

Data Use Agreement

The Alberta Policy Coalition for Cancer Prevention (APCCP) was funded by the Alberta Cancer Prevention Legacy Fund (Alberta Health Services) for the period January 1, 2009 – June 30, 2011. In October, 2011, the APCCP changed its name to the Alberta Policy Coalition for Chronic Disease Prevention.

The APCCP funds were administered through the research team at the University of Alberta and subsequently there are financial, scientific, and ethical reporting obligations which arise from this arrangement.

Release of Data

Requests to use APCCP data should be directed to the APCCP Research Committee, who will provide a timely response and/or follow up as appropriate.

Requests can be made initially via telephone or personal email to any member of the committee, but MUST be followed up with a brief written request to the official APCCP e-mail address: info@abpolicycoalitionforprevention.ca

Research data will be released to APCCP stakeholders where:

- a) the release of the data will not violate ethical approvals obtained through the research ethics board;
- b) the release of the data will not affect the ability of the APCCP Research Committee to publish the results in appropriate academic journals/ venues.

Generally, data will be released in *summary form* (i.e., summarized results); raw data files will not normally be shared outside the (academic) Research Committee (and never without appropriate approvals).

APCCP stakeholders have the right to request and receive specific analyses/ data which meet their needs.

The release of certain data may be embargoed or restricted:

- a) due to a need to obtain approval from appropriate research ethics board(s);
- b) where sensitivities exist around the identification of individuals (i.e. when the possibility exists that individuals could be identified from published reports of the research);
- c) due to academic publication requirements (e.g., where a journal requires that data be embargoed until the date of publication).

The Research Committee will endeavour to include the use of data by APCCP stakeholders in all *initial* applications to research ethics boards, thus ensuring that the release of data will not be delayed by the need to amend existing applications.

Provision of the data in no way implies transfer of ownership by the University of Alberta.

Use of Data

Once data has been released to APCCP stakeholders, they are immediately free to share it *internally* within their organizations, in compliance with the terms of this data use agreement.

Data released to *external* partners, stakeholders or the media will be subject to additional conditions (below) and must be in compliance with the terms of this data use agreement.

Use of data collected as part of the APCCP must be used in accordance with the following conditions:

- a) The APCCP must be **named** and given credit for conducting the research
- b) The *Research Committee member(s)/ investigator(s)* who led the research must
 - i. be **named** on all internal and external releases of data,
 - ii. be provided with the opportunity to ensure that any technical aspects and/or the interpretation of the data are 'correct,' and
 - iii. ensure that funders have been acknowledged appropriately (where applicable).

Media Releases (and other external releases of data)

Media releases should proceed as follows:

- a) The APCCP *Research Committee*
 - i. must be notified in writing, in advance of any planned media releases, normally with a minimum of 24 hours notice of the release,
 - ii. will normally provide a quote for media releases using APCCP data,
 - iii. will ensure that the interpretation of the data is consistent with other APCCP messaging,
 - iv. may elect to participate directly through a joint media release between the APCCP and the stakeholder.

The APCCP *Research Committee* can decline on behalf of the APCCP to participate directly in a release.

Should the APCCP Research Committee fail to respond within a timely manner (i.e., within the allotted 24+ hours), or decline to participate, APCCP members can proceed with a public release the data ***unless otherwise notified.***

- b) The Research Committee member(s)/ investigator(s)
 - i. must be notified in advance of any planned media releases, normally with a minimum of 24 hours notice of the release, and
 - ii. will normally provide a quote for media releases using their APCCP data.

The investigator(s) can, but would not normally, decline to participate directly in a media release.

The investigator(s) can request the temporary or permanent delay of the external release of data in order to fulfill their research obligations. A permanent delay in the release of data must be confirmed by the APCCP Research committee.

APCCP Research Committee:

Dr. Candace Nykiforuk

Dr. Kim Raine

info@abpolicycoalitionforprevention.ca

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Appendix

66.4 Research Requiring Ethics Review

66.4.1 Research

For the purpose of the UA Standards, *research involves a systematic investigation to establish facts, principles or generalizable knowledge.*

66.4.2 Research that Must Receive Ethics Review

All research that involves living human participants or involves human remains, cadavers, tissues, biological fluids, embryos or foetuses (except as stipulated in this 66.4.2) requires review and approval by an REB before the research is started regardless of:

- a) whether it is funded (eg, by grant, award, fellowship, contract) or is non-funded;
- b) whether funding is internal (ie, University) or is from an external source (including domestic and foreign public, governmental, and private sources);
- c) whether participants are drawn from University sources or from any other sources (eg, workplaces, residences, public places, day care centres, non-University hospitals, other universities, the military, public/private/separate schools);
- d) whether participants are paid or unpaid;
- e) whether it is conducted inside or outside Canada;
- f) whether it is conducted on University property or at any other location;
- g) whether it is conducted in a laboratory or in the field;
- h) whether it is conducted in person or by some other means (eg, mail, telephone, computer link);
- i) whether information is collected via direct observation, apparatus, questionnaire, interview, or review of records or other materials not normally available to the public;
- j) whether it is experimental, correlational, qualitative, or descriptive in nature;
- k) whether it is conducted to acquire basic or applied knowledge (eg, safety and function assessments of equipment and materials, product development assessments, personnel selection, consumer preferences, and product evaluation);
- l) whether the information collected has as its focus the human participant or some aspect of the environment with which the human participant interacts;
- m) whether the research is a pilot study or a fully developed project;
- n) whether it is primarily for teaching or demonstration purposes or whether the primary purpose is the acquisition of new knowledge;
- o) whether or not it is intended for publication or other public presentation.

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Research about living persons, including persons in public life and artists, based on information contained in publicly available materials is not subject to REB review unless the subject, or a third-party, is approached directly for interviews or for access to private papers or other materials, and then only to ensure that such approaches are conducted according to professional protocols. Note that research involving the observation, assessment, or recording of public behavior normally does require REB review. However, research involving observation of participants in, for example, political rallies, demonstrations, public meetings or similar activities does not require REB review since it can be expected that the participants are seeking public visibility and therefore observation and possible recording.

Quality assurance studies, performance reviews of an organization, or its employees or students within the mandate of the organization, or testing within normal educational requirements, are not subject to REB review unless they contain an element of research in addition to assessment. Researchers shall seek the advice of their REBs whenever there is any ambiguity or doubt about the applicability of the UA Standards to a particular project.

Procedures and practices exclusively used for pedagogic purposes (eg, classroom discussion, practicum observation), without a research component are not subject to REB review. Such procedures and practices do require attention to other professional standards of ethical conduct

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