Il consenso alla donazione di campioni biologici per finalità di ricerca

ELENA MANCINI

Consent to Donate Biological Samples for Research Purposes

Abstract: Biobanks constitute a resource of primary importance in the development of diagnostic and therapeutic tools and represent the essential information platform for the advancement of personalized medicine, of great interest for diseases which are currently difficult to treat. In order to obtain this, the biobank needs to act as a third party to donors, funders and researchers themselves through the definition and adoption of a system of rules and warranty measures. In particular, the implementation of measures for lawful data processing associated with samples and for the protection of the rights and freedoms of donors, is the main conceptual and organizational issue in the management of a biobank. The article offers an analysis of informed consent as an ethical and legal instrument that is preparatory to any model of governance of a biobank.

Keywords: Informed consent, Data protection, Rare diseases, Models of consent.

notizie di POLITEIA, XXXVII, 142, 2020. ISSN 1128-2401 pp. 33-53