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Perspectives on Linkage Involving Indigenous data

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Topic: Perspectives on Linkage Involving Indigenous data

Indigenous populations across the globe are reaffirming their sovereignty rights in the collection and use of Indigenous data. The Indigenous data sovereignty movement has been widely influential and can be unsettling for those who routinely use population-level linked data that include Indigenous identifiers. Ethical policies that stipulate community engagement for access, interpretation and dissemination of Indigenous data create an enabling environment through the critical process of negotiating and navigating data access in partnership with communities. This session will be designed to create space for leading Indigenous voices to set the tone for the discussion around Indigenous population data linkage.

Objectives:

- To provide participants with an opportunity to build on the themes of Indigenous Data Sovereignty presented in the keynote session as they apply to diverse Indigenous populations.

- To explore approaches to the linkage of Indigenous-identified population data across four countries, including First Nations in three Canadian regions.

- To share practical applications of Indigenous data sovereignty on data linkage and analysis and discussion.

- To center Indigenous-driven data linkage and research.

Facilitator:

Jennifer Walker. Canada Research Chair in Indigenous Health, Laurentian University and Indigenous Lead, Institute for Clinical Evaluative Sciences.

Collaborators:

1. Alberta: Bonnie Healy, Tina Apsassin, Chyloe Healy and William Wadsworth (Alberta First Nations Information Governance Centre)

2. Ontario: Carmen R. Jones (Chiefs of Ontario) and Jennifer Walker (Institute for Clinical Evaluative Sciences)

3. British Columbia: Jeff Reading (Providence Health Centre) and Laurel Lemchuk-Favel (First Nations Health Authority)

4. Australia: Raymond Lovett (Australian National University)

5. Aotearoa / New Zealand: Donna Cormack (University of Otago)

6. United States: Stephanie Rainie and Desi Rodriguez-Lonebear (University of Arizona)

Session format: 90 minutes

Collaborators will participate in a round-table introduction to the work they are doing. Collaborators will discuss the principles underlying their approaches to Indigenous data linkage as well as practical and concrete solutions to challenges. Questions to guide the discussion will be pre-determined by consensus among the collaborators and the themes will include: data governance, community engagement, Indigenous-led linkage and analysis of data, and decision-making regarding access to linked data. Other participants attending the session will be encouraged to listen and will have an opportunity to engage in the discussion and ask questions.

Intended output or outcome:

The key outcome of the session will be twofold. First, those actively working with Indigenous linked data will have an opportunity for an in-depth and meaningful dialogue about their work, which will promote international collaboration and sharing of ideas. Second, those with less experience and knowledge of the principles of Indigenous data sovereignty and their practical application will have an opportunity to listen to Indigenous people who are advancing the integration of Indigenous ways of knowing into data linkage and analysis.

The output of the session will be a summary paper highlighting both the diversity and commonalities of approaches to Indigenous data linkage internationally. Areas where consensus exists, opportunities for collaboration, and challenges will be highlighted.