

## **Governance of Emerging Technologies Conference (GETS) 2020 Abstract Submission**

**Abstract Title:** Access Principles in Research Governance: Lessons from the Sangre por Salud Biobank

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### **Abstract (489 Words):**

Biobank initiatives aim to facilitate access to biospecimens for research projects developed well beyond the time of sample collection. However, governance models for ongoing engagement of various stakeholders are still debated. Current biobank governance mechanisms are often adopted to supplement contributors' broad consent to the use of their biospecimens and data in biobank research. Broad authorizations are often considered incomplete due to the unpredictable and unspecifiable nature of future research. In the United States, surveys of biobanks reveal a lack of uniformity when including community perspectives in biobank governance; rather, biorepositories have sought out community views in various aspects of biobanking including: creation, recruitment, biospecimen utilization, and results dissemination.

Our work focuses on the ethical and practical challenges of including community perspectives in biobank principles governing biospecimen access and utilization and the opportunities that engaging with the community may bring to advancing the field. In the formulation of our biobank access principles and policies we encountered following questions: a) What scientific and ethical tenets should guide access to biobanks? b) How can such principles respond to the contextual features of unique collections? c) Which processes support the inclusion of the views of multiple stakeholders?

*Sangre Por Salud* (SPS) Biobank is a collaborative effort between academic institutions (Mayo Clinic and Arizona State University) and a federally qualified health center, Mountain Park Health Center (MPHC) in Phoenix, AZ. This biobank has recruited 3,732 Latinx participants from the MPHC practice. The biobank seeks to address two important gaps in current biobanking research: underrepresentation of racial and ethnic diversity among contributors, and creating translational research opportunities for health systems providing care to underserved populations. From its inception, SPS biobank was accompanied by the creation of a community advisory board (CAB). In this presentation, we describe the efforts of a CAB and a multi-institutional governance team to articulate SPS biobank access and utilization principles. First, we summarize prior work in bioethics articulating principles of regulatory compliance, scientific rigor, privacy, confidentiality, transparency, reciprocity, benefit sharing, trustworthiness, and justice, as relevant to biobank governance. Second, we identify previous efforts to empirically describe community or public perspectives on biobank access and utilization. Third, we describe the recent

efforts of SPS biobank governance stakeholders to articulate guidance principles for access and utilization. Relevant contextual features that contributed to the genesis of SPS access principles included:

- involvement of multiple institutions with a stake in governance and as gatekeepers to access and utilization
- underrepresentation of Latinx communities in biospecimen research
- unmet needs of medically underserved populations, the barriers to access to clinical care that SPS contributors could encounter, and how these affect their perception, attitudes toward, and experience of ongoing research efforts
- overcoming language and health literacy issues among biobank contributors
- overcoming cultural and community awareness issues among investigators
- need for capacity building in both genomic research fields and local communities

Our experience highlights the importance of responsiveness to local communities in the development of SPS Biobank governance access principles.