

## **Data must be shared - also with researchers outside of Europe**

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Preventing disease and premature death from chronic diseases requires understanding of risk factors and their underlying mechanisms. This process is possible with appropriate analyses of individual level data. However, to be efficient, data from a large number of individuals are usually necessary. Adequate sample sizes can only be reached when researchers share individual level data with each other in large collaborative efforts. Within Europe, the [General Data Protection Regulation](#) (GDPR) opens up new possibilities to achieve this goal because legislation across the European Economic Area (EEA) has been harmonised.

Unfortunately, data sharing outside of the EEA remains difficult. Articles 45–49 in GDPR provide no straightforward solutions for sharing de-identified or pseudonymised data outside of the EEA. GDPR combined with non-compliant regulations in many countries create serious obstacles to wider sharing of data.

Future European studies can include informed consent with appropriate language that will make data sharing easier. However, for studies currently being analysed, data were often collected decades ago, without the required language in the consents on data sharing outside of the EEA. For older European studies with a large number of participants, reconsenting all living participants is not practical because of the costs and because one cannot find every cohort member decades later.

Anonymous data fall outside of GDPR, so why not simply anonymise? The reason is that the definition of anonymisation according to GDPR is very stringent. Thus, for epidemiological and so called big registry data linked to detailed cohort data, anonymisation is essentially impossible.

What do we need to solve this issue? We need the EU Commission and the governmental institutions in other countries, such as the USA, to put general agreements in place. They must agree on conditions that will protect the privacy of the individuals who participated, while acknowledging that some parties are not subject to European law.

What are the consequences of not solving this problem? Diseases such as cancer require global efforts. Less data sharing and less research will hurt everyone—Europeans, more than anyone. If data and samples from Europeans are no longer part of the large international efforts, we will not learn whether what holds true in non-EEA collaborations also applies to European populations.

We therefore ask the European Commission to find solutions, in collaboration with non-European entities, such that all parties can accept to facilitate important research. GDPR should enable and safeguard collaborative science, not prevent it.

We declare no competing interests. Where authors are identified as personnel of the International Agency for Research on Cancer or WHO, the authors alone are responsible for the views expressed in this Correspondence, and they do not necessarily represent the decisions, policy, or views of the International Agency for Research on Cancer and WHO.