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An intriguing Insubria Research Biobank model: Ethical framework and opportunities for a Biobank Ethics Consultation Service (BECS)

Elena Ferioli and **Mario Picozzi**

University of Insubria, Department of Biotechnology and Life Science, Varese Category

Setting-for about two decades at the University of Insubria researchers have been independently collected and stored a lot of human biological samples to study the pathological mechanisms of diseases. Furthermore the University provides specific training programs in Bioethics, Applied Ethics and Clinical Ethics Consultation aimed to face to critical topics related to medicine and research.

Objectives: The aims of our project are: to design an academic Insubria Biobank as a unique key research infrastructure, to identify an appropriate Ethical Framework, and to create an institutional Biobank Ethics Consultation Services (BECS).

Methods: We maps the key challenges and controversies of biobanking ethics with reference to: i) research protocols submitted to ethical evaluation, ii) research conducted in ethics training programs (PhD and Master) and iii) the international literature.

Results: Regarding the ownership of biological samples and the intellectual property rights we approve the concept of solidarity and open science. The model of broad informed consent seems to prevail. Regarding the confidentiality we reflect upon the right to privacy, data coding and authorized access.

Discussion: We believe that the patients trust is the main matter. The Insubria Biobank would become subject responsible for the custody and management of biological materials and the protection of data confidentiality according to a model of Charitable Trust.

Conclusion: This credit of trust must be fed and confirmed by the ethical choices of the Insubria Biobank: Independent Ethics Committee, Ethics Code and Biobank Ethics Consultation Services (BECS).

Biography

Elena Ferioli obtained a degree in Biology from the University of Insubria (1998) where she undertake her academic career attaining two PhD, the first in Evolutionary Biology and Development (2002) and the second in Clinical and Experimental Pharmacology. Since 2007 she cover a technical and scientific role in the Department of Medicine and Public Health and recently in the Department of Biotechnology and Life Science, in support to forensic research.

Since 2010, with higher education courses in Clinical Risk Management and in Ethics Health Management, she deals with research in bioethics with particular reference to genetics and biobanks.

elena.ferioli@uninsubria.it

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