"Prima potevate chiedermelo": potenzialità e limiti del consenso al trattamento secondario di dati e campioni biologici per finalità di ricerca scientifica

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"You Could Have Asked Me First": Potential and Limits of Consent to Secondary Use of Genetics Data and Biological Samples in Healthcare for Scientific Research Purposes

Abstract: The present work initially tries to better analyze the nature of biological samples and gradually aims to reconstruct the legal, ethical and deontological framework on biological samples and biobanks, considering the current European regulatory developments. We are tried to analyze the role of informed consent in the secondary use of genetics data in healthcare for human research aims, and the motivations that lead donors to donate or give their sample into 'custody'. Finally, in the light of the new European Health Data Space (EHDS) which inspire an active coordination between healthcare and researcher use of genetics data, we are proposing a re-evaluation of the biobank as an integral part of the healthcare system (Italian National Healthcare System), leading to the emergence of issues relating to liability for the use of genetic data for public health purposes.

Keywords: Biobanks, Research ethics, Informed consent, Secondary use of health and genetics data, Rare diseases.

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