

Implementing the General Data Protection Regulation [2016/679] to maintain a competitive environment for research in Europe

Position of research and patient organisations – September 2016

Personal data is a vital resource for research that can save and improve lives. The Data Protection Regulation provides a strong basis for the safe use of personal data in research. Member States now have a crucial role to play in implementation.

Member States should:

- **introduce clear laws for research** with safeguards and exemptions that support research while respecting people's privacy;
- **work across national ministries and with the research community** to ensure that laws and guidance are practical, proportionate to any risks, and build on current good practice; and
- **work together to promote harmonisation and compatibility between national systems where possible**, to facilitate cross-border research.

What is the Regulation, and why is it important for research?

- The Data Protection Regulation **updates the EU's data privacy law**. Once the Regulation takes effect in May 2018, the processing of personal data will have to comply with the rules it sets out.
- The Regulation **applies to any research that uses personal data, including scientific research and studies in the arts and humanities**. This may include public health research, studies on health outcomes, epidemiology, clinical trials, social sciences, politics and modern history. It does *not* apply to anonymous data, which does not identify specific individuals.

What do Member States need to do now?

- The Regulation includes **special rules for scientific research and academic freedom of expression** that provide exemptions from some general requirements. This recognises the contribution that research makes to improving health and quality of life in Europe, while respecting privacy.
- Some of the rules for research are included in the main text of the Regulation and will apply automatically in all Member States. However, **some rules are delegated to Member States and need to be implemented at a national level before they can apply**.
- It is **essential that Member States take action as soon as possible to review and amend their current laws to enable research to take place and provide legal clarity and certainty for researchers**, including:
 - Introducing safeguards that allow the special rules for scientific research, such as those in Articles 5, 6 and 9, to apply.
 - Introducing further scientific research exemptions under Article 89.
 - Introducing exemptions for freedom of expression for academic purposes under Article 85.

How can implementation of the Regulation support research?

- These laws for research, and accompanying guidance, must be **practical; proportionate to the risks to individuals; and build on current good practice**.
- To achieve this, we encourage national lead ministries and data protection authorities to **work with other relevant ministries, such as research and health, and to seek input from the research community and patient groups**.
- **We urge Member States to work together to facilitate cross-border research by promoting harmonisation and compatibility, where possible, between national laws, processes and guidance**.

Further detail, including a [detailed analysis of the Regulation and the key clauses for research](#), is available at wellcome.ac.uk/dataprotectionregulation and on request.

CONTACT

Marie Timmermann, Science Europe +32 (0)2 226 03 21 / marie.timmermann@scienceeurope.org
Dr Beth Thompson, Wellcome Trust +44 (0) 20 7611 7303 / b.thompson@wellcome.ac.uk

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Signatories



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Marie Timmermann, Science Europe +32 (0)2 226 03 21 / marie.timmermann@scienceeurope.org
 Dr Beth Thompson, Wellcome Trust +44 (0) 20 7611 7303 / b.thompson@wellcome.ac.uk