

Date: January 22, 2016

To: Repository Owners of AHS Data

From: AHS Provincial Research Administration

RE: **Centralized Process for HIA Research Agreements for Data Requests**

As Alberta's largest provider of care, AHS partners with Alberta's universities, funders and others to enable front-line teams to test ideas and adopt them. By integrating research and innovation into the delivery of care, AHS can nurture health research breakthroughs, innovations and new knowledge to the point where they generate tangible, real world clinical value. A critical component of this work is to initiate research studies led by our academic partners.

Further to the 2012 [memo](#) from Dr. Kathryn Todd regarding the requirement for s54 Health Information Act Research Agreements (in the absence of an AHS-negotiated Clinical Trial Agreement) to be executed prior to providing access to AHS data for research purposes, AHS Provincial Research Administration (PRA) team has been working over the past 18 months to streamline this activity. With over 900 new studies requiring these agreements each year, the administrative burden on researchers and repository holders is considerable and the lack of a central data base has limited our ability to ensure that the agreements are appropriately completed.

To enhance our compliance with privacy legislation, standardize the completion of these agreements and permit repository holders to focus their efforts on data extraction rather than searching for documents, the PRA team has developed a new resource to standardize and facilitate this process.

Effective February 1, 2016, all HIA Research Agreements will be prepared by the Provincial Research Administration team.

The Research Ethic Boards in Alberta have established processes that will allow PRA to receive notification of studies and/or amendments that require AHS data. A Research Administration Advisor will then:

- assess the study for data requirements as well as impacts to privacy and data security that require mitigations to be imposed in the HIA Research Agreement.
- facilitate the development of the Research Agreement by working with relevant AHS repository owner(s) and/or the repositories' knowledgeable analysts (using established processes where they exist) to assist the researcher to identify the data elements to be disclosed from each repository (Schedule C of the Research Agreement).
- negotiate data linkage or matching when needed once the list(s) of data elements have been received from all impacted repositories.
- compile the agreement and coordinate the review and signature process for the Principal Investigator ("PI") and all repository owners (to be signed in counterpart).

Electronic copies of the fully executed agreement are circulated to all signatories and stored in a central repository to: 1) serve as AHS' data disclosure log, and; 2) provide the approval signal for release of AHS data to the researcher.

Repositories can and should work with researchers prior to ethics submission/approval to identify the data sources and elements required for their study. However, in compliance with the HIA, repositories cannot release/allow access to AHS data for research until the fully executed agreement is received.

Our experience with 350 Research Agreements over the past few months has helped us to create a lean process that includes a fast track mechanism for studies where AHS repositories are already working on a data product or only a single data source is needed.

We look forward to supporting our repository holders and to making AHS data more easily available to answer research questions that are essential to the delivery of the best possible care for our patients.

If you have any questions, please contact Research.Administration@ahs.ca.

Marc Leduc
Executive Director, Innovation & Research Operations
AHS Research, Innovation & Analytics

Becky Wong
Director, Research Administration