Research biobanks
Providing information and sharing resources

May 19, 2015 – 10:30 AM
Sapienza University of Rome, Anthropology Building
Room 1, First Floor

10:40 Ethics of biobanking: from informed consent to dynamic consent
Flavio D’Abramo

11:30 Sample and data accessibility in research biobanks: an explorative survey
Marco Capocasa, Paolo Anagnostou, Flavio D’Abramo, Giulia Matteucci, Valentina Dominici, Giovanni Destro Bisol and Fabrizio Rufo

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The project here presented addresses the challenge consisting in allowing research participants to biobank research in giving their consent on the base of information provided. Indeed, disclosing to prospective participants biobank research goals, risks and benefits is not an easy task as this information is not known or not clearly stated at the time of eliciting consent. Difficulties in enacting informed consent processes lie in communicative aspects such as state of mind of the recipient that in turn is influenced by factors related to age, state of the illness, gender, and other social characteristics. Moreover, a one-time consent is not always suitable for biobank research. The trajectory we want to sketch with this project goes towards the dynamic consent approach, where an interactive communication among researchers, health personnel and patients is enacted through different kinds of means (written texts, ICT, face-to-face encounters), where patients can receive project updates, handle consent options over time, give feedback on their psychophysical states, and express their expectations and opinions on the communicative process itself. To sketch such a trajectory towards a dynamic consent approach opinions of people involved in the research (doctors, nurses, patients, patient support groups) are central for the development of policies calibrated around specific contexts.
Sample and data accessibility in research biobanks: an explorative survey

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Biobanks hold human biological samples and/or data giving a crucial contribution to the progress of biomedical research. However, the effective and efficient exploitation of these resources depends on their accessibility. In fact, making bioresources promptly accessible to all, collaboration among research groups and multidisciplinarity are encouraged. Although this has become a rather common belief, several laboratories still apply secrecy and withholding of samples and data. In this study we conducted a questionnaire based survey in order to investigate sample and data accessibility in research biobanks operating all over the world. 46 out of the 238 contacted biobanks have decided to participate. Most of them provide permission to access their samples (95.7%) and data (85.4%), but free and unconditioned accessibility seems not to be a common practice. Three aspects are mainly considered in the biobanks guidelines as information needed in order to gain access to their resources: (i) request for applicants to explain what they would like to do with the required resources; (ii) the role of origin of research funds in the establishment of fruitful collaborations between biobanks and research labs; (iii) request of co-authorship in order to give access to their data. These results suggest that economic and academic aspects are involved in determining the extent of sharing of samples and data stored in biobanks. As a second step of this study, we investigated the reasons for the observed high heterogeneity of the requirements for the access to the biobanks’ resources. The analysis of informative answers suggested that the different modalities of resource accessibility seem to be highly influenced by social context and legislations of the countries where biobanks operate.