

## HLD XI – Practicum Project

### Objective

Develop a portfolio of recommendations to address community harm that has affected tribal communities and other vulnerable populations from health research and data collection/usage practices.

### Scope

The HLD Practicum Project team limited the scope of this project to focus on the “Community of Focus” (i.e. Tribal communities and other vulnerable populations). The portfolio of recommendations being presented would be limited to recommendations for the Community of Focus and not the Researcher/Research Institution or Funding Organization.

### Executive Summary

#### Community Harm:<sup>1,2</sup>

Often, research takes place on underserved populations rather than with underserved populations. This approach can further isolate and stigmatize groups that are already made marginalized.<sup>1</sup> As the *Report of the Royal Commission on Aboriginal Peoples* (1999) pointed out, First Nations people have historically had a problematic relationship with researchers, academics, and other data collectors:

*“In the past, Aboriginal people have not been consulted about what information should be collected, who should gather that information, who should maintain it, and who should have access to it. The information gathered may or may not have been relevant to the questions, priorities and concerns of Aboriginal peoples. Because data gathering has frequently been imposed by outside authorities, it has met with resistance in many quarters.”*

First Nations have often complained that they have been the focus of too much research (i.e. “Researched to Death”), that research projects are too often conducted by non-First Nations people, that research results are not returned to communities, and that the research does not benefit First Nations people or communities.

Prominent examples of this can be found in the Barrow Alcohol Study of alcoholism in Alaska in the 1970s, the Nuu-chah-nulth First Nation “Bad Blood” research of the 1980s, and the diabetes study of the Havasupai Tribe in Arizona during the 1990s.<sup>2</sup>

#### Community of Focus:<sup>3</sup>

The community with whom the research will be conducted, i.e. the community of focus, should be involved with the development of the research proposal from the beginning. Additionally, it is important that there be an ongoing process involving the community of focus and the researcher where interim goals are developed, check-in points are pre-determined and the goals revisited throughout the project.<sup>3</sup> The community of focus should protect all information concerning themselves, their

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<sup>1</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5689138/>

<sup>2</sup> <http://fnigc.ca/ocap.html>

traditional knowledge and culture, including information resulting from research. One way to accomplish this is through the approach of community based participatory research.

### **Community Based Participatory Research:<sup>3</sup>**

Community-based participatory research (CBPR) is a partnership approach to research that equitably involves community members, organizational representatives, and academic researchers in all aspects of the research process. It enables all partners to contribute their expertise, with shared responsibility and ownership; it enhances the understanding of a given phenomenon; and, it integrates the knowledge gained with action to improve the health and well-being of community members, such as through interventions and policy change (Israel, Schulz, Parker, and Becker, 1998). While every CBPR project may not involve an intervention, there is a commitment to feeding back the data, jointly interpreting the data, disseminating the data, and translating the data into interventions and/or policy.<sup>3</sup>

### **Successful Models to Reference<sup>4</sup>:**

There are successful models in existence for a community of focus to consider following when entering into research studies. One of the most documented and successful models is OCAP. The principles of Ownership, Control, Access and Possession (OCAP) enable self-determination over all research concerning First Nations. It offers a way for First nations to make decisions regarding what research will be done, for what purpose information or data will be used, where the information will be physically stored and who will have access. OCAP is about doing research the First nations way – for First Nations, by First Nations.

Good research has the potential to create valuable new knowledge or substantiate what is already known. It can foster positive change or confirm that things are working well. Research has been used by First Nations to access funds for programs and services, assess community health and evaluate the effectiveness of health interventions, and to develop strategies or plans for community services and programs to name a few.

In the past, research was usually conducted in ways that excluded the people it aimed to understand. In general, an outside researcher would initiate a research project while the community and its members were simply the research subjects. Communities were seldom consulted with and had very little, if any, control over the research process.

The principles of OCAP are one aspect of First nations aspirations towards self-determination and self-governance. The principles represent a comprehensive framework developed by First Nations to bring self-determination into the realm of research and information management. OCAP applies to all research data or information initiatives that involve First Nations, and encompasses all aspects of research (including funding and review), monitoring, statistics, cultural knowledge and so on.

The OCAP principles are defined as follows:<sup>4</sup>

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<sup>3</sup> <http://www.detroiturc.org/about-cbpr/what-is-cbpr.html>

<sup>4</sup> <http://cahr.uvic.ca/nearbc/documents/2009/FNC-OCAP.pdf>

- **Ownership:** Refers to the relationship of a First Nations community to its cultural knowledge/data/information. The principle states that a community or group owns the information collectively in the same way that an individual owns their personal information. It is distinct from stewardship [or possession].
- **Control:** The aspirations and rights of First Nations to maintain and regain control of all aspects of their lives and institutions include research, information, and data. The principle of control asserts that First Nations Peoples, their communities and representative bodies are within their rights in seeking to control all aspects of research and information management processes which impact them. First Nations control of research can include all stages of a particular research project – from conception to completion. The principle extends to the control of the resources and review processes, the formulation of conceptual frameworks, data management and so on.
- **Access:** First Nations people must have access to information and data about themselves and their communities, regardless of whether it is currently held. The principle also refers to the right of the First Nations communities and organization to manage and make decision regarding access to their collective information. This may be achieved, in practice, through standardized, formal protocols.
- **Possession:** While ownership identifies the relationship between a people and their data in principle, possession or stewardship is more literal. Although not a condition of ownership per se, possession (of data) is a mechanism by which ownership can be asserted and protected. When data owned by one party is in the possession of another, there is a risk of breach or misuse. This is particularly important when trust is lacking between owner and possessor.

Insisting on the OCAP principles is a way to turn a good research idea into a good research process. OCAP allows First nations to not only judge the merits of a proposal, but also to put forward conditions so that good research ideas can be done in an effective way. All stakeholders in a research project stand to gain from OCAP-compliant research.<sup>4</sup>

### Summary

In summary, depending upon the community of focus and the research study being proposed, there are many tools and resources available for the community of focus to reference and use in order to protect themselves and their data. While we focused on the OCAP principles, the Navajo Nation Human Research Review Board and Rocky Mountain Tribal Institutional Review Board are also great resources. We highly recommend that the community of focus develop a community review board to vet the research proposal. Additionally, clear check in points with the researchers should be established throughout the project and appropriate agreements should be in place to protect themselves, the data collected, and outcomes resulting from the research.

It is important for the community of focus to ask questions when deciding whether to participate in a research study or not. Please see the attached Questions to Ask document. These questions are intended for a community of focus to consider and can assist in deciding the value of the research project to the community, the risks/benefits to the community, whether or not to approve the research proposal, or how the project could be modified to be acceptable. Additionally, please refer to the Recommended Resources for Communities of Focus document when considering different models and approaches to community based research models.