

Telephone Conference: CoC Drafting Group

24 August 2017

09:00 – 10:30

Summary Report

Researchers, are in some instances, eager to anonymize data as a way of avoiding data protection requirements, thereby posing the question of whether the application of the GDPR represented a significant hurdle for data sharing. The aim is to find a balance between fostering research and data sharing on the one hand, and protect research participants and patients on the other. Concerns being expressed from researchers however stem from the need for legal expertise in order to identify restrictions, and to establish adequate measures. This is one of the primary reasons for the Code of Conduct, namely to clarify limitations for researchers under the GDPR and communicate them in a non-legalistic and accessible manner.

Broad consent for secondary use of data could be one approach taken by Member States to facilitate compliance with regards to data sharing, as well as in consent forms for clinical trials. This is increasingly accepted by data protection authorities provided that sound governance with regards to access and use of data is guaranteed, which would therefore also require ethics committee approvals (also see Rec. 33 GDPR). Anonymization is another approach in certain contexts.

Relative anonymity was discussed, namely whether pseudonymized data could be considered as anonymized when in the hands of researchers who have no access to the key. Whilst a ECJ ruling regarding IP addresses deems this to be the case, having “no access needs to be understood in relatively strict terms. This would need to be addressed and require further elaboration with regards to research data in the Code of Conduct.

The possibility of using federated networks, namely whereby identifiable data is not transferred but only transferred once analysed and anonymized, was viewed as an interesting approach albeit not fully compatible within the working of the GDPR. This could however be one approach taken in dialogue with data protection authorities.

All the aforementioned issues are viewed as key for the Code of Conduct and would need to be discussed, with a position being taken in the Code. The next steps focus on anonymity and the organisation of a workshop with technical/statistics experts.
