

AB189. SOH21AS236. General Data Protection Regulations [2018] and clinical research: perspectives of patients and doctors in a model four teaching hospital

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Background: In May 2018, General Data Protection Regulations (GDPR) were introduced by the European Union (EU). GDPR poses significant new challenges for ongoing clinical research. The aim of this study was to evaluate the knowledge and expectations of patients and doctors regarding GDPR and implications for future clinical research.

Methods: An anonymous 12-item questionnaire was distributed to patients and doctors at a single institution.

Results: A total of 509 participants were included; 261 females (51.3%) and 248 males (48.7%). Among them, 350 were patients (68.8%) and 159 were doctors (31.2%); 159 participants had previously allowed their data to be used in clinical research (31.2%); 82 of which were doctors ($P<0.001$); 334 participants were aware of GDPR (65.7%); 116 doctors (73.0%), and 218 patients (62.3%, $P=0.018$); 71.1% of doctors were willing to allow their data to be processed anonymously as part of a clinical research project compared to 43.4% of patients ($P<0.001$); 80.2% of patients believed explicit consent is needed before using personal data in clinical research in comparison to 60.4% of doctors ($P<0.001$); 91.8% of doctors and 72.6% of patients would be happy to allow their information to be used in an international research collaboration ($P<0.001$).

Conclusions: GDPR 2018 has introduced significant confusion as to the appropriate processing of confidential data for the purpose of clinical research. The perspectives of doctors and patients vary regarding GDPR. Doctors are more aware of the changes brought in by GDPR and are more likely to allow their data to be used in clinical research projects. Measures to educate prospective research participants on the changing landscape of data protection should be considered to ensure that high quality clinical research can be carried out in the future.

Keywords: Data protection; General Data Protection Regulations (GDPR); healthcare

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Footnote

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Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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