



*Personal data is a vital resource for research, including studies in medicine, public health and social science. Over decades, researchers have developed approaches to use this data safely and securely to improve our understanding of society, health and disease. Reform of European data privacy laws is now threatening the way that data is used in research, and in this article Beth Thompson, Policy Adviser at the UK-based Wellcome Trust, London, UK, explains why we need your help now, to ensure a positive outcome for research.*

## **Preserving data privacy while enabling research**



### **A new petition fights the cause of scientists in allowing some exemption for research in the revised Data Protection Regulation**

The initial draft of the Data Protection Regulation proposed in 2012 by the European Commission set out a mechanism to protect privacy. At the same time, it was designed to enable health and scientific research to continue. However, following Edward Snowden's leaks about the use of personal data by the US National Security Agency, the European Parliament has sought to [strengthen protections for data](#) across all sectors. We know that in doing so the Parliament did not intend to harm progress in research. But research has become an unfortunate inadvertent victim of this reaction.

If adopted, the European Parliament's amendments would restrict the way personal data could be used in research. Of most concern, the amendments have all but removed a vital exemption from a requirement for specific consent for the use of personal health data in research.

Consent is an important principle in health research, but the exemption in the current law and Commission's proposal is really important because there are instances where the requirement to seek individual consent would undermine the study.

What's more, where individual consent is not sought, law and international guidelines require safeguards to be in place--such as review of the research proposal by an independent ethics committee--to ensure that personal data is used appropriately.

Parliament had good intentions. And we all agree that protecting individuals' data is crucial. But requiring specific consent in almost all cases would make much research involving personal data at worst illegal, and at best unworkable. In addition it does not recognise these important existing safeguards.

Organisations across Europe have come together with one voice to make sure these concerns are heard. The [European Data in Health Research Alliance](#) brings together academic, patient and research organisations. Alliance members are asking policy makers to find a solution that ensures that personal data can continue to make a vital contribution to health research without compromising the safety of precious personal data. To do so, we propose the inclusion of an exemption from consent supported by proportionate safeguards.

The position agreed by the EU Member States in June 2015 was much more positive for research than the European Parliament's text. However, we have reached a crucial point in negotiations. In November and December 2015, the European institutions will be working together to find a compromise position.

We need your help to make sure that the voice of research is heard among the noise of all the other issues that the Data Protection Regulation touches on. Please sign our [petition](#), and encourage your colleagues to join you, to show the EU institutions that you care about the outcome for research.

Beth Thompson

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