

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

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. National governments now have a crucial role to play in implementation.

If the Data Protection Regulation or something similar is implemented in the UK, the UK Government should:

- **introduce clear laws for research** with safeguards and exemptions that support research while respecting people's privacy;
- **work across government departments 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 with other countries 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**, the Data Protection Directive. Once the Regulation takes effect in May 2018, the processing of personal data in the EU 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 does the UK Government 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**.
- There is a lack of certainty about EU legislation following the referendum. If the UK Government implements the Data Protection Regulation or something similar, it is **essential that current laws are reviewed and amended 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 the Department for Culture, Media and Sport and the Information Commissioner's Office to **work with the devolved administrations and other government departments, including the Department of Business, Energy and Industrial Strategy and the Department of Health, and to seek input from the research community and patient groups**.
- **We urge the UK Government to work with other countries 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](#), and background on our work to support research and safeguard privacy is available at wellcome.ac.uk/dataprotectionregulation.

CONTACT

Dr Beth Thompson, Wellcome Trust +44 (0) 20 7611 7303 / b.thompson@wellcome.ac.uk

Signatories



CONTACT

Dr Beth Thompson, Wellcome Trust +44 (0) 20 7611 7303 / b.thompson@wellcome.ac.uk