

European medical research escapes stifling privacy laws

Proposed legislation had threatened the use of genomic and clinical data in medical studies.

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A threat to medical-research projects in Europe has been averted. European Union politicians and officials agreed on 15 December to exempt research from some of the strict provisions in planned data-protection legislation.

“This is very positive for us — the biggest threats are over,” says Michaela Mayrhofer, senior project manager at the Biobanking and Biomolecular Resources Research Infrastructure in Graz, Austria, which is building collections of billions of biological samples across Europe.

The legislation, first proposed three years ago, is mostly intended to protect people from having their digital information exploited for commercial or other purposes. At first, medical researchers viewed the proposed rules positively because they clarified procedures for sharing clinical and genomic data across EU member states.

But earlier this year, the European Parliament added amendments that would have [made it hard for scientists](#) to use such data efficiently and to link them to tissue samples.

Data unmasked

One amendment removed an exemption for researchers from a rule that all personal data remain anonymous in perpetuity. This would have created problems for scientists who need to unmask data to assess the progression of diseases and the long-term outcomes of treatments.

Another required researchers to obtain fresh consent from donors each time their data or tissues are used in a different study, something that medical scientists say is unworkable.

But the compromise agreement between the European Parliament, Council and Commission now permits medical researchers to unmask data in special circumstances and to re-use an individual's data and samples for multiple studies in different diseases, provided that person agrees to a general type of consent that covers all ethically and scientifically approved studies.

The agreement is expected to be rubber-stamped by the European Parliament's civil-liberties committee, and by EU member states, in the next few days.

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