Keynote Plenary: Future Biobanks

Global Biobank Week, Stockholm

13 September 2017

Abstract

The evolution of healthcare, regulation and medical practice, and lately precision medicine, is not an arbitrary choice made by academic and industrial researchers, or policy and decision makers. It is driven by science and the availability of new tools and knowledge originating from different sectors.

BBMRI-ERIC announces the availability of new tools aiming to improve quality, findability and accessibility of biobanking resources. In addition to the development of IT tools to do just the above, BBMRI-ERIC also suggested FAIR – Health Principles, building on the more generic FAIR data principles, in order to better address the major challenges in health research, namely reproducibility and privacy protection. These principles include quality and traceability, incentive schemes, as well as privacy regulations compliance.

The new EU General Data Protection Regulation, which enters into force in May 2018, is especially critical. It does not adequately address medical research in a way that permits clarity for transnational research for the benefit of citizens and researchers alike. As a result, the process for developing a Code of Conduct has commenced, which aims to clarify the requirements of the General Data Protection Regulation in non-legalistic terms for the benefit of researchers. The development of such a Code is supported by more than 80 organisations worldwide and should be approved by the European Commission next year.

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