



A vision for principled research

First Nations will be stewards of information that pertains to them

Anyone wondering why information governance has become such an important issue for First Nations people doesn't have to look far for an answer.

In the early 1980s, Richard Ward, a researcher at the University of British Columbia, took 883 blood samples from the Nuu-chah-nulth First Nation under the auspices of a Health Canada study of rates of arthritis among the Nuu-chah-nulth. In 1986, Ward moved on to the University of Utah and then to Oxford University, taking the blood samples with him and continuing to use them to obtain research grants and advance his career. He published more than 200 papers, on such topics as HIV/AIDS and population genetics, with the blood samples as their focus.

Ward even used the samples to support his theories about migration across the Bering Strait, entirely disrespecting and undermining the Nuu-chah-nulth traditional beliefs about Creation.

This case is not an isolated incident. Similar

breaches of First Nations rights have occurred in Canada, the U.S. and around the world. As a result, First Nations people have learned that we cannot expect government officials, researchers and corporations to understand or be aware of our interests and concerns. We've also learned that control over our own data is something that we have to claim for ourselves. There is no law in Western society that recognizes community rights and interests in information.

Enter OCAP, a set of principles created 15 years ago that lay out the ground rules for how First Nations data can and should be used.

OCAP, which stands for *ownership, control, access and possession*, guides a community in making decisions regarding why, how and by whom information is collected, used or shared. It reflects First Nation commitments to use and share information in a way that brings benefit to the community, while minimizing harm. It expresses First Nation jurisdiction over information about the First Nation.

The principles of OCAP are integral to the work of the First Nations Information Governance Centre (FNIGC), Canada's premier source of information about First Nations people living on reserve and in northern communities. As part of its mandate, FNIGC conducts the First Nations Regional Health Survey and the First Nations Regional Early Childhood, Education and Employment Survey.

The Assembly of First Nations has adopted the principles for their own research practice, and Health Canada and Aboriginal Affairs and Northern Development Canada are exploring new service contracts that better respect the principles of OCAP. I suggest that anyone interested in conducting research on First Nations should get up to speed on OCAP before they begin.

First Nations people understand the importance of research and appreciate the role that quality data plays. But before First Nations consent to any research initiatives, they have to be confident that the data will not be mismanaged. Understanding and following the principles of OCAP is the surest way a researcher can earn that confidence. ■

GAIL MC DONALD (AKWESASNE MOHAWK) IS THE OPERATIONS MANAGER FOR THE FIRST NATIONS INFORMATION GOVERNANCE CENTRE AND HAS BEEN A STRONG ADVOCATE FOR FIRST NATIONS JURISDICTION OVER INFORMATION FOR MORE THAN 20 YEARS.