

EU Data Protection Regulation: Vital economic and social research could be prevented

Europe needs a consistent Data Protection framework that protects individual privacy and the European Commission's proposed Regulation provided this. However, the suggested amendments adopted earlier this year by the European Parliament would undermine important research using personal data. If the amendments are passed, there would be dire consequences for European research and the value it can bring to government, the economy and society at large.

Scientists across Europe are unleashing the power of personal datasets to address issues that affect almost every aspect of our lives. The use of personal data in medical research is well-known, but such data also underpin vitally important advances in many other areas of scientific discovery. For example, social science research has demonstrated the link between unemployment and health; linked smoking in pregnancy to child birth weight; and identified the long-term socio-economic benefits to children who are breastfed. Restricting the use of personal data for these and many other types of study would limit our ability to ensure European policy making is informed by the most robust evidence base.

The examples above are based on large population cohorts where participants have given broad consent for data about them to be linked from different sources. Researchers running these cohorts maintain contact with participants over years to build these data sets. The European Parliament's proposed amendments could make this ongoing contact difficult or impossible by excluding identifiable data from the research exemption, despite the fact that participants agreed to contribute their data, and that the research is conducted subject to ethical approval and strict confidentiality safeguards. In addition, research using socio-economic datasets that include health data is likely to be subject to even stricter controls due to other provisions Parliament have introduced for "data concerning health".

As robust, well-tested, protocols are in place, *bona fide* research using personal information should be allowed. Hence the undersigned oppose the European Parliament's amendments to both Articles 81 and 83 which would undermine research in a wide range of academic disciplines.

Yours,

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