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Making a Difference in Bioethics

**NOTHING ABOUT US
WITHOUT US: AN
INUK REPLY TO**



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EXPLOITIVE RESEARCH

H

June 13, 2019 · by impact ethics · in Canada, Canadian Bioethics, Community, Indigenous Health, Law & Policy, Privacy and Trust, Public Health, Research Ethics, Social Justice · 1 Comment

Julie Bull articulates the duty of researchers to ensure ethical and responsible conduct of research with Inuit in light of recent media attention regarding skin graft experiments that occurred on Inuit in the 1970s.

On May 13, 2019 the CBC posted an article called [“We are not monkeys’: Inuit speak out about skin grafts done without consent in 1970s”](#). This story was met with little attention (i.e., no critique or shriek) from the biomedical community, which comes as no surprise to Inuit communities and scholars who have been, and continue to be, subject to the colonial gaze of Southern researchers. This commentary reflects the duality of my perspective as both an Inuit community member and Inuk scholar.

The CBC article is one of many mainstream media illustrations of the exploitation of Inuit (and other Indigenous peoples) in research. Yet, a common

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response to any critique of the research ethics scenario described in the article is that we cannot hold researchers and institutions accountable for past research by today's standards. Because in the 1970s when this research was conducted, the Medical Research Council was just developing guidelines for research ethics, no national or institutional policies or protocols were in place to mitigate research harms or facilitate data governance requirements. Perhaps one of the most disheartening and disturbing aspects of this research is the honorific of international leader in medical ethics bestowed upon Dr. John B. Dossetor. Yes, important contributions were made to fields such as nephrology and though Dossetor stated that he obtained permission from the community to conduct the research, we must acknowledge that significant contributions and unethical behaviour can occur simultaneously.

Community permission can only be granted with adequate language translation and interpretation and Dossetor's work does not meet this ethical test. Even if local Indigenous communities had established protocols at the time, researchers and clinicians were not obligated by law or policy to acknowledge, honour, or integrate any of these. That we cannot measure past actions by contemporary standards is true, however, at the same time as Dossetor was conducting his research, "contemporary ethical standards" were emerging through various international movements. While no official Canadian research ethics policies existed, there

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were international guidance documents (such as the [Nuremberg Code](#) (1947)) that clearly articulated the necessity of voluntary consent in research with humans. And, in 1954, the UN drafted the [International Covenant on Civil and Political Rights](#) which reiterated that no one ought to be subjected to medical and scientific experiments without their free consent. Then and now, we have a collective academic responsibility to name unethical behaviour, habits, and thinking and hold one another accountable for our actions.

□

Photo Credit: [@KBeHereNow](#). Image Description: "Medicine Woman" (lithograph, 1981-84) by [Helen Hardin](#).

Researchers, whether well-intentioned or not, tend to conflate and skirt their responsibilities in research involving Inuit and there is general confusion about the necessity for both collective and individual consent. Inuit communities and governing bodies across Canada are asserting their inherent rights to determine what research happens to our people and on our lands. In my community, for example, the [NunatuKavut Community Council implements a robust system of research governance](#), which was formalized in 2004 and undergoes regular revisions and revisioning (in 2010-2013, and again currently in 2018-2020). Further, as a response to the exploitive and exoticizing nature of research that is conducted by non-Inuit, Inuit Tapiriit Kanatami, a national Inuit political body, released a [Strategy on Research and Implementation Plan](#) in 2018

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that clearly articulates how they expect research involving Inuit peoples and lands to be undertaken and fully exerts Inuit sovereignty in research. Inuit in Canada are not the only Indigenous Peoples who are working toward self-determination in research – a global movement is afoot. Global networks of [Indigenous data sovereignty](#) are mobilizing and the momentum is strong. Indigenous Peoples are clear that when it comes to research, “nothing about us without us”.

We cannot continue to elevate researchers and scientists who behave like Dossetor. For Inuit, like many Indigenous Peoples around the globe, we are more interested in what you *do* than what you *say*. This means research ethics are *not* separate from “how-you-live-your-life” ethics, and therefore, research is about being and becoming an able human. We must speak the truths and take up the teachings that Inuit share with us, like this skin grafting experiment, through actioning ethical research. We must hold space for Inuit truth-telling to ensure we honour and learn from the past so we do not make the same mistakes in the future. We all make mistakes, but when we engage in the same behavior repeatedly, a choice is made. We all have a responsibility to journey together in research, respecting one another’s wisdom, gifts, ethics, and walking our talk. As [I have stated elsewhere](#), we all have a responsibility to be and become able humans and able institutions; choosing to become able will only ever be evident in the actions undertaken.

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[Julie Bull](#) is an Inuk researcher, ethicist, and poet from NunatuKavut and is a Research Methods Specialist at the Centre for Addiction and Mental Health (CAMH) in Toronto. [@julierbull](#)

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John Williams · June 13, 2019 - 10:47 pm · *Reply*→

In 1964 the World Medical Association adopted the Declaration of Helsinki The Introduction states, “The Declaration of Geneva of The World Medical Association binds the doctor with the words, ‘The health of my patient will be my first consideration’ and the International Code of Medical Ethics declares that ‘Any act or advice which could weaken physical or mental resistance of a human being may be used only in his interest’.” Since most medical research in the 1960s and 1970s was conducted by physicians, they were obliged to follow the provision of the Declaration that “Clinical research on a human being cannot be

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undertaken without his free consent after he has been informed.””

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potentially eradicate HIV. But in Ontario, only about a 10th of the people it could help are taking it.

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