

EU Data Protection Regulation 'Crucial' For Future Cancer Research



The European Society for Medical Oncology (ESMO) has [welcomed](#) the European Parliament's adoption of the EU General Data Protection Regulation, a uniform set of rules governing how personal data can be used in today's digital age, which it describes as being "crucial" for the future of cancer research.

The new regulation will aim to harmonise public health research across all 28 EU member states by providing a 'one-time consent' from patients that will allow their data and tissues to be used for future research, which will also ensure the viability of bio-banking.

"The inclusion of a one-time consent for retrospective research on clinical data and biological tissues is crucial because it means the oldest form of medical research – going back to patient records to analyse and correlate data – can continue to make a contribution today, to solving the challenges of tomorrow," said Dr Paolo G. Casali, Chair of the EU Policy Committee of ESMO, the leading professional organisation for medical oncology with more than 14,000 members.

ESMO had previously expressed concern that an earlier draft of the Regulation could have made retrospective clinical research impossible because it stipulated the need for 'explicit and specific patient consent'. This would have required researchers to approach patients every single time new research was planned, to obtain their agreement to consult their personal data or tissue samples stored for research purposes.

The new Regulation also ensures that researchers have access to high-quality, population-wide data, which by definition must include the entire population, and therefore cannot be subject to patient consent. This exemption from consent is important because it allows disease-based registries to continue to exist and benefits not only cancer research but medical research in general. In the case of cancer, this data is collected and stored in cancer registries, which are used by governments to formulate new cancer control policies and update national cancer plans and ultimately improve patient outcomes.

"Under ESMO's leadership, the European cancer community has achieved a tremendous success, ensuring that crucial aspects of cancer research can flourish in the years ahead," continued Casali.

ESMO President Fortunato Ciardiello, added: "We want to thank the EU legislators for the diligence, dedication and the openness with which they listened and responded to the concerns of the cancer community and have successfully managed to strike the right balance between protecting personal data and encouraging progress in cancer research."

The General Data Protection Regulation is an essential component of the European legislative framework which will underpin research in the field of cancer on a pan-European basis and beyond in the future.

Source: <http://www.esmo.org>

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