

Cells, Genes and Data: Biobanks as Common Goods

Células, Genes y Datos: Biobancos como Bienes Comunes

Boris Julián Pinto-Bustamante*  

Bioethics Department, Life Sciences Research Group, Universidad El Bosque. School of Medicine and Health Sciences, Medical and Health Sciences Education Research Group, Universidad del Rosario, Bogotá, Colombia.

ABSTRACT

Contemporary biomedical research, propelled by bioinformatics, has revolutionized the exploration of the world through the collection and analysis of data from various biological materials. These advancements have given rise to ethical challenges, such as transformations in the practice of informed consent, issues related to privacy, equitable access to research benefits, and the privatization of genetic information. In this context, the governance of biobanks introduces ethical and legal tensions between liberal and communitarian perspectives. The privatization of biomaterials hinders global collaboration and restricts the involvement of developing countries. Experiences of community-based governance in Norway, New Zealand, Argentina, and other cases suggest alternative models. Community-based governance of biobanks emerges as an ethical approach that acknowledges cultural values such as privacy, cooperation, and active community participation in decision-making.

Keywords: Bioethics, Biological Specimen Banks, Community-Based Participatory Research, Tissue Preservation.

RESUMEN

La investigación biomédica contemporánea, impulsada por la bioinformática, ha revolucionado la exploración del mundo a través de la recolección y el análisis de datos de diversos materiales biológicos. Estos avances han dado lugar a desafíos éticos, como transformaciones en la práctica del consentimiento informado, cuestiones relacionadas con la privacidad, el acceso equitativo a los beneficios de la investigación y la privatización de la información genética. En este contexto, la gobernanza de los biobancos introduce tensiones éticas y legales entre las perspectivas liberales y comunitaristas. La privatización de los biomateriales dificulta la colaboración global y restringe la participación de los países en desarrollo. Las experiencias de gobernanza comunitaria en Noruega, Nueva Zelanda, Argentina y otros casos sugieren modelos alternativos. La gobernanza comunitaria de los biobancos emerge como un enfoque ético que reconoce valores culturales como la privacidad, la cooperación y la participación activa de la comunidad en la toma de decisiones.

Palabras clave: Bioética, Bancos de Muestras Biológicas, Investigación Participativa Basada en la Comunidad, Conservación de Tejidos

INTRODUCTION

The processes of contemporary biomedical research, stemming from the growing understanding of complex biological and environmental interactions and the development of information sciences applied to the life sciences, have revolutionized the ways in which we explore and understand the world. These bioinformatic research processes are impossible without the collection, storage, and analysis of various types of biological material and their derived and associated data. Bioinformatics has propelled the development of fields such as molecular biology, organic chemistry, cellular biology, genomics, and omics sciences, while also inaugurating novel interdisciplinary fields such as translational medicine and radiogenomics, among others (Coppola *et al.*, 2019).

The establishment of repositories for diverse biomaterials (cells, tissues, blood components, nucleic acids, cell lines, proteins, other subcellular components, and organoids) is linked to the need to address complex global health issues. This involves characterizing individual and population susceptibility to certain diseases and risk factors, identifying biomarkers, and developing diagnostic tests and therapeutic strategies. These efforts are carried out through large-scale population studies, basic biomedical research, clinical trials, pathology archives, diagnostic images, and countless databases from genomic sequencing techniques, stored in virtual biobanks.

Bioinformatics applied to biomaterials achieves the transformation of individual bodies into biological data, converting the unique, individual, private, secret, and personal trait into serial, common, and representative data. This article analyzes the ethical tension between the private and communal nature of biological specimens and their derived data from the perspective of liberal communitarianism.

CHALLENGES TO THE INDIVIDUALISTIC MODEL OF BIOETHICS IN RELATION TO BIOBANKS: SOME BACKGROUND

Despite the evident public utility of biorepositories, some precedents raise concerns regarding research involving biomaterials. A 2009 lawsuit against the Texas Department of State Health Services alleged that researchers had violated the rights of newborns by not obtaining parental consent to use their blood samples for research, leading to the destruction of 5 million samples (Carmichael, 2011).

*Author for correspondence: Boris Julián Pinto
e-mail: boris.pinto@urosario.edu.co; pintoboris@unbosque.edu.co

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In 2010, Rebecca Skloot's book "The Immortal Life of Henrietta Lacks" (Skloot, 2010) raised questions about researchers' obligations to Henrietta Lacks, who unwittingly became a research subject when her cancer cells were used to create a significant research tool: the HeLa cell line. Concurrently, her story raises issues related to privacy, impacts on the rights of her relatives, and equitable access to the benefits of research.

In Iceland, a parliamentary agreement granted a private company, deCODE Genetics, the privilege of accessing the medical records of the entire population. The goal was to link this database with the genealogies of the Icelandic population and the collection of biological samples. The project allowed the transfer of medical data through presumed consent to a private biotechnology company. Public and medical sector distrust regarding the transfer of private data and its proper handling, as well as the use of common data for the commercial benefit of a private company, diminished the credibility of the Icelandic project (Merz *et al.*, 2004). The forensic thriller "Jar City" or "Tainted Blood," written by Icelandic author Arnaldur Idriðason and adapted into a film, portrays this public mistrust through Nordic noir. The story revolves around crimes, exhumations, and family secrets revealed by an official from deCODE Genetics who has access to the Icelandic biobank's database.

In 1984, John Moore sued the Regents of the University of California over the issuance of a patent protecting rights to the human T-lymphoblast cell line, with an estimated economic potential of \$3 billion by 1990. This cell line was derived from Moore's spleen cells, obtained after he underwent a splenectomy for hairy cell leukemia (Lluch-Roselló, 2017), and he was unaware of these research activities. In 2010, Arizona State University settled a lawsuit arising from the alleged unauthorized use of blood samples from the local Havasupai tribe.

Given the shared nature of genetic information, a primary concern revolves around respecting the rights and interests of third parties, as "the disclosure of genetic information by individual DNA donors also exposes information about other individuals with similar genetic profiles". It is challenging to ensure confidentiality in the genomic and post-genomic era (Laurie, 2002). The challenges posed by genetics to the individualistic model of bioethics, especially regarding the practicality and relevance of individual informed consent and confidentiality, prompt a "reconsideration of the individual's primordial position in ethics" (Laurie, 2002).

GOVERNANCE OF BIOBANKS: BETWEEN LIBERALISM AND COMMUNITARIANISM

Research from biorepositories raises various questions about the relationship between the individual and society, the responsibilities, rights, and obligations of each involved party, as well as the value of these biobanks as a common resource. This involves combining genetic data characterization with health information and lifestyle data. It begs the question

of whether this collective genetic heritage, by potentially contributing to better health and prosperity for communities and future generations, justifies a duty to contribute to the common good, while promoting beneficence—the notion of a good life that each agent chooses based on their own freedom.

From a liberal perspective, the relevant principle respecting the private realm of individual freedoms is the principle of permission, expressed in the practice of informed consent, which should be sought from each person for obtaining any samples aimed at any line of research.

Authoritarian communitarianism, on the other hand, emphasizes public duties over individual freedoms. For instance, Rosamond Rhodes (2008) argues that autonomy should be understood as a social norm rather than an individual ideal. Rhodes contends that all members of a society should participate in medical research, as the focus should be on the well-being of future patients rather than the present participant in the research. Instead of choosing whether to participate in research, the choice would be in which study to participate. All projects should be approved by public medical authorities and meet certain criteria to ensure their quality and relevance. Rhodes considers participation in medical research as a social duty to contribute to the common good.

From a liberal communitarian perspective, while there are obligations to the community, these must be safeguarded through the protection of individual rights. From this approach, participation in biomedical research represents an imperfect moral duty rather than an absolute obligation.

As we have stated in previous texts, the hypertrophy of the public domain of common goods without consideration of permission is equivalent to an authoritarian policy (Pinto-Bustamante, 2021). Communal duties should be promoted through affirmative actions articulated through the will of individuals and not against them. The requirement for consent in research using samples and/or associated data can only be waived in cases where its solicitation is impracticable (e.g., deceased patients, insurmountable logistical difficulties, retrospective studies with significant samples, etc.), the risk of research is not greater than the minimum, and the social value of the research justifies it, always on the basis of proper governance processes for biobanks and collections (CIOMS, 2016). It is worth noting at this point that not every sample collection constitutes a biobank. If there are no adequate governance processes, such as standards for obtaining, storing, and processing samples and data, material transfer agreements, transparent coding and anonymization processes, among others, these exceptions cannot apply (Chandrasekar *et al.*, 2022).

In this regard, since the samples and the derived and associated information come from collective donation, community participation in the governance of biobanks and the oversight of research projects is relevant from the principle of reciprocity. This includes deliberation on the social value of research and access to shared benefits. Equitable participant selection should be understood as avoiding the



underrepresentation of populations that can benefit from research and preventing the exploitation of populations in vulnerable conditions. The principles of equal opportunities and difference are fundamental in determining how to distribute the benefits derived from research using biobanks. In this context, differences (e.g., the heterogeneity of samples and data as an expression of biological and cultural diversity) benefit the community at large, particularly those who are more vulnerable.

Another consideration in the context of research using biobanks pertains to property rights over bioobjects (biological samples and data). For this purpose, it is helpful to adjust the typology of private goods and common goods proposed by Elinor Ostrom (*et al.*, 1994).

Distortions of ownership models (Resnik, 2004) that have characterized patent systems and intellectual property regimes, include opportunism (the scenario in which common goods are exploited to turn them into privatized goods), or refusing to be part of a patent consortium (Osorio *et al.*, 2013) (like the failed regional C-tap initiative in the context of access to vaccines and technologies related to the COVID-19 pandemic), both in the pharmaceutical and biotechnological industries (e.g., through intellectual property agreements - TRIPS), transform pure common goods (the genetic heritage of biotic communities), impure common goods (the genetic heritage of anthropic communities), and private goods by dignity (the genetic information constitutive of each person), into impure private goods (e.g., genetic databases that only those who pay the corresponding licenses can access) and into goods privatized by alienation, turning biological information and its products into a commodity for private consumption (Pinto-Bustamante, 2021) (e.g., inequitable access to genetic tests and therapy) (Carmichael *et al.*, 2015).

In the field of biotechnological research, biobanks become a vital source of private capitalization, although they represent biodiversity, heterogeneity, and the common genetic heritage of human and non-human biological families, ethnicities, and communities. For this reason, among others,

private cord blood stem cell banks have been either prohibited in several European countries or discouraged, while the social value of public banks, such as IDCBS in Colombia, must be promoted (Pinto-Bustamante, 2021).

This trend towards the privatization of biological information, as demonstrated by cases like Myriad Genetics, DeCode Genetics in Iceland, and Celera Genomics, promotes conditions for a “tragedy of the anticommons” (Osorio *et al.*, 2013) by hindering collaborative efforts among research groups globally, limiting the participation of researchers from developing countries, and delaying the building of research capacities in these countries.

For this reason, modifications to patent systems have been introduced (Lesser, 2017), and in some jurisdictions, the possibility of patenting natural genetic sequences has been limited. Principles have also been consolidated to make genomic sequences available in public databases within 24 hours of their generation, as required by the Bermuda Agreement and in line with ethical principles outlined by the Human Genome Organization (HUGO) Ethics Committee (1996) and the Universal Declaration on the Human Genome and Human Rights by UNESCO (1997). In this sense, it is worth noting that Law 2253 of 2022 in Colombia requires that “Public and private Cord Blood Hematopoietic Progenitor Banks must share their respective databases and registry to be included in the National Public Official Registry of Hematopoietic Progenitor Cell Donors (RNDCPH)” (Congreso de la República de Colombia, 2022).

COMMUNITY-BASED GOVERNANCE OF BIOBANKS: SOME EXPERIENCES

The contemporary paradigm of biomedical research seeks to overcome the paternalism that has characterized it and normative reductionism, moving towards what Emanuel *et al.* (2008) call “community-based participatory research”, in which patients, research volunteers, and the community in a broader sense become partners in research efforts (Kaye *et al.*, 2012). Community participation also contributes, through the diversity of collected biological specimens, to distributive justice by favoring the involvement of underrepresented populations in pharmacogenomic studies (Cohn *et al.*, 2017).

Other models have been proposed to manage the governance of the common genetic heritage, from the perspective of shared responsibility and community administration of biological resources. For example, the PXE International Foundation, an initiative of families with children affected by pseudoxanthoma elasticum, a hereditary condition that affects connective tissues, established a model of a shared benefits patent between the biotechnology company that developed diagnostic tests and biomarkers (Transgenomic), and the families that contributed to the establishment of the biobank and research tests (Goold *et al.*, 2014a). The project is funded by private capital and NIH public funds. It is a public-private model of collaborative research partnership that goes beyond the notion of private ownership of biomaterials

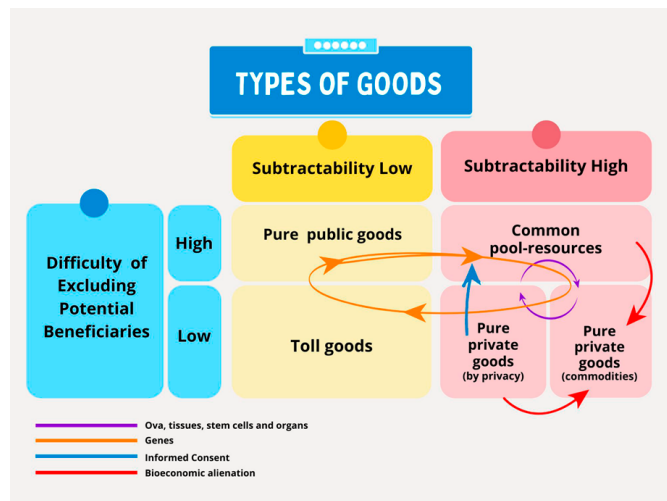


Figure 1. Bioobject classification matrix. My own proposal based on Elinor Ostrom’s typology (Ostrom, 1994).

and promotes a partnership between the community, researchers, and sponsors in pursuit of common goals benefiting affected populations. It recognizes the rights of all parties involved and encourages community participation in the management of the biobank as a common good, including stewardship of the rights and interests of future generations (Resnik, 2004). This model allows for “correcting a market failure regarding the added value to research companies by patients and affected groups” (Goold *et al.*, 2014b).

There are multiple examples of community participation in the governance of biobanks. One such example is the collaborative effort EngageUC (Garrett *et al.*, 2015) at the University of California, where researchers, health service providers, university officials, and community members, trained to promote deliberation, participate in the governance of biobanks, as well as in the formulation of policies for managing biological specimens, associated information, and the practice of informed consent. Shared governance models have been proposed for biobanks working with genomic information (O’Brien, 2009), for managing genetic databases for forensic purposes (Etzioni, 2004), and for the administration of biobanks preserving information from indigenous communities (Allyse *et al.*, 2015). Additionally, models for producing collective goods in genomic research include the Center for the Study of Human Polymorphism (CEPH), European genomic research consortia, the Personal Genome Project at Harvard University, as private sector data-sharing initiatives (SNP Consortium, Merck Gene Index, International HapMap Project, etc.), and technological proposals for interoperability that can contribute to the democratization of genomic data, such as federated data platforms (Alvarellos *et al.*, 2023).

In 2009, the UK Biobank, based in Liverpool, formally invited citizens to a guided tour of the institution’s facilities, lasting 2 to 3 hours. The aim was to expose the community to the project’s purposes and benefits, as well as the guarantees regarding the proper use of samples and personal data. This initiative, based on building trust, is rooted in the principle of “researching with people rather than researching about people” (Thornton, 2009). A similar initiative took place in 2009 at the Vancouver Biobank (BC BioLibrary), following a structured public deliberation methodology (O’Doherty, 2012).

In Norway, citizens of Nord-Trøndela are invited to participate in the HUNT project, which includes health studies, application of instruments, and blood sample collection for the biobank. Participation in this project is based on the cultural value of “dugnad,” a Norwegian tradition of voluntary and unpaid work for the benefit of the community, as well as collective action and cooperation in Norwegian society (Ursin *et al.*, 2009).

In April 1977, a collective of women, mothers of individuals who disappeared during the dictatorship that ruled Argentina between 1976 and 1983, founded the organization Mothers of the Plaza de Mayo. In October of the same year, it evolved into the Grandmothers of the Plaza de Mayo

movement, whose resistance was based on identifying children adopted by the dictatorship after the disappearance of their dissident parents. The resistance of this community of mothers and grandmothers led to the creation of the National Commission on the Disappearance of Persons (CONADEP), the National Commission for the Right to Identity (CONADI), as well as the creation of the National Genetic Data Bank (Pencaszadeh, 2011). This forensic bank in Argentina advises on the consolidation of the Genetic Profiles Bank of the Disappeared in Colombia, in the context of the armed conflict and forced disappearance phenomenon.

In New Zealand, a research project was carried out to construct a relational model for the development of culturally informed policies and practices related to participation in biobanks. This project included a characterization of the cultural values of the Maori community. In this context, biological samples are considered precious (taonga), sacred (tapu), and their restricted use should be entrusted to a guardian (kaitiaki). The spiritual sense of taonga (na te tapu i puta mai te tikanga) implies moral obligations, such as “sharing the gift,” which means establishing a relationship through consent, and the “return of the gift,” as an obligation of reciprocity and respect for the community (Beaton *et al.*, 2016). In Colombia, there is a reported exercise of community-based participatory research with the Tule (or Kuna) population in Urabá, where the collective actively participates in the collection of blood samples and their subsequent disposition, following the cultural values defined by the community.

CONCLUSIONS

Beyond biological characterization and its countless clinical and research applications, bioinformation incorporates a set of values, tensions, and vital impulses. Genomic information represents the changing result of continuous interactions and mixtures between living beings, families, communities, environments, as well as cultural and political contexts. These interactions are shaped by migratory processes, emotions, violence, deprivations, and life stories, constituting a common will to live through the establishment of connections and their contradictions.

Laurie Zoloth proposes a critique of the notion of a biobank. According to her perspective, the concept of a “bank,” rather than being a deposit, museum, or collection, refers to the idea of a market, secrecy, competitiveness, and hierarchy. In contrast, the concept of a “library,” as a mode of organizing shared knowledge, suggests that “what we have in common should be common”. In this sense, she advocates for the creation of a new Library of Alexandria based on diverse specimens and data from both locals and foreigners. This library would be linked to human freedom, creativity, and citizenship, guided by principles of justice, hospitality, and reciprocity. Following this notion, we propose understanding biobanks as vital libraries that house the movements of individual and collective memory (Vallejo, 2021), simultaneously unfolding the idea of a flexible knowledge continuously constructed and reconstructed among alphabets (biological



information), decoders (information analysts), and meanings (critical epistemologies and knowledge reconfiguration).

Community participation allows for more meaningful individual autonomy. It is worth noting that the recent Law 2287 of 2023 in Colombia, “By which the national system of biobanks is created, the operation of biobanks for biomedical, biotechnological, and epidemiological research is regulated, and other provisions are dictated”, does not grant greater importance to the role of communities in the governance of collections for research purposes and biobanks. As an expression of tensions between the values of the *polis* (or the public sphere) and the *oikos* (the private sphere), we advocate in this context for a liberal communitarian model for the governance of biobanks, articulated in support of a political economy of privacy and a political economy of the common good.

CONFLICTS OF INTEREST

I declare that I have no conflicts of interest, whether financial or non-financial, pertaining to the subjects discussed in the article submitted for evaluation.

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