Strengthening knowledge for future generations: Cancer bio-banks in the landscapes of the Haudenosaunee

Building trust through education and outreach

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The Haudenosaunee are a Confederacy of Tribes in the Northeastern areas of New York State whose bloodlines are distinctly related through clan systems, language, and traditional practices. The Haudenosaunee include:

- Mohawk – The People of the Flint
- Oneida – The People of the Upright Stone
- Onondaga – The People of the Hills
- Cayuga – The People of the Great Swamp
- Seneca – The People of the Great Hill
- Tuscarora – The Shirt Wearing People
Indigenizing Biobanks

- Haudenosaunee Perspectives
- Guiding principles of Peace, Good Mind, Strength
- Community Empowerment
- Equity in Research
- Respect
Total 301 Identified Native: 112 male; 189 female
Number of patients per county

# Subjects

- Cattaraugus, NY: 38%
- Chautauqua, NY: 12%
- Chenango, NY: 3%
- Erie, NY: 12%
- Genesee, NY: 8%
- Niagara, NY: 1%
- Canada: 1%
- Other States: 22%
- Other NY counties: 3%
Gender by site group

![Gender by site group chart](image_url)
Collection by year and material type

- Blood
- Buccal
- Saliva
- Sputum
- Urine
Purpose

O Report holdings of Native American bio-specimens collected between 2004-2016 and housed in RPCI’s bio-repository to Seneca Nation and Native American Community Services

O The purpose of the report back will be to share and engage discussion on RPCI’s DBBR process and cancer biobank holdings back to the Native communities for guidance on next steps in potential, territory-based, bio-specimen related research as well as building ideas on how to indigenize current bio-specimen resources.
Goal

- To gain guidance at the community, macro and policy level on how we can work together to build research pathways and approval for future broad-based bio-specimen research;

- Seek guidance on respecting and honoring storage facilities by discussing ways to indigenize current DBBR space.
Aims

O Develop culturally appropriate methods and guidelines for the collection, storage, and use of bio-specimens for research in collaboration with local Native American community partners using a community-based participatory research approach.

O Create a framework and action-oriented macro-level policy strategies for cancer research requests involving bio-specimen collection from Native American participants.
Expected outcomes

- Important feasibility data on next steps for advancing bio-specimen research with a federally recognized Native American tribe and a Native Urban Center in RPCI’s immediate catchment area;

- Collaborative efforts with a Native American tribe and Native Urban Center on creating health research policy as it relates to bio-specimen research in the realms of cancer and specific to tribes of this region;

- Guidance on how to indigenize RPCI’s DBBR current holdings;

- A foundation of direction in developing specimen and biomedical informatics banks to solidify tribal policies on banking bio-specimens (e.g., buccal DNA, urine) and biomedical information (e.g., health histories such as cancer incidence) for the tribal and urban areas.

- The long-term aim is to test these samples at RPCI’s Center for Personalized Medicine for the benefit of Senecas and the Native Urban Population in RPCI’s catchment area.