Panel Session: Code of Conduct for Health Research - A Resource in Turbulent Times?

26 January 2018, Brussels

Summary Report

BBMRI-ERIC was active at the Computers, Privacy and Data Protection (CPDP) Conference in Brussels, 24-26 January 2018 by organising the panel session, "**Code of Conduct for Health Research: A Resource in Turbulent Times?"**

With the implementation of the GDPR fast approaching, there are still many issues related to health research that remain unanswered. As a result, experts and stakeholders were brought together during a panel session to introduce and discuss the Code, which was born from the collaboration of more than 90 research organisations. The aim of the Code is to create a faciliatory regulatory environment that promotes data collection and sharing, thereby enabling and enhancing health research, whilst safeguarding patient and citizens' rights.

The panellists outlined how the Code is being created, offered critiques, spoke about the hurdles ahead, and engaged with the audience, composed of lawyers and DPOs interested in the specific (and neglected) data protection needs of health research. Evert-ben Van Veen, from MedLaw, set the scene, explaining the mission of the Code in detail, "The Code of Conduct for Health Research tries to fill the gap in the GDPR to protect patients' rights and safeguard health research, biobanking and registries."

Anastassia Negrouk, Head of International Policy Office at DPO at EORTC further elaborated, stressing that without a sensibly broad informed consent , health research would be blocked and ultimately people's lives would be wasted.

Alastair Kent from Genomic Alliance UK and Chair of the BBMRI-ERIC Stakeholder Forum, simplified and shared the position of patients towards the GDPR and the Code, "I'm a patient advocate, not a lawyer. I want my health data to be shared, put to good use. And I want my data to be identifiable, so researchers can get back to me and/or my family when a breakthrough is available" He underlined the key role that patient organisations have in the drafting of the Code, primarily via the BBRMI-ERIC Stakeholder Forum. Kent stressed the relevance of the Code for international research collaborations, given that the Code will assist researchers, data protection authorities and lawyers in applying the GDPR and the Clinical Trials Regulation more effectively in the health research field.

Finally, Michaela Mayrhofer, BBMRI-ERIC Chief Policy Officer and Chair of the session, updated the participants regarding the developmental process of drafting the Code. The first draft will be open soon for consultation.

To view a video of the panel session, please click here.