personal data cannot be attributed to an individual without the use of an additional information (see Article 4(5) General Data Protection Regulation (GDPR)). Researchers evaluate the data provided by the individuals to recognize potential COVID-19 symptoms, using it in order to identify epidemiological developments with regard to the spread of the pandemic for the purpose of public health. This is ought to be achieved, inter alia, through the creation of a map which indicates the amount of people with fever within a certain region (the concrete steps may be found here). At the time of writing, more than 537.000 people have donated

over 195.000.000 data since the beginning of the project, amongst other things, about their gender, age, body temperature, pulse, and footsteps.

Data donation – what’s in the name?

Data donation is a concept which aims at enhancing scientific research

by providing citizens with the opportunity to offer data concerning their health to researchers. The donation of personal data, in general, encompasses the transfer of personal data or data concerning one’s own health from an individual to another party. The transmission of such data constitutes a data processing activity which falls under the scope of the GDPR (see Article 4(1) and (2) GDPR). This regulation grants EU citizens protection regarding the processing of their personal data and data concerning health, also in a pseudonymised form as pseudonymised data is still personal data (see Article 4(5), recital 26 GDPR). Although the term “donation” may be associated with the indefinite transfer of (ownership) rights potentially indicating that the data can be used for any purpose, once it has left the sphere of the individual, data donors do not automatically lose protection over their personal data. The term data donation, thus, creates ambiguity and has been criticised for standing in opposition to the GDPR, as the regulation does not introduce such a concept. From the regulation’s perspective, it seems rather appropriate to refer to the transmission of personal data or data concerning health between different stakeholders as a data processing activity instead of data donation.

Legal drawbacks associated with the data-donation-app

Despite its well-intended purpose to serve scientific research, Germany’s Federal Commissioner for Data Protection and Freedom of Information has expressed his concern about the misleading terminology of the “corona-data-donation-app”. A topic of debate surrounding the concept “data donation” is inter alia the decrease in data protection standards (FlfF, p. 17). For instance, some fear that the relatively new concept could be misinterpreted and would shift away from data protection principles, such as the principle of data minimisation which requires that the collection of personal data should be limited to the minimum amount that is necessary for the purpose it has been collected (see Article 5(1)(c) GDPR) (FlfF, p. 17).

The German Commissioner clarified in his statement that data protection standards need to be upheld. This includes, inter alia, that individuals must be adequately informed about what kind of data is being collected through the app, and that citizens do not revoke their rights after having donated their data. The Robert-Koch Institute has to regularly assess the processing activities in terms of lawfulness and fulfilment of the purpose of data processing. These points shall support compliance regarding the purpose limitation principle, the right to withdraw consent, and the data subject's rights as laid down in the GDPR. However, challenges may occur regarding the involvement of fitness tracker manufacturers, who are private companies. To this end, the Commissioner pointed out that the level of data protection might deviate between the various fitness-trackers and smartwatches used by citizens, as these commercial devices constitute a point of intersection for transmitting data through the corona-data-donation-app.

Besides, the corona-data-donation-app has been criticized for supporting primarily the transfer of pseudonymous data and not the transfer of data in an anonymised form. Anonymised data does not enable any conclusions to be drawn on the identity of a person, whereas pseudonymised data could still be attributed to an individual through the use of additional information. Although the app does not request the user's name and address, it might still be possible to identify citizens if the data should be publicly available through a data breach. Also, this choice may have a negative impact on individuals in the future, for instance, in terms of potential discrimination and public health surveillance.

Conclusion

Data donation is an interesting concept for citizens who would like to support scientific research with their personal data, but the concept still needs further exploration. This concept is not embedded in the law yet, which raises challenges with regard to its interpretation and potential legal implications. Also, potential drawbacks putting individuals at risk call for an particular awareness and responsibility of researchers with regard to the secure and confidential handling of health data.

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This article gives the views of the author(s), and does not represent the position of CiTiP, nor of the University of Leuven.

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