

Clinical Trials, Pandemics, and Sovereignty: Tribal Governance and Community Education

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Beaver: diversity in clinical trials



Pandemics: Indigenous populations

Indigenous Peoples have been impacted by a variety of diseases and epidemics over the centuries that have resulted in thousands of deaths and the extinction of some tribes.

Indigenous populations were not previously exposed to most diseases introduced by European colonists, populations rarely had built up individual or population immunities to those diseases (i.e., small pox and measles).



<https://www.nlm.nih.gov/nativevoices/timeline/232.html>

Different types of “trials” or “investigations”

Prevention trials involve tests to find ways to prevent particular medical conditions or to prevent them from reoccurring. The emphasis of these studies might be related to medicines, screening techniques, or lifestyle changes.

Intervention trials or treatment trials are research projects which set out to test treatments which have not been officially approved. For example, a new drug which it believed would be effective in the treatment of cancer.

Therapeutic trial is one in which the treatment under investigation is believed to be likely to benefit the participants in some way

Non-therapeutic trial is one which is unlikely to produce any direct benefit to the participants involved. The aim of a non-therapeutic trial is to obtain knowledge which may contribute towards the future development of new forms of treatment or procedure.

Importance

- Indigenous populations face some of the greatest cancer health disparities (co-occurring conditions) and there is a need for equitable participation in research if deemed beneficial by the tribe.
- Participation increases the chance that interventions, including **cancer prevention or screening trials**, are effective and translatable with, to, and for Indigenous Peoples.
- Bringing awareness of the diversity in operational and administrative structures amongst Native Nations and how to work with tribes or consortia of Nations is vital.
- Educating community members, after tribal approval, about clinical trial process is important.

Research, Pandemics and Indigenous Communities

- Tribes/researchers need to be aware of the potential of cohesion (i.e., “needs (treatment/testing) vs research”) = benefit must outweigh risks to Nation and citizens.
- During emergency/pandemic responses tribes must be consulted and research projects must honor the CBPR process (Full Tribal review, Tribal Employment Rights Ordinances, empowerment, grievance procedures, licensing fees).
- Consideration of intellectual property compensation (especially Indigenous Knowledge that leads to western scientific advancements), robust data-sharing agreements, and profit-sharing if commercialized.
- Honoring and respecting Nation to Nation Governance and Sovereignty including the incorporation of the United Nation Declaration on the Rights of Indigenous Peoples, where applicable (https://www.un.org/esa/socdev/unpfii/documents/DRIPS_en.pdf)

Translating the Interplay: Indigenous Knowledge and Modern Medicine

Translating the Interplay: Indigenous Knowledge and Modern Medicine. Roswell Park Comprehensive Cancer Center. Buffalo, NY: Roswell Park Comprehensive Cancer Center, 2019. 1 video (11:02 min.).
MH19D14681 <https://www.youtube.com/watch?v=wlfNDSYcyjA>



The screenshot shows the HHS.gov website. At the top, it says "HHS.gov" and "U.S. Department of Health & Human Services". Below that is the "OMH" logo, which stands for the "U.S. Department of Health and Human Services Office of Minority Health". There are navigation links for "About OMH", "Resource Center", "Policy and Data", "Cultural Competency", and "Funding and Programs". The main content area is titled "Knowledge Center Selected New Acquisitions - August 2019". It includes a search bar and a "Go" button. Below the title, there are links to "See the complete list of new documents added in August read more" and "See the complete list of new journal articles added in August read more". At the bottom, there is a partial list item: "1. 2010 Assessment on State Health System Performance, Bradley D. Co. Collins, S. B. Hays, S. J. Washington".



Article 24 1. Indigenous peoples have the right to their traditional medicines and to maintain their health practices, including the conservation of their vital medicinal plants, animals and minerals. Indigenous individuals also have the right to access, without any discrimination, to all social and health services.

Post-Pandemic Research

What prevention research is needed going forward related to Indigenous peoples (cancer prevention intervention/screening, substance use, healthy eating, tobacco, mental health).

Looking beyond the US to global Indigenous populations and reviewing successful pandemic prevention interventions and how they may be translated, implemented or disseminated.

Building sustainable CBPR plans beyond emergency/pandemic related research.



Contact Information



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