

Professor Dr. Katja Becker
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By e-mail only

Dear Dr. Becker

I refer to your letter dated 7 May 2020 regarding the impacts of the GDPR on Research. Thank you very much for sharing the views of the Deutsche Forschungsgemeinschaft on this important topic. We appreciate your efforts and willingness to contribute on this very relevant subject.

First of all, I would like to emphasize that the GDPR does not stand in the way of scientific research and development. On the contrary, the GDPR provides for several provisions that allow for the processing of personal data for the purpose of scientific research, while at the same time ensuring that the fundamental rights of data subjects are respected. This being said, the EDPB is well aware of the importance of scientific research and the need to have clear guidance. In this respect, the EDPB is currently working on guidelines on the processing of personal data for the purpose of scientific research.

With regard to your concerns on the anonymization of personal data for the purpose of scientific research, the EDPB underlines that, where the research requires the processing of personal data and it complies with the relevant provisions of the GDPR, it can be possible to process personal data without resorting to anonymization. If anonymization is performed, the EDPB recalls that anonymization refers to “the use of a set of techniques in order to remove the ability to link the data with an identified or identifiable natural person against any “reasonable” effort.”¹ In order to perform a “reasonability test”, the objective aspects (e.g. time and technical means) and contextual elements (e.g. nature and volume of the data) must be taken into account.² If personal data can be re-identified using a reasonable effort, the data cannot be considered as anonymous in the meaning of the GDPR and, therefore, it would fall within the scope of the GDPR. Considering this, anonymization of radiological data or image/film material, as mentioned in your letter, would generally require more than just the deletion of the name or address of the data subjects. With regard to genome data, the EDPB has previously stressed the impossibility of definitively de-identifying biological samples.³ When genome data is derived from such samples, it is therefore highly doubtful that anonymisation of this data is achievable.

¹ Guidelines 4/2020, par. 15.

² Guidelines 4/2020, par. 15.

³ See [EDPB letter to the Presidency of the Council of the EU on WADA](#)

Indeed, in the Guidelines 3/2020 on the processing of data concerning health for the purpose of scientific research in the context of the COVID-19 outbreak, the EDPB stated that, in accordance with the data minimisation principle, “data has to be anonymised where it is possible to perform the scientific research with anonymised data”.⁴ Conversely, where the research *requires* the processing of personal data, it is possible, provided the provisions of GDPR are complied with. In this regard, the Board acknowledged that other up-to-date measures may also ensure a sufficient level of security of the personal data, such as, inter alia, pseudonymisation, encryption or non-disclosure agreements.⁵ Thus, in some instances, other measures than anonymization may be more appropriate, taking into account the circumstances of the processing operation. In any case, the decision on the measures adopted has to be taken on a case-by-case basis and the controller is tasked with the examination of their effectiveness and appropriateness to protect the rights and freedoms of the data subjects.

Furthermore, the EDPB would like to underline that the processing of personal data for the purpose of achieving anonymization falls within the scope of the GDPR and, therefore, needs to comply with it, including the existence of a legal basis and the respect for the data protection principles. As anonymisation is frequently connected to processing on a large scale (of the datasets to be anonymised) and the use of new technologies, it will trigger the criteria for conducting a data protection impact assessment under Article 35 GDPR in many cases. Therefore, also in this context, the controller also has to take into account the consequences of a possible re-identification.

With regard to the processing of personal data for research purposes, a data protection impact assessment pursuant to Article 35 (1) GDPR must be carried out when the processing is “likely to result in a high risk to the rights and freedoms of natural persons”. The lists pursuant to Article 35 (4) and (5) GDPR shall be taken into account. The EDPB endorsed the A29 WP’s Guidelines on Data Protection Impact Assessment⁶, which address, inter alia, the processing of sensitive data or data of a highly personal nature like health data or genetic data. Besides, the EDPB also adopted several Opinions on the draft lists submitted by the supervisory authorities regarding the processing operations subject to the requirement of a data protection impact assessment.⁷

Finally, with regard to codes of conduct, the EDPB is of the opinion that they can be a useful and effective accountability tool, which provide a detailed description of what is the most appropriate, legal and ethical set of behaviours of a sector. As stated in the Guidelines 1/2019,⁸ “codes represent an opportunity to establish a set of rules which contribute to the proper application of the GDPR in a practical, transparent and potentially cost effective manner that takes on board the nuances for a

⁴ Guidelines 3/2020, par. 46.

⁵ Guidelines 3/2020, par. 51.

⁶ Available at: https://ec.europa.eu/newsroom/article29/item-detail.cfm?item_id=611236

⁷ The lists adopted by the supervisory authorities are available at: https://edpb.europa.eu/our-work-tools/consistency-findings/register-for-decisions_en; for research performed by public bodies of the Federation in Germany, see:

https://www.bfdi.bund.de/SharedDocs/Downloads/DE/Datenschutz/Liste_VerarbeitungsvorgaengeArt35.html?sessionid=0B8F983AD3FDC113ED927DCB16CB1D97.1_cid329?nn=9937868

⁸ See Guidelines 1/2019 on Codes of Conduct and Monitoring Bodies under Regulation 2016/679

particular sector and/or its processing activities.”⁹ The EDPB encourages the work on codes of conduct and welcomes the development of a specific code for the scientific research sector.

Yours sincerely,



Andrea Jelinek

Chair of the EDPB

⁹ Guidelines 1/2019, par. 11.