

## CIHR Ethics Office Comment to “Panel on Research Ethics: Proposed Guidance for Public Consultation”

### Broad Consent –

- **The shared responsibility to protect participants:** How can TCPS guarantee participants that the researcher will protect their interest where their data/samples are handed over to other researchers who have no previous contact with the participants? Some guidance would be needed to protect the chain of responsibility.
- Indigenous perspective/voice has been reflected on. How can we avoid potential future misuse of, for instance, communal data, samples of individuals who live outside of the physical (geographical locations of) communities but consider themselves Indigenous and hold Indigenous values strongly?
- **Voluntary Broad Consent:** In situations where individual data may be anonymised, but their community remains un-anonymise-able, can whole communities withdraw their collective participation (data, samples etc.) in the future and on behalf of individuals who may be part of their communities? Guidance should be provided to clarify or define a pathway to address this kind of issue.
- **Informed Broad Consent:** In communal settings (e.g. Indigenous communities), where there may be a communal change of mind with future revelation of the previously unknown research, there may be need for a renewed contact with those communities by researchers. It may be useful to maintain traceable codes to the data to help communities to more easily review or withdraw their participation, where there may be a communal change of mind.
- **“Possibility that participant data or human biological materials will be used for research of which the participant is unaware *and to which the participant might object*”:** Is there a way to guarantee participants that their samples may not be used for research that they may otherwise not consent to? There may be need to ask participants to indicate possible kinds of research that they would not consent to. The researcher can provide broad guidance about possible kinds of future research to help participants anticipate the kinds of things to which they might object. This can then guide potential future use of the materials, but also ensure that the consent given is legitimate.

### Multi-jurisdictional Research –

- The document lays down the guidelines for research conducted across various institutions. It does not provide adequate guidance for research that may be conducted across various locations (i.e. in several/different participation communities/locations) with varying socio-cultural outlooks. For instance, how will these guidelines apply where research is conducted by Canadian researchers in two or more participating locations (say one in Canada, another in Guinea, etc)?

### Cell Line Exemptions –

- There may be implications for Indigenous communities regarding uses of de-identified cell lines of individual members of their communities, and the potential future impact of these on communities. Indigenous perspectives should also guide this part of TCPS.

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