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| TITLE: | Data Sharing Agreement: First Nations Inuit Health Branch (FNIHB) and Brogan Consulting Inc. |
| SUBJECT: | Brogan – Non-Insured Health Benefits Data Sharing Agreement |
| MOVED BY: | Chief Arlen Dumas, Mathias Columbe Cree Nation, MB |
| SECONDED BY: | Chief Maureen Chapman, Skawahlook First Nation, BC |
| DECISION: | Carried by Consensus |

WHEREAS:

A. First Nations and Inuit Health Branch (FNIHB), Health Canada, entered into an agreement with Brogan Consulting Inc., an International pharmaceutical data company, to share First Nations (FN's) Non-Insured Health Benefits (NIHB) data without the consent of First Nations. The agreement transmits NIHB data to Brogan for pharmaceutical marketing, which negatively impacts First Nations control over data.

B. NIHB chose to sell First Nations health data in exchange for services without consultation or the consent of First Nations, and chose not to involve First Nations during this whole period, and maintained a total disregard for Ownership, Control, Access and Possession (OCAP) principles.

C. Brogan provides FNIHB with quarterly analysis and reports on specific issues annually, without any First Nations' consent, direction, or interpretation, and advertises on its website that is has NIHB data available for pharmaceutical companies to purchase or commission research using First Nations health data.

D. NIHB data was first released to Brogan in 2001 without First Nations' knowledge, and other First Nations information may have also been released to the public and exploited for commercial purposes by Brogan without the knowledge of First Nations.

E. NIHB is releasing information pursuant to the *Access to Information Act* (AIA). The Government of Canada and Brogan have avoided consideration of First Nations' collective privacy interests (which are

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not recognized by the federal government), and national and international ethical guidelines for the use of health data in research (which are recognized by the federal government).

F. NIHB's failure to prevent disclosure by finding that Brogan's request would unreasonably interfere with the operations of NIHB, and NIHB's continuing allegations of cost pressures which is passed along to First Nations, when an argument for "unreasonable interference" could have been made, NIHB choose to incur the costs to de-identify the data, and to obtain a legal opinion, and enter into an agreement with Brogan and to have Statistics Canada conduct a lengthy review of the data and the agreement to see if there are risks to personal privacy.

G. Part of NIHB's budget was diverted to these expenses and away from their primary purpose of improving First Nations health and the addition of administrative costs which "unreasonably interfere" with the operations of NIHB.

H. NIHB's creation and sale of these records for Brogan's commercial purposes harms the relationship between First Nations and NIHB, and may negatively impact future programs and negotiations, and places NIHB in a conflict of interest between its commercial interests, its obligations under ATIP and its fiduciary duty to First Nations which all are seen as "unreasonably interfering" with the operations of NIHB and all constituted for clear grounds for refusing to disclose the NIHB data to Brogan.

I. NIHB choose not to inform First Nations of the sale of NIHB data for over 7 years and signed a new agreement with Brogan in 2007 for another five years, with an option for another two year extension.

J. NIHB chose to sell First Nations' health data in exchange for services without consultation or the consent of First Nations; chose not to involve First Nations during this whole period, and maintained a total disregard for Ownership, Control, Access and Privacy (OCAP) principles.

K. First Nations recognize there is a serious failure of the NIHB Program management and software when it allows data to be anonymzed, extracted, disclosed and used for any purpose without ethical considerations and are concerned about community harms from such disclosure.

L. NIHB is responsible to First Nations for any community harms (whether it be physical, psychological, social, economic, legal, dignitary, and relational harm caused by release of health data, and is in breach of the governments fiduciary duty to First Nations in relation to the custodianship of sensitive First Nations health data and are responsible and accountable to First Nations for the use of our health data and are complicit in the exploitation of First Nations data.

THEREFORE BE IT RESOLVED that the Chiefs-in-Assembly:

1. Direct the AFN to demand Health Canada – First Nations and Inuit Health Branch (FNIHB) to account for all disclosures of First Nations health data so that the extent of the problem can be assessed and options for remediation considered.

2. Direct the AFN to inform the Minister of Health of the pressing need to reduce vulnerability to First Nations health data being disclosed to the public by government, and that First Nations must be in the

control of First Nations health data (such as a First Nation organization and not the federal government) to protect First Nations health data from Access to Information Act (AIA) requests.

3. Direct the AFN to proceed with upholding the OCAP principles for all First Nations health data through the First Nations Information Governance Committee.

4. Direct the AFN to address the Minister of Health in writing to terminate the contract with Brogan immediately, and AFN to enter into negotiations with Health Canada to ensure no agreements or contracts be made unilaterally by FNIHB to share any NIHB data of First Nations without a process that allows for First Nations' prior informed consent and confirmed benefits to First Nations, as defined by AFN Chiefs-in-Assembly.

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SHAWN A-IN-CHUT ATLEO, NATIONAL CHIEF