Developing research agreements between communities and academic researchers: A case-study from northern Canada

Janis Geary1, Amy Colquhoun1, Crystal Lennie1, Tania Bubela1, Karen Goodman1
1. University of Alberta, Edmonton, AB; 2. Inuvialuit Regional Corporation, Inuvik, NWT

Background

Historically, population-based research with Aboriginal Peoples in northern Canada has primarily benefited academia.

Aboriginal groups advocate for greater control over the type of research being conducted and what happens with the data.

Research Agreements are tools to outline community-academic researcher partnerships

Some funding agencies and research-support organizations have begun to require that Research Agreements be developed before community-based research can begin.

Existing guidelines do not ensure that the research is mutually beneficial to communities and researchers.

The CANHelp Working Group has developed a research agreement which aims to balance interests of the communities and academic researchers, within the bounds set by funders and academic institutions.

Developing the research agreement:

Publicly funded research conducted in Aboriginal communities may have multiple parties who hold competing values and may be bound by conflicting norms and rules.

Community Guidelines

(OCAP, Doing Good Research-Yukon First Nations)

- Only research that benefits the community targeted for the research should be undertaken
- Communities should seek respectful researchers who develop long-term relationships with them
- Communities have collective ownership of data collected from them for research purposes
- Communities should control who has access to data
- Community representatives are entitled to review research reports before they are published to provide input and any dissenting interpretations
- Community-Academic Researcher Memorandum of Agreements in place before the researcher commences work in the community.
- Community consent should be obtained before publicly reporting findings after data analysis has taken place

Funder Guidelines

(CIHR, ArcticNet)

- Results must be published in a timely manner
- De-identified data must be made accessible in public databases
- Terms of community engagement are determined jointly by the researcher and the community
- Local governing structures should be respected
- Where possible, research should be relevant to community needs and priorities
- Researchers should let community representatives participate in the interpretation of data before completing final publications

Academic Guidelines

(University of Alberta)

- Individual faculty members cannot be party to research agreements
- Promotions of academic faculty are largely based on publication activity
- Academic researchers have intellectual property rights to the products of their research
- Academic researchers must be allowed professional autonomy and freedom of inquiry
- No one should censor what academic researchers publish (especially in the case of students)

A written Research Agreement should balance all interests of all parties. It should not replace a relationship between the individuals and groups involved in the research, but should reflect it.

CANHelp Working Group Research Agreement

was developed in partnership with a regional community leadership body, academic researchers, and the University of Alberta. Key Points:

Relationships

- The individuals who cultivated the relationships are named, not solely the institution or organizations
- Expectations of the community partners and the academic researchers are explicit
- Community partners will have a key role in shaping research priorities

Access to Data and Ownership

- Distinct uses of data are recognized: policy/advocacy uses and scientific discovery uses
- Participating communities will collectively own the aggregate data generated by the research
- University researchers are stewards of the data and will provide the community partners with de-identified databases on an ongoing basis
- Individual privacy is safeguarded by all parties
- Secondary uses of data will be approved by all parties

Publications

- All parties will have the opportunity to review all documents prior to publication
- In the case of dissenting interpretations, parties can request re-analysis, request that a statement of their dissent be included in the document, or publish an alternative interpretation
- Authorship is attributed to individuals who made a significant contribution to the publication and agree its content

The CANHelp Working Group was established in 2006 to address community concerns about health risks from a common stomach infection, *Helicobacter pylori.*