

Open Letter

Data Protection and Medical Research: Striking the Right Balance

We are in an exciting time for medical research. Major progress in our understanding of the factors underpinning good health is leading us towards developing ever better, more targeted treatments for diseases from cancer to Alzheimer's. But this progress is facing a grave threat from legislation being considered by the European Parliament.

Personal data, such as our health records, provide a vital resource for research. Without access to this data, medical progress would be seriously impeded. It was essential for making the link between smoking and lung cancer, for example, and demonstrating that there is no link between the measles, mumps and rubella vaccination and autism.

The European Commission rightly set out within its proposed Data Protection Framework a mechanism for protecting privacy whilst enabling important health research to continue. However, amendments adopted by the Civil Liberties and Home Affairs committee of the European Parliament undermine this proposal and will make vital research at worst illegal and at best unworkable. The use of personal health data in research without specific consent would be prohibited or become impossible in practice, even though medical research is subject to ethical approval and strict confidentiality safeguards, and the identity of individuals is often masked.

This also poses a significant risk to millions of euros of investment in scientific infrastructure, including cancer registries, cohort studies and biobanks. These large studies involve millions of individuals across Europe who have given consent for their data to be used in health research.

We, the undersigned European research organisations, believe it is vital that regulation strikes an appropriate balance to protect the interests of individuals while enabling research that benefits all society. The European Union is at risk of getting this dangerously wrong, and the Council of Ministers and European Commission must take steps to ensure that this does not happen.

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