

“TRAINING SCHOOL on Bio-Banking on Neutropenias”

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Biobanks and biomedical research: expectations and challenges in sociotechnical systems

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Humanities and social science research regarding biobanking practices

- History of science, technology and medicine / Science and Technology Studies
- Research project “Contextualizing biobanking in Greece: histories, practices, discourses – BIO-CONTEXT”
 - We are going to study the histories and the practices of Greek biobanks; their development and their positioning in the current biomedical research environment.
 - Our approach seeks to provide deeper understandings on the workings of the biobanking sector by exploring specifically how biobanks have operated in the past and operate in the present, and how their operation is being communicated.
 - Our research aim is to explore how biobanks have been developed in Greece and, more specifically, the ways different types of biobanks/biorepositories have positioned themselves in a biomedical/research/clinical landscape formed by publics, patients, researchers, regulators, research institutions, clinical facilities and industries.

Biobanks: a key infrastructure in biomedical research

- Biobanks are organised collections of biological samples and associated data.
 - Being repositories of human biological material, biobanks are not new. Collecting, processing, and classifying tissues and biological matter, not necessarily human, is not a novel practice in scientific research and experimentation or clinical practice, and neither is data collection, as associated to recent discourses about Big Data.
- However, biobanks have emerged as ‘new’ types of institutes that collect biological samples and data that may be used in medical-scientific research beyond the confined site of their production, by outsiders.

Biobanks: a key infrastructure in biomedical research

- Biobanks offer a site of interaction between the public, patients, researchers, physicians, bioinformaticians, regulators, policy makers and companies. The relationships between these actors are not always smooth. Debates over biobanking design and practices have been rather frequent.
- The governance of biobanks is a complex process “since the domains of science and technology, healthcare, economy, law as much as the public administration each operate according to different logics and emphasize different values or motives to different degrees”, according to Gottweis & Lauss.

Gottweis, H. & Lauss, G. (2012). Biobank governance: heterogeneous modes of ordering and democratization. *Journal of Community Genetics*, 3(2), 61-72, p. 62.

Issues and challenges in biobanking

- a. One cluster of issues corresponds to those regarding the functions of biobanks, the governing bodies and the institutional forms of biobanks.
- b. A second array of issue is about the ways a biobank interacts with the community/society.
- c. The ways biobanks intersect with, are being shaped by and shape biomedical research.

Biobanking practices

- The biobanks are complex sociotechnical systems, which are constituted by materialities and practices, meaning biomaterials, technologies, laboratory practices, norms and regulations, as well as economic interests, ethical values, citizens/donors understandings of their function in the community and of their personal identity.
- Biobanks as complex institutions do not attain controversial aspects after their establishment, but these are to be considered part of their heterogeneity from the start.

Types of biobanks

- Biobanks are diverse in form and function, as they collect different types of biospecimen, from humans, animals and plants. They range considerably in size (varying from very small to quite large ones). They also vary in scope (disease specific or more generic).
- Distinction:
 - research-oriented biobanks (bioinformation biobanks, genetic or genomic or DNA / population-based or of smaller scale).
 - tissue biobanks that serve clinical purposes (blood banks, organ and reproductive tissues banks, umbilical cord blood banks).

Types of biobanks

- Another categorization of biobanks is according to their institutional setting and funding. There are no clear-cut distinctions here, for instance between the public and the private sector.
- Gottweis and Lauss differentiate between three types of biobanks:
 - (1) the **entrepreneurial** biobank model (often carried out in a public-private partnerships);
 - (2) the **biosocial** model (originating from patient groups/activists);
 - (3) the **public** biobank model in which biobank networks are supported mostly through taxpayers money and not for profit research.

These institutional models, however, do not capture instances of public-private partnerships that can emerge, as the pharmaceutical and biotech industries access and engage with public or biosocial biobanks.

Gottweis, H. & Lauss, G. (2012). Biobank governance: heterogeneous modes of ordering and democratization. *Journal of Community Genetics*, 3(2), 61-72, p. 66.

Informed consent and tissue ownership

- Sociologist Klaus Hoeyer has argued that informed consent “became the solution to the anxiety that tissue storage began to provoke in policy-making circles in Europe and North America”. This is because informed consent seems easier to deal with, than the underlying issues of commercial entitlements and tissue ownership.
- Due to the ever-growing commercial interests in the field of genetic research, the funding to biobanking projects has grown. At the same time, concerns have been more visible than before regarding the commodification of human tissues and benefit-sharing.

Hoeyer, K. (2008). The Ethics of Research Biobanking: A Critical Review of the Literature. *Biotechnology and Genetic Engineering Reviews*, 25(1), 429-452.

Informed consent and tissue ownership

- In the case of disease specific biobanks, patients involved in such projects tend to accept more easily commercial agreements in search for therapies. And, it has been the case that biobanks supported by patient groups seek cooperation with biotech companies.
- More broadly, the participation of patient organizations in biomedical research has become more active, and this is also the case with biobanking. In the biosocial banking models, participants assume an active role in scientific research, engage politically and negotiate their identity and health status.

Sharing data

- Connected to the issue of the ownership of biobanking contents is that of sharing them and of promoting cooperation.
- In the case of population biobanks operating under BBMRI (BBMRI LPC, large prospective cohort biobanks), STS scholar Aaron Tupasela noted that there is a tension in the practices: “existing policies ... encourage biobanks to compete, while at the same time expect them to provide open access to competitors”.
- These competing logics affect the financial sustainability of biobanks. But, also affect the way scientific research is conducted, and who gets merit. Tupasela shows that sharing is not a neutral practice. And, for biobanking promoting a sharing culture needs to come with adequate public funding, for biobanks to continue their operation without participating in market practices.

Tupasela, A.M. (2017). Data-Sharing Politics and the Logics of Competition in Biobanking. In V. Pavone and J. Goven (eds.), *Bioeconomies. Life, Technology, and Capital in the 21st Century* (pp. 187-206). Cham: Palgrave Macmillan

Populations and biobanks

- Genetic homogeneity can be considered an asset of a biobank, as in the case of Iceland.

A way that bioresearch can involve racial, religious and ethnicity issues and collective identities in general, is seen in the work of Barbara Prainsack who has investigated biobanks in Israel. Social and political variables influence the discussion and function of biobanks more than the scientific ones. Considerations about the perceived relationship between genetic data and the collective body of Jewish identity as well as concerns about “the continuity of the existence of Jewish populations in Israel” must be taken into account when studying the practices of biobanking in the Jewish society.

- On the other hand, national/population biobanking projects claim to be more valuable when they are more inclusive and diverse.

As Tutton argues the formation of biobanks is entangled with discourses of collective identity, community, nationhood or ideas about racial/ethnic groups and differences.

Prainsack, B. (2007). Research populations: biobanks in Israel, *New Genetics and Society*, 26:1, 85-103.

Tutton, R. (2010). Biobanking: Social, Political and Ethical Aspects. In *eLS*.

Genomics and biobanks

- Social science research seeks to understand the political economy of life sciences, permeated with multiple techno-scientific practices surrounding the productivity of tissues, as in the case of biobanking.
- In the context of genomics research, through high-throughput genomics techniques, it is expected that population biobanks will assist research to explore the contribution of genetic, environmental and lifestyle factors to the etiology of more common diseases.
- According to such projects, genomics is going to lead to the development of more targeted personalised medicines, therapies and interventions, as well as better diagnostics.

Genomics and biobanks

- For Mitchell and Waldby, “genomics companies, which sequence and as a ‘partnerssell genetic information, pharmaceutical companies, which seek to apply high-throughput approaches to drug design, and academic researchers interested in basic biology are all using genomic technologies to pursue their interests”.
- They argue that “national biobank research, at least as currently configured hip’ between national polities and biomedical corporations, will both multiply risk categories for disease and expand the scope of risk, defining more and more people as being at risk for future illness and in need of testing and medication”.

Mitchell, R., & Waldby, C. (2010). National Biobanks: Clinical Labor, Risk Production, and the Creation of Biovalue. *Science, Technology, & Human Values*, 35(3), 330-355.

Genomics and biobanks

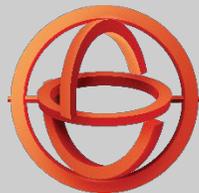
- Mitchell and Waldby argue that the identification of some genetically-linked risk factors could in principle lead to noncommercial interventions, such as changes in diet or exercise.
- The way genomics research is promoted emphasizes that the maintenance of “health” is mostly connected to pharmaceutical interventions. For instance, it is more compatible with the growing market of genetic testing and related diagnostics, and pharmaceutical products for prevention.

Thank you for your attention!

BIO-CONTEXT

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