Get ready for GDPR as a new era of data protection is about to start

On May 25th this year the Data Protection Act will be replaced by the European Union’s (EU) General Data Protection Regulation (GDPR), a framework with succinct rules that have greater scope, harsher penalties and actionable fines for those who do not comply with its rules regarding the handling and storage of personal data. The context of this Regulation aims to strengthen privacy rights while at the same time facilitate digital innovation within the EU. The GDPR also aspires to resolve the sometimes conflicting values of privacy and innovation. It aims to do this by coordinating different privacy legislations across the EU and by creating various exemptions for different types of research within its mandate.

Even though this new framework will come into place as Britain starts the process of leaving the EU, the Great Repeal Act means that the GDPR is likely to become part of British law which will ultimately have an impact on research and transform the way researchers manage personal data within its new elements.

Research however is in a good position within its outlines as it permits organizations that process personal data for research purposes to evade some restrictions on secondary processing and on managing sensitive data as long as they have appropriate ethical standards and safeguards in place. Furthermore under the regulations organizations can find themselves in a unique position where they are able to overrule a data subject’s right to object to the processing of data or the subsequent destruction of personal data.

In its endeavours to encourage innovation the GDPR can also permit organizations to process personal data for research purposes without the data subject’s consent and in some cases even transfer personal data for research purposes to third countries that do not provide a satisfactory level of protection. The GDPR strives to facilitate a Digital Single Market across the EU and in doing so exempts research from the principles of limitations in storage which will allow researchers to process personal data beyond the purposes for which it was first intended.

Researcher will also have to consider the new rules in terms of gaining consent as this infers “any freely given, specific, informed and unambiguous indication of the data subject’s wishes by which he or she, by a statement or by a clear affirmative action, signifies agreement to the processing of personal data relating to him or her”. Consent can no longer be affirmed from silence or from inactivity. Opting out for recruitment purposes therefor is no longer permissible and removes this option; researchers can no longer presume any agreement to take part unless participants have specifically agreed to it.

The new regulations are far from straightforward and the NHS Health Research Authority issues specific guidance for researchers which is aimed specifically at researchers, sites and sponsors managing individual research projects. This guidance is published as a living document that will be
updated over the coming weeks so researchers would be advised to review it when submitting research now to the NHS.

Hilary Paniagua
Editor in Chief