

Self-determination and data control vital to Indigenous health research

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Health research involving Indigenous peoples must be based on their self-determination and ethical protocols for control of data, said Carrie Bourassa, scientific director of the Institute of Indigenous Peoples' Health, but "I don't think that's well accepted in the research community."

Bourassa, who is Métis, was a speaker at the Pathways Annual Gathering, an event involving the Canadian Institutes of Health Research (CIHR), First Nations, Indigenous organizations and other partners. The meeting is part of the Pathways to Health Equity for Aboriginal Peoples initiative, which includes several CIHR institutes. It is aimed at improving health in four areas: mental wellness, diabetes/obesity, oral health and tuberculosis.

The fourth annual gathering, held recently in Alberta, was not a typical medical research meeting. One day was devoted to "land-based learning and learning from place," explained William Wadsworth (also known as Iskotoohka), a policy analyst with First Nations Health and Social Secretariat of Manitoba Nanaandawewigamig, a co-organizer of the event. First Nations elders "shared aspects with respect to health and stories of the land," said Wadsworth.

What does this have to do with health research? "The way that First Nations look at health is holistic," said Wadsworth. "You have to be aware of mind, body, spirit." He said that Indigenous views of health also include the whole community. "If you have a healthy person, they can go out and be in the community in a healthy way."

He said the gathering is also about building relationships, and Bourassa agreed. In the year and a half since she took the helm of the Institute of Indigenous Peoples' Health at CIHR, Bourassa has worked to build trust with First Nations. That's not an



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easy task, as research into Indigenous health has been dominated by non-Indigenous researchers and fraught with controversy about how data are collected and used.

This led, in 1998, to a national ethical standard for research involving Indigenous people called OCAP (ownership, control, access and possession). Under the standard, Indigenous communities own their knowledge, data and information. The OCAP standard led to trepidation among some researchers, said Bourassa. "There is fear that communities are not going to share their data. Those may be legitimate fears, but they may be unfounded." Ideally, OCAP principles are negotiated with researchers from the beginning of the research through to publication, she said.

The CIHR is committed to the self-determination of Indigenous peoples

throughout research projects, said Bourassa. This principle can influence the type of research conducted. Indigenous peoples have asked, for example, that researchers not focus only on deficits. This means avoiding "well-meaning" but stigmatizing statements, like comparing HIV rates among Saskatchewan Indigenous peoples to those in Third World nations. It also means selling researchers on community-based research, she said, which is "different, but not foreign" to those from a traditional academic background.

"We hope the scientific, Western world people will realize another way of seeing things that is just as valid," said Wadsworth. "We believe this is a good step forward to reconciling the two worlds."

Carolyn Brown, Ottawa, Ont.