Indigenous Data Sovereignty on the Path to HCV Elimination

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7TH CANADIAN SYMPOSIUM ON HCV. TOWARD ELIMINATION OF HCV. HOW TO GET THERE
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Overview

Indigenous Perspectives on Health and Wellness

Indigenous Data Sovereignty and Indigenous Research Ethics

What do population data tell us about HCV in Indigenous populations?

Guided by the Truth and Reconciliation Commission

Calls to Action

Christi Belcourt, *The Wisdom of the Universe* © 2014 Christi Belcourt
Wellbeing as total health of the total person in the total environment

Determinants of Indigenous Health

TRC Call to Action #18

“acknowledge that the current state of Aboriginal health in Canada is a direct result of previous Canadian government policies, including residential schools”
“You can’t manage what you can’t measure”

But

“Not everything that can be counted counts...and not everything that counts can be counted”

TRC Call to Action #19

“establish measurable goals to identify and close the gaps in health outcomes”

"The act of knowing is a collective, cultural and political imperative for indigenous peoples. Information, data, and research about our peoples - collected about us, with us, or by us - belongs to us and must be cared for by us" - Elizabeth Medicine Crow
Diverse Indigenous Populations in Canada →
diverse health needs and
diverse protocols for permission and engagement in research

First Nations

Métis

Inuit

TRC Call to Action #20
“recognize, respect, and address the distinct health needs of the Métis, Inuit, and off-reserve Aboriginal peoples”
Framework for working with Indigenous data

First Nations Data Governance Principles – OCAP®

- developed through the First Nations Information Governance Centre.
- refers to the rights of First Nations communities to own, protect and control how their information is used for research and other purposes.
Engagement

Beyond permissions and data governance: TCPS, Chapter 9 requires Indigenous community engagement

- Article 9.1 Where the research is likely to affect the welfare of an Aboriginal community, or communities, to which prospective participants belong, researchers shall seek engagement with the relevant community. The conditions under which engagement is required include, but are not limited to:
  
  (a) research conducted on First Nations, Inuit or Métis lands;
  (b) recruitment criteria that include Aboriginal identity as a factor for the entire study or for a subgroup in the study;
  (c) research that seeks input from participants regarding a community’s cultural heritage, artefacts, traditional knowledge or unique characteristics;
  (d) research in which Aboriginal identity or membership in an Aboriginal community is used as a variable for the purpose of analysis of the research data; and
  (e) interpretation of research results that will refer to Aboriginal communities, peoples, language, history or culture.

First Nations-driven Estimation of HCV Infection

Sioux Lookout First Nations Health Authority


Alberta First Nations Information Governance Centre

http://www.afnigc.ca/main/includes/media/pdf/frnhta/HTAFN-2017-12-12-HepC.pdf
Summary of Key Considerations

- HCV research, prevention and treatment needs to
  - respect Indigenous perspectives and ways of knowing
  - acknowledge the impacts of both past and ongoing colonialism
- Diversity of Indigenous populations, Nations and communities
- Importance of counting and including Indigenous people in HCV research
- Acknowledgement that the patterns and trends of HCV are different from the general population
- Requirement for Indigenous engagement and permissions/governance in
  - HCV research processes and
  - recommendations about HCV policy, treatment and strategies

Nia:weh
Miigwetch
Thank you