





#### **Assembly of Treaty Chiefs**

# Resolution #2013-06-12/R04

Subject: Request for Access to the Indian Status Register for the Purpose of Identifying Status First Nations within the Alberta Health Care insurance Plan Registry

Whereas the Chiefs of Treaty No. 6, Treaty No. 7, Treaty No. 8 (Alberta) known as the Assembly of Treaty Chiefs (AoTC) did meet in a duly convened Chiefs Assembly on June 11, 12, 13, 2013 at the Radisson Hotel Edmonton South, AB.;

Whereas, research funding agencies and or Government Departments/Agencies funding research are required to have a specific research mandate endorsed by the Alberta Chiefs with regards to Research in First Nations communities of Treaty No.6, Treaty No.7 and Treaty No.8 (Alberta);

Whereas, recognizing the historical harm resulting from research in First Nations communities and First Nations assertions of governance over community information, the Assembly of Treaty Chiefs ratified First Nations principles of Ownership, Control, Access and Possession (OCAP™) through Resolution 30-03-2010#03 R, and adopted a research mandate to implement First Nations Leadership's right to self-determination, control and jurisdiction in research;

Whereas it has come to the attention of First Nations leadership that, without the consent of the Chiefs of Treaty No. 6, Treaty No. 7 and Treaty No. 8 (Alberta) First Nations, Alberta Health (AH) and Alberta Health Services (AHS)

has been accessing and using the Indian Registry System (IRS) provided by Aboriginal Affairs and Northern Development Canada (AANDC), for the purposes of First Nations health surveillance, sharing reports with First Nations and Inuit Health Branch - Alberta Region (FNIH) and for AH and AHS policy development and health service planning;

Whereas the IRS data held by AH/AHS is dated from 2009 and is not current, therefore, Alberta's Chief Medical Officer of Health has asked FNIHB to assist in acquiring an updated IRS data set which could be used to extract First Nations-specific data from provincial health information systems for research, surveillance and other purposes;

Whereas neither Alberta Health nor the Chief Medical Officer of Health sought the consent or participation of First Nations of Treaty No. 6, Treaty No. 7 and Treaty No. 8 (Alberta);

Whereas the First Nations of Treaty No. 6, Treaty No. 7 and Treaty No. 8 (Alberta) assert self-determination over First Nations' information, including the IRS and any First Nation-specific data that is extracted from provincial health information systems;

Whereas section 21 of the Alberta *Freedom of Information and Protection of Privacy Act*, including the "harm clause", can be relied upon to provide privacy protection over First Nations information held by the Government of Alberta or any public body;

Whereas the Government of Canada and the Chiefs of Treaty No. 6, Treaty No. 7 and Treaty No. 8 (Alberta) adopted the UN Declaration on the Rights of Indigenous Peoples wherein Article 19 ensures the free, prior and informed consent on matters that may impact the Indigenous peoples;

Whereas the leadership of the First Nations of Treaty No. 6, Treaty No. 7 and Treaty No. 8 (Alberta) wish to ensure that their First Nations participate in the governance of all First Nations information, regardless of where it is held, while also sharing information with provincial and federal partners to aid them in fulfilling their roles and duties to improve the health of the citizens of those First Nations.

#### BE IT THEREFORE RESOLVED that:

- 1. Resolution 30-03-2010#03 R is hereby explicitly extended to the creation or use of data regarding First Nations for surveillance activities, such as health status reporting.
- 2. Assembly of Treaty Chiefs hereby directs the Minister of Aboriginal Affairs and Northern Development Canada to deny all requests for access to or disclosure of the Indian Registry System (IRS) in relation to Alberta First Nations, without Alberta First Nation consent.
- 3. Until a collaborative protocol or data sharing agreement is established; and Alberta First Nations' consent is provided, Alberta Health is hereby directed to cease any attempts to access the IRS or to otherwise identify First Nation individuals within their provincial health information systems.
- 4. Any research or surveillance of Alberta First Nations must be conducted in accordance with a First Nations of Treaty No. 6, Treaty No. 7 and Treaty No. 8 (Alberta) Information Governance model, based upon First Nations principles of Ownership, Control, Access and Possession (OCAP™).
- 5. First Nations health data shall be leveraged, in a manner consistent with OCAP™, to assist all partners in fulfilling their roles and duties to improve First Nations' health.
- 6. The Alberta First Nations Information Governance Centre is hereby directed to work in partnership with Alberta Health Service, Alberta Health, First Nations and Inuit Health (Alberta Region) and any other necessary parties, to develop a Data Governance Agreement that will permit First Nations to govern the creation, use, access and disclosure of First Nations public health data; AFNIGC is hereby required to provide an update to leadership by March 31, 2014;
- 7. Any collection, use and disclosure of First Nations' data, First Nations' information and First Nations' traditional knowledge must adhere to a First Nations of Treaty No. 6, Treaty No. 7 and Treaty No. 8 (Alberta) Information Governance model, clearly stating the Chiefs are stewards of their own data, that would require free, prior and informed consent and that leadership must be involved in every stage of research involving Alberta First Nations communities which reflect First Nation research

ethics, values and accountability to First Nations Leadership in Treaty No. 6, Treaty No. 7 and Treaty No. 8 (Alberta).

Moved By: Chief Charles Weaselhead, Blood Tribe

Seconded By: Chief Romeo Cardinal, Bigstone Cree Nation

Vote:

**UNANIMOUS** 

Certified Correct By:\_\_\_\_\_