

AB192. General Data Protection Regulation (GDPR) 2018—attitudes and expectations of patients and doctors relating to data protection and clinical research

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Background: The new guidelines pertaining to data protection brought in by the General Data Protection Regulation (GDPR) act 2018 have posed a significant challenge to clinical researchers. Our aim was to assess the perspective of doctors and patients as to how their personal data is now being processed and the implications of GDPR 2018.

Methods: Doctors at Galway University Hospital (GUH) and patients attending surgical outpatient clinics were invited to complete an 11-part questionnaire assessing their knowledge of data protection and attitude towards data control in clinical research.

Results: A total of 111 questionnaires were completed (68 patients, 43 doctors). 30% of all responders had previously allowed their data to be used in clinical research, and 73% were aware of changes in data protection brought in by GDPR. 70% believe consent should be explicitly obtained prior to using clinical data for research while 45% believe consent should be re-obtained for said anonymized data to be used in a different project. 87% would allow their data to be used in an international collaboration. Doctors were more likely to be aware of GDPR 2018 compared to patients (86 vs. 64%, P=0.011) and less likely to believe initial and secondary consent should be obtained for anonymized data to be used (49% vs. 83%, P<0.001 and 28% vs. 67%, P=0.002 respectively).

Conclusions: Efforts to educate all stakeholders on current data protection laws should be made to enable robust clinical research to be performed in the era of evidence-based medicine

Keywords: General Data Protection Regulation (GDPR); clinical research; patient attitudes; data protection; patient survey; new guidelines; patient data

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