

IMPROVE LIFE.

Decades of Doing: Indigenous Women Academics Reflect on the Practices of Community-Based Health Research by Kim Anderson and Jaime Cidro

### Introduction

It has been several decades since the establishment of the Ownership, Control, Access, and Possession (OCAP) principles and increase scholarship on Indigenous research ethics. OCAP was developed to promote self-determination for Indigenous peoples and communities when conducting research. Through conversations with Indigenous health scholars, Kim Anderson and Jaime Cidro review the key themes shaping understandings and practices of Indigenous health research. These themes include (a) research in relationships, (b) creating partnerships and negotiating across systems, (c) self-determination applied to research, and (d) community-engaged research.

### Summary

## 1. Research in Relationship

Research in relationships revolves around community-based and Indigenous research methodologies. Indigenous communities may at first be fearful and untrusting of researchers given the historical abuse done by researchers. Thus, establishing good relationships is the most important factor in doing Indigenous health research. Building relationships can involve participating in activities that may not appear to be directly related to the tasks of data collection, such as informal meetings. Participants discussed how relationship building is not easy to learn and researchers need to recognize when something is appropriate or when to step back.

## 2. Creating Partnerships and Negotiating Across Systems

With Indigenous health research, there's a need to negotiate expectations for all parties; ask what everyone is bringing to the table, what does everyone need from this and acknowledge that people have different needs. Researchers need to make sure community partners are aware of what tasks they are responsible for and don't assign extra tasks without discussing it.

## 3. OCAP - or Self Determination Applied to Research

The OCAP has allowed communities to find a voice related to research but there's a need to "fine-tune" this process. Some participants discussed how the discourse around OCAP can create barriers in their work. That is, the OCAP has created more controls for those working with

and in communities. This OCAP discourse can be used for gatekeeping and prohibiting research that might be unpopular (i.e. on reserve-based communities).

The OCAP has also created a lot of jurisdictional challenges for researchers in terms of gaining or distributing information. One participant stated that the OCAP is all about ownership, control and access of research materials. These conflicting and demanding systems make it difficult to determine how to apply the discourse into health research regarding appropriate distribution of personal information.

# 4. Community-Engaged Research, Agent of Change

Participants expressed the need to do research that was community driven (i.e. engages communities in the problems people face and moves them to action) to ensure methodologies are centered around Indigenous people. Yet, researchers still play a crucial role in community driven research. There are things they as academics are aware of that Indigenous communities might not know but would benefit from. To ensure equal participation and effort from researchers and community members, research should include capacity building at the community level. This can be described as advancing skills to understand, use, and conduct research at the individual or community level.

## Discussion and Key Findings

Anderson and Cidro discovered that there is a reluctance to follow the OCAP principles as it is challenging to meet its standards. The principles of the OCAP require navigating through several systems that may not sync with research protocols or community engagement guidelines. For instance, institutional realities do not allow for relationship building as university protocols are fast moving and strict. This can create great stress on Indigenous health researchers as they struggle to meet all the demands of working in university environments with contributions from community members.

Also, university REBs, research ethics at the community or partner level, and expectations from funders, all require a set of negotiation systems that may not coincide with the OCAP principles, making it difficult to implement. The processes required by REBs are often incompatible with social science and community-based participatory work. Also, the slow pace of university ethics can interfere with the timing and needs of community-driven work. University protocols, including ethic applications, can put relationships and best practices at risk when engaging in community-based research. The OCAP's link to self-determination in research is also hard to apply in practice as their principles remain colonial. That is, the principles of "ownership" and "possession" make it difficult to encourage involvement from Indigenous communities as they do not promote self-determination.

Indigenous researchers, therefore, are hesitant to use the OCAP due the inflexible discourse surrounding it. This creates a gap between OCAP in principle and theory and OCAP in action. Overcoming this gap is central to moving into a more nuanced consideration of how

Indigenous scholarship can be both meaningful to community and meaningful for the Indigenous scholar.

Currently, Indigenous health researchers find themselves constantly caught up in discussions of OCAP as it is not fully understood by all and thus not applied properly. Therefore, there is a need to develop better protocols and understanding between universities and communities. This will include: developing more suitable finance arrangements, further understanding between community partners and university partners about their distinct work demands and environments.