Appendix: Key guiding principles for health research and data governance

<u>**OCAP® principles to guide First Nations research data**</u> (1)
Ownership: specifies the collective relationship of First Nations to knowledge, information and data
Control: First Nations, their communities and representatives have the right to control all aspects of research and data management, from collection, use, disclosure and destruction of data
Access: First Nations must be able to access information and data about themselves and communities
Possession: clear physical control of data, and the mechanism by which ownership is asserted and protected

<u>**OCAS principles to guide Métis research data**</u> (2)
Ownership: legal possession of data, e.g. the Métis Population Data-Base in Manitoba
Control: the "power to make decisions about something and decide what should happen"
Access: the "right or opportunity to use something that will bring benefit"
Stewardship: "responsible planning and management of resource" so research that is completed is in the best interests of Métis health, and will improve health and health services delivery

<u>**Inuit Qaujimajatuqangit (IQ) principles related to knowledge to support wellness**</u> (3)
1. **Pijitsirniq:** the concept of serving
2. **Aajiiqatigiingniq:** the concept of consensus decision-making
3. **Pilimmaksarniq**: the concept of skills and knowledge acquisition
4. **Piliriqatigiingniq**: the concept of collaborative relationships or working together for a common purpose
5. **Avatimik Kamattiarniq**: the concept of environmental stewardship
6. **Qanuqtuurunnarniq**: the concept of being resourceful to solve problems

<u>**CARE Principles for Indigenous Data Governance**</u> (4)
Collective benefit: Indigenous data used for inclusive development and innovation, improved governance and citizen engagement, and to realize equitable outcomes
Authority to control: Indigenous peoples determine data governance protocols, and are actively involved in stewardship decisions
Responsibility: a duty to nurture respectful relationships with Indigenous peoples from whom the data originates, including capacity development and embedding data within Indigenous languages and cultures
Ethics: a focus on Indigenous peoples rights and wellbeing, including minimizing harm, maximizing benefits, promoting justice and allowing for future use

<u>**Black Health Equity Working Group principles of data governance**</u> (5)
Engagement: genuine, cyclical, accessible consultation with communities
Governance: community decision-making about engagement and data collection, management, analysis and use
Access: communities are able to access their collective data and determine who can access it
Protection: safeguarding of individual rights around identifiable, de-identified, and anonymized data

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