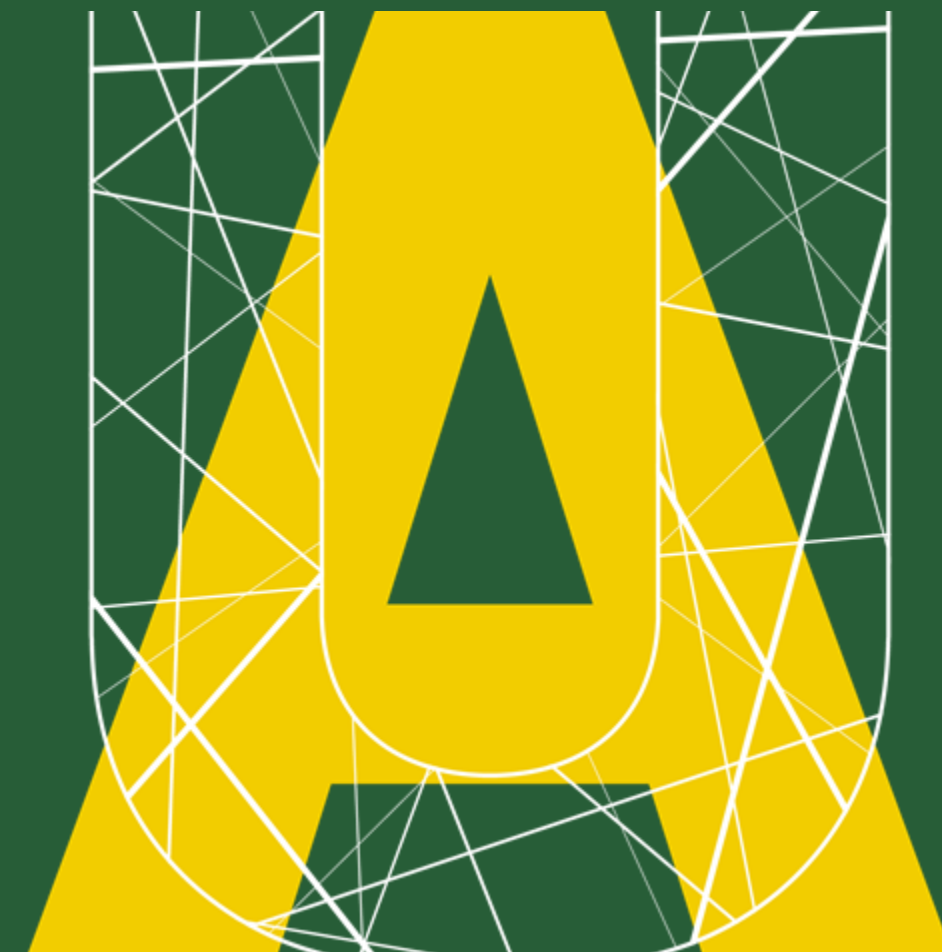


Indigenous Health Committee - Update

Presented by:
Tibetha Kemble (Stonechild), PhD



The Accelerating Clinical Trials - Indigenous Component

- The ACT Indigenous Health Committee was established in May 2023 to support and advance Objective #10 of the [ACT Consortium](#) which seeks to

“Improve the process of involving Indigenous Peoples in trials and establish a process to identify Indigenous Health Priorities and interventions for evaluation.”

- The imperative of the ACT Indigenous Health Committee extends beyond mere symbolic procedural/process improvements towards substantive efforts that resist the tide of western scientific research.

The Imperative & Intention

- Addressing the conflict pertaining to the rights of Indigenous Peoples vis-à-vis data sovereignty and self-determination within a contemporary western scientific and legal framework.
- Moving away from clinical trial interventions that reinvigorate the settler-colonial dynamic within research that have sought, almost exclusively, behavioural change among Indigenous populations as opposed to rehabilitation or drug interventions.
- Data collection methods and community engagement methodologies that are incongruent with Indigenous epistemologies and that contradict or undermine Indigenous principles, values, and natural laws.
- Limited approaches/methods for engaging with First Nation, Inuit, or Métis peoples and communities about their distinct and diverse health priorities/needs within clinical trial research (i.e. a pan-Indigenous approach).

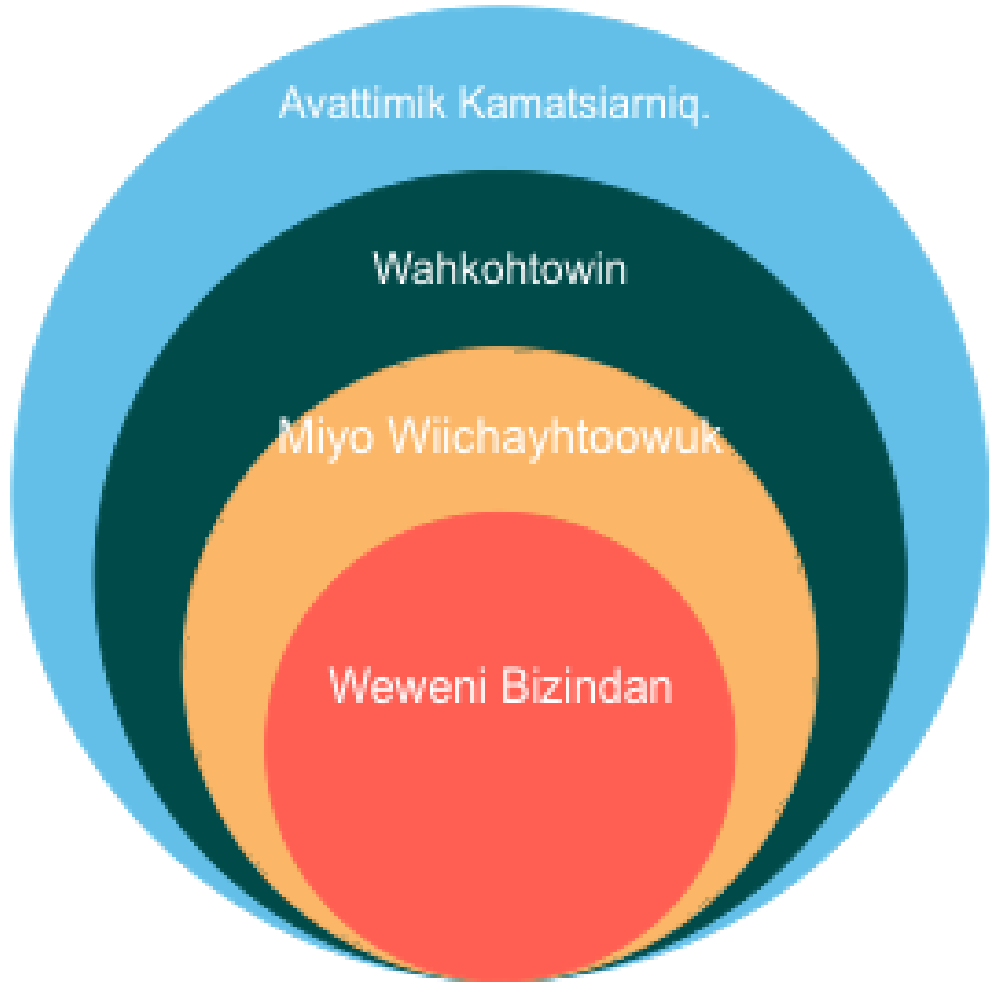


Indigenous Health Committee: Priority Focus Areas

1. Establish Grandmother's Council
2. Develop safe and respectful distinctions-based engagement framework & guidelines
3. Establish distinctions-based cohorts (First Nations, Metis, and Inuit)
4. Determine distinctions-based health priorities in clinical trial research
5. Articulate and develop distinctions-based culturally-safe and anti-racist engagement protocols

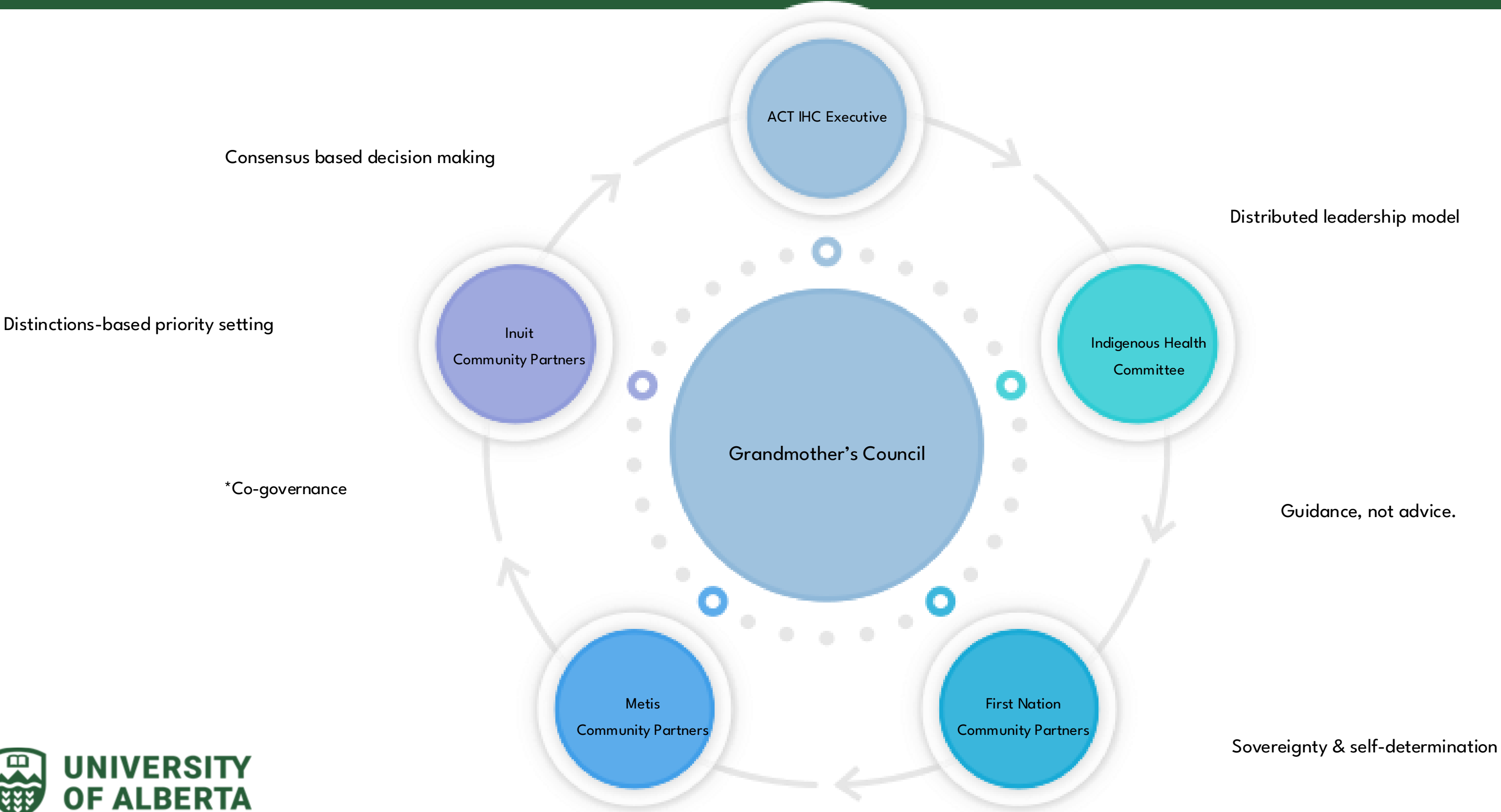


The Grandmothers Council



- Inuit
- Cree
- Metis
- Anishinaabe.

Uplifting Indigenous Ways of Knowing and Being



Progress to date: Outcomes and Trust Building

- 4 Grandmother Council meetings
- Inuit & First Nations Focus Groups
 - Emerging themes in health priority setting
 - Focus Group Reports - Draft
- Setting the stage for demonstration projects in the North and central Canada
- Distinct Communications Plan
- Draft Engagement Guidelines
- Laying the foundation for the establishment of an Indigenous Clinical Trials Unit
 - Hub and spoke model
- Shifting the understanding of the role of the IHC within and across the



Inuit Update: Integrating Inuit Knowledge & Context-Sensitive Methods

Incorporate Inuit Knowledge:

- Design interventions that reflect Inuit values, environmental contexts, and social dynamics.
- Integrate Inuit perspectives into the trial framework for cultural alignment.

Context-Sensitive Methods:

- Utilize Inuit research methodologies to capture the complexity of health disparities.
- Align data collection with Inuit principles, natural laws, and epistemologies.

Build on Existing Clinical Trials:

- The team is using successful multi-level interventions (MLI) case studies used by NHI in other American Indigenous communities to inform study design.
- Tailor strategies to fit Inuit cultural, social, and political contexts.

Pilot Demonstration Projects:

- Launch demonstration projects in Nunavut using the hub-and-spoke model.
- Adapt interventions to respect local community nuances.

Regular Collaboration:

- Engage in consistent collaboration with community partners and governance structures.
- Hold regular meetings to discuss progress and adapt as needed.

Other Distinctions-Based Indigenous Component Updates

First Nation

- Dr. Phillips-Beck

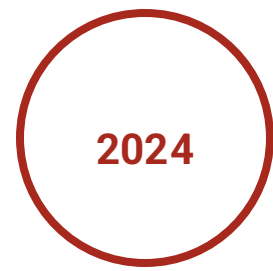
Metis

- Proposal approved by REB at the U of A who oversees and manages the Metis component alongside Dr. Morris
- Currently in the process of hiring a Research Assistant
- Elder Barbara Bruce and Dr. Morris meeting with several Metis governments and organizations to seek participation in Metis focus groups (re: Metis health priority determination)
- Focus group(s): likely in November 2024.
- Proposal due on December 2024.

Distinctions-Based Engagement Guidelines

- Based on the identified principles and priorities of First Nation and Inuit participants in the focus group sessions in early 2024 (see also, [Reports](#)). Metis component is forthcoming.
- An early articulation of the **shared and unique requirements** of the Distinctions-Based Components of Research with Indigenous Peoples and communities.
- In the present context, these guidelines serve as a discussion paper to support ongoing dialogue about requirements for clinical trial research alongside Indigenous community partners.
- Will be refined to focus narrowly on Applying the Requirements for Distinctions-Based Engagement in CTR with Indigenous Peoples & Communities.

Timeline of Next Steps



October

- Meeting with Nunavut Research Institute (Inuit) & Dr. Turner (First Nation)
- Demonstration projects developed and submitted (First Nation & Inuit)
- Budgets developed and submitted

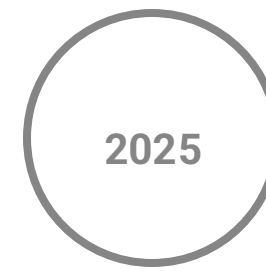


November

- Metis community partners identified
- Engagement session/focus group re self-determined health priorities

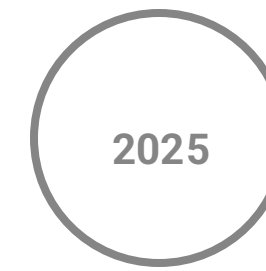
December

- Metis community partners identified
- Engagement session/focus group re self-determined health priorities



April / May

- Inuit and First Nations demonstration project begins.
- Data collection
- Between December to March, various levels of approval will be sought with Indigenous organizations and government agencies.



June - Sept

- Analysis, reporting findings.
- Distinctions-based guidelines finalized.
- ICTU established and serves as the central body for Indigenous Clinical Trials in Canada.

Thank you!