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Biobanking harmonization & globalization in the new context of genomic era & data sharing across borders

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Biobanking activities are of major scientific importance since they allow for the creation of very large datasets-as needed to study complex disease aetiology-optimize the use of already collected research material and avoid the limitations of research conducted among smaller numbers of participants. While the literature on biobanking has traditionally focused on issues such as informed consent, privacy, access and return of research results, emergence of biobanking activities in new research domains, such as International Harmonization Projects and also Data Sharing, has raised unexpected socio-ethical and legal issues (ELSI). Moreover, internationalization of research activities and development of international research consortia has clearly shown the limitations of nationally based legal and ethical frameworks. Biobanks, defined as an organized collections of human biological samples and associated data stored for one or more purposes have become a key emerging research infrastructure, and those established as "population biobanks" are viewed as particularly promising drivers for the advancement of biomedical sciences. Rapid knowledge in medical research produces a continuous stream of new knowledge about disease process. However the possibility for early detection or preferably prevention of complex diseases remains elusive. Population based prospective studies investigating the interaction between genetic predisposition to a disease and exposure to environmental factors is a prerequisite to gain knowledge for the development of preventive strategies. As the studies of complex diseases require comparison of affected and unaffected individuals ("cases & controls"), different kind of biobanks has thus become indispensable to elucidate molecular processes and aetiologic pathways through powerful omics approaches (genomics, proteomics, transcriptomics, metabolomics, microbiomics) that integrated by bioinformatics programs will promise to greatly advance the understanding of disease developments, sharing data through multiple research sites. The Global Alliance for Genomics and Health (GA4GH) is a big international coalition that brings together stakeholders from different sectors and localities, such as healthcare providers, research organizations, disease advocacy organizations, and life science and information technology companies with the aims to accelerate progress in human health by advancing a common framework of harmonized approaches that enables effective and responsible sharing of genomic and clinical data, and by catalyzing initiatives that drive and demonstrate the value of data sharing as a best practice.

Biography

Pedro Rondot Radío is certified as Medicine Doctor in 1986 from National University of Rosario. He is also certified as Clinical Internist Physician in 1990. He is a certified Hematologist at the Nacional Academy of Medicine of Buenos Aires in 1996, with over 20 years of experience in Oncologic Patients Care. He has been working at the University of Buenos Aires since 1992. He has been working as CEO-Biobank from 2009 to 2014, involved in Biobanking science and business, working multidisciplinary in writing Biobank Local Best Practices and Guidelines and also designing SOPs and Contingency Manuals for Emergencies occurrences in Biobank daily practice.

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