

Open letter re: amendments to EU Data Protection Regulation

Sir,

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.

Yours,

Professor Jeremy Farrar, Wellcome Trust
Sir John Savill, Medical Research Council
Professor Christian Brechot, Institut Pasteur
Professor Paul Boyle, Science Europe / Economic and Social Research Council
Professor Dermot Kelleher FMedSci, Federation of European Academies of Medicine (FEAM)
Professor Dr Jörg Hacker, German National Academy of Sciences Leopoldina
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Dr Edvard Beem, ZonMw
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Professor Mats Ulfendahl, Swedish Research Council
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Dr Harpal Kumar, Cancer Research UK
Professor Sir John Tooke PMedSci, UK Academy of Medical Sciences
Professor Peter Weissberg, British Heart Foundation
Sharmila Nebhrajani, Association of Medical Research Charities

Alastair Kent OBE, Patients' Network for Medical Research and Health (EGAN)
Professor Enric Banda, "la Caixa" Foundation
Dr Artur Santos Silva, Gulbenkian Foundation
Professor Mikael Rørth, Lundbeck Foundation
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Dr Barbara Ensoli, National AIDS Center, Istituto Superiore di Sanità, Italy
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Jackie Hunter, Biotechnology and Biological Sciences Research Council
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Professor Peter Gruss and Professor Herbert Jäckle, Max Planck Society
Prof. Peter Strohschneider and Prof. Leena Bruckner-Tuderman, Deutsche Forschungsgemeinschaft