Indigenizing cancer bio-banks as a form of cultural resistance and resiliency

**PURPOSE/OBJECTIVES**

Roswell Park is the oldest comprehensive cancer center in the US founded in 1868. Roswell is also situated within the largest confederacy of Native American Nations in the Northeast, the Haudenosaunee, People of the Longhouse, also known as the Iroquois. Holdings of Indigenous bio-specimens collected and housed in Roswell’s bio-repository were reported back to Indigenous urban communities and the largest Haudenosaunee Nation in the region. The purpose of the presentation was to share and engage discussion on indigenizing bio-repository collections, procedures, storage, and utilization for investigation as a means of cultural resistance.

**BACKGROUND**

**HAUDENOSAUNEE** (People of the Longhouse)
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 of the Haudenosaunee (People of the Longhouse). The Longhouse, also known as the Iroquois.

**METHODS/MATERIALS**

Two projects were conducted. The first reviewed feedback on clinical trial recruitment methods in urban indigenous communities related to bio-specimen research and a second study underway investigating reservation-based and urban perspectives on bio-banking storage, perceptions of genetic research, ethics, and policy. Between the two projects there were a total of 61 individual interviews and 6 focus groups with Indigenous participants residing in urban, reserve, reservation, and territory settings. Both studies utilized a qualitative framework to collect, analyze, and report experiences, perceptions on clinical research, recruitment, bio specimen donation and investigation. Multiple analysts were incorporated from interdisciplinary qualitative paradigms, training, cultural backgrounds, and experience to enhance rigor.

**RESULTS/SUMMARY**

**Study 2:** Reported holdings of Native American bio-specimens collected between 2004-2016 and housed in Roswell’s bio-repository.

- **Total 301 Identified**
  - Native: 112 male; 189 female

**Indigenous urban views: bio-banking, clinical trials and recruitment**

- **Study 1:**
  - "It appeared that this study was not for me or us (Native Americans). There was little imagery that would show that Nations seem to be part of this project." (Enrolled materials)
  - Participants shared that, “study materials should understand exactly what they are signing”, another indicated that the signing process should be done carefully and in more detail. As one participant stated, “know what you are signing up for”
  - Participants also shared that having a “key point” or “summary is what” that shares important features of the study would be very helpful.

One aim to participate in research to help future generations. However, questioned, “how many studies were going to be conducted from my donation?”

**Preliminary results** from the Indigenous-urban study included the process of creating trust through respectful partnerships, developing culturally meaningful recruitment and educational materials, understanding the consenting process, respecting traditional views, the need for education on the field of genetics and benefit to family and future generations. Other conclusions focused on macro level recommendations for indigenizing cancer based bio-repository collections, procedures, storage, and utilization for investigation as a means of cultural resistance and honoring. Second study findings (urban, territory, reservation) are under review for release.

**CONCLUSION**

Conversations included conceptualization of macro level policy initiatives that have the ability to enlighten the process of “western science” in creating new narratives for future generations and building meaningful biological specimen research agendas towards culturally attuned prevention and personalized medicine. It is important that unique societies contribute to the science and crucial that science respects the sovereignty of Native Nations to contribute for the benefit of all generations.

This work was funded by the Roswell Park Alliance Foundation.