



Collaborative Research: an "indigenous lens" perspective

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Who are Indigenous People?

Identifying and defining Indigenous peoples internationally is complex and the source of much contestation. It is best to allow Indigenous peoples themselves determine how they will be defined and how they will be viewed for the purposes of research.¹

What is Collaborative Research?

This work builds upon previous work that highlights the IAPH-CIHR guidelines for research with Indigenous communities and is therefore intended to advance and not duplicate previous presentations and statements prepared for the Coalition regarding research collaboration with the Indigenous community. In addition this work is limited in that it does not take into account the unique circumstance where researchers in high income countries are engaged in research in low or medium income countries where many layers of intermediaries (e.g., national or regional governments or universities) may act as a filter or gatekeeper to the Indigenous community that is the focus of the research effort.

Collaborative (or participatory) research can be defined as researchers working together to achieve the common goal of producing new scientific knowledge.² In order to make this definition useful, the following criteria for determining who is a collaborator on a given research project is proposed: (1) individuals involved throughout the project's duration or make frequent/substantial contribution(s); (2) those whose names appear on the original research proposal; (3) those responsible for at least one of the main elements of the project, such as design or analysis; (4) if appropriate, an individual responsible for a key step in the process, such as producing the original hypothesis; and (5) if appropriate, the original project proposer or funder who serves in a more managerial role rather than directly conducting research. While this definition is not without difficulties, few attempts to define collaborative research have been undertaken

and it is beneficial to determine what a collaborative research relationship is before attempting to define how one is established.

Collaborative research may be viewed more as an attitude or approach rather than well-defined techniques to be followed.³ The focus is on empowering local people to take charge of the research process, and this empowerment may be achieved via numerous methods that should be determined by the details of the population and project at hand. Truly collaborative research involves respecting and understanding the participants and recognizing the knowledge and capabilities of the local people who can work with researchers to obtain analyses and solutions. It should be viewed not only as something that should be done for ethical reasons, but also as a way to improve the quality of research.

Costs and Benefits of Collaborative Research

Many benefits of collaborative research have been identified.⁴ Collaboration increases the probability that the knowledge, skills and techniques required will be available within the collaborators, and the time spent learning information or skills is minimized. This is particularly relevant given the increasing complex nature of research. Relatedly, transfer of knowledge and skills often occurs within collaborative research relationships, and is often a more effective way of learning than classroom instruction. A sharing of perspectives and ideas can foster creativity and expanded knowledge that would not occur during sole research initiatives. Collaborative relationships may also provide researchers with unique opportunities to work with other researchers that they would otherwise not be exposed to, creating increased opportunities for joint publications that are extremely valuable and beneficial to research careers.⁵

A comprehensive review of collaborative research would be incomplete without the acknowledgement of existing costs of collaboration.⁶ Most obviously is the financial cost, which is often associated with travel and shipping in collaborative

relationships. Time costs are also an important consideration, particularly given the high time demands often places on researchers. Additional time is often associated with travel, the establishment of a collaborative relationship and the joint preparation of research material and results for dissemination (including agreement on research problem, design, etc). Generally, participatory research encompasses more than traditional research does (e.g., more communication, conferring with a larger number of individuals and organizations), and thus an increased cost, monetary or otherwise, is logically associated with this type of research.⁷

Collaborative Research Concerns

Structural Inequality

Structural inequality in collaborative research settings is of primary concern in all aspects of the relationship from creation of the partnerships to project management to evaluation.⁸ While many criticize north-south partnerships for inequalities⁹, others have found that this pervasive view may not actually be true.¹⁰ In fact, misunderstandings and conflicts regarding cultural understanding and publication may actually be rarer than once thought.¹¹ Nonetheless, all available precautions must be taken to establish and/or maintain equality among partners in a collaborative research endeavour.

Competent Management

In order to establish and maintain collaborative research partnerships, competent management is vital. A potentially dangerous assumption widely exists that most, if not all, prominent and successful research can successfully manage international research based on their experience (i.e. established through trial and error).¹² However, great care and, indeed, specialized training, is essential to good research management, which is a vital resource in international research. Competent research management involves an awareness of group processes and sensitivity to diversity (e.g. language, race, ethnicity, gender, disability).

Colonialism

Although the frequency has declined, much foreign-led research in developing countries continues to be semi-colonial in nature

despite encouragement to move away from such an approach.¹³ For obvious reasons, this approach may have negative effects on partner countries. In order for collaborative research to take place, researchers who endeavour to conduct research with indigenous populations must surrender their claim to dominance and superiority.¹⁴ This may be particularly difficult with those who do indeed hold such views, yet do not admit it.

Capacity Building

Capacity building in collaborative research should be viewed as reciprocal, and not as something bestowed upon one partner by another.¹⁵ One-sided views of capacity building perpetuate the stereotype of partner domination by the researchers who seek to work with indigenous populations, and thus are in discord with the principles of collaborative research at its core. Two widespread assumptions, which have been the target of refutation, strengthen this misguided perception of capacity building: (1) transfer assumption (i.e. poor countries cannot produce knowledge themselves, and therefore need the transfer of knowledge and technology from the North); (2) professional knowledge assumption, (i.e. the South needs to rely on professional, objective knowledge rather than traditional knowledge).¹⁶ Moving past these assumptions and viewing capacity building as a reciprocal relationship is essential for collaborative research.

Consent

While individual consent is essential, the need to address community consent arises in research with many Indigenous communities.¹⁷ If community consent is required, it should be considered supplementary to, not a replacement for, individual consent. This consent should not be viewed as a simple signing of a form, but a process in which researchers and community representatives engage in together. If major changes are made to the agreed-upon protocol, then renewed consent is required for the changes.

Who speaks for the community in these situations? A clearer definition of "community", more detailed guidelines regarding what a community entails, and an increased understanding of who is in a position of leadership or authority within the community are needed to help guide Regional Ethics Boards

(REBs) in such matters.¹⁸ It may be unclear who the representatives are, and there may even be multiple organized bodies within the same community, such as a traditional band council and elected municipal government.¹⁹ While there is much debate on the definition of a community, many Indigenous communities do have the distinctions of being geographically isolated, having common histories and traditions that are distinct from the dominant culture and having political sovereignty. These issues are particularly salient for genetics research which studies groups and not individuals.

Implementation: From Theory to Practice

Collaborative research is often much more complicated and uneven than theoretical writings can convey.²⁰ Complete control is rarely assumed by the local people for numerous reasons, not the least of which is that the community may not want complete control. Local people are often sceptical and hesitant to partake in a project that has little direct benefit. Such scepticism is particularly evident in Indigenous populations, possibly due to the extensive research that has been conducted on Indigenous peoples in many parts of the Americas and Australia.^{21,22,23} Many Indigenous peoples feel as though they have been the subject of numerous research projects of varying experiences, resulting in attitudes toward research that span irrelevant to a serious violation of integrity and autonomy.²⁴

Despite a reluctance to participate, Aboriginal communities, and their health authorities, have a need for health information and education that will further decolonize the long history of pathologizing in Aboriginal health research. Quality programming is clearly needed to develop appropriate health programming and services. Even after participation is secured, it waxes and wanes over time in accordance with interest and motivation, making participation unpredictable and uneven.²⁵

Care must be taken to ensure that the perspectives and needs brought forth by the stakeholders in the indigenous group are representative of the group as a whole.²⁶ Additionally, perception of need may change over time and researchers should be aware that these changes may take place and accommodate them when reasonable.

Principles of Research Partnership

The Swiss Commission for Research Partnership with Developing Countries outlined 11 principles for conducting research with developing countries throughout the process from determining the objectives of the research to disseminating and applying the results and beyond.²⁷ These comprehensive guidelines provide practical advice that is worth closer examination, and thus will be explored here in further detail.

1. Decide on objectives together

While the researchers often take the initiative and offer suggestions regarding research topics, providing fully developed research projects to potential partners should be avoided, as this approach provides little room for input from others. Interests and needs of both sides must be considered. Researchers with an idea for a study should contact potential partners as soon as possible in order to avoid the imposition of a fully formulated project.

2. Build up mutual trust

Mutual trust is obviously essential to a collaborative research relationship. The time and patience necessary to establish such trust varies between groups, but the investment is necessary even when the establishment of such a relationship is arduous. Past experience is an important element of trust and renewed contact with individuals and organizations that you have successfully collaborated with in the past is therefore advisable. If new partnerships are to be established, personal contact and preliminary visits prior to a commitment to collaboration is preferable.

3. Share information and develop networks

An effective communication system must be created to overcome both geographical and culturally differences. An adjustment in way of thinking and self-expression may be required for truly effective communication. All partners should have comparable levels of information

regarding the joint research activities which often involves including all partners in regional and international information networks. If the partnering group does not have adequate methods for communication then investment in infrastructure (e.g. telephones, internet connections) must take place and should be included in the research budget. Expectations regarding regular communication should also be determined.

4. Share responsibility

Within the confines of competence and resources, leadership and management of the joint project should be shared as much as possible. Inclusion of partners at all levels of the project fosters a sense of ownership toward the research. This approach also allows individuals to gain expertise and experience participating in various aspects of the project which aids in capacity building. Clarification of responsibility of leadership and management should take place early in the process. Discussions should preferably occur in a face-to-face meeting with a written record of decisions, particularly if culture and language differences exist which can lead to misunderstandings.

5. Create transparency

Contribution by all partners, and a valuing of contributions both monetary and otherwise, will strengthen the research. All partners must be aware of the way in which resources are used and financial decisions should be made by all partners together whenever possible. The creation of a binding written agreement laying out the contributions, rights and duties of all partners is advisable. All partners must be permitted unlimited access to relevant documents and regular audits should be carried out.

6. Monitor and evaluate the collaboration

Continuous monitoring of the partnership, including regular external evaluations by a representative team, should take place. Success of all aspects (e.g.,

management, communication, decision-making, implementation, capacity building) from the perspectives of all partners should be examined. Regular meetings facilitate the acknowledgement of problems at an early stage which improves capacity to solve problems effectively. Writing of interim reports should be jointly undertaken and criteria for regular evaluations should be established as early as possible.

7. Disseminate the results

That unlimited access to the research results must exist is obvious. As partners may have varying degrees of experience in publishing of results, particularly with regard to peer-reviewed journals, special care must be taken to ensure participation of all partners in dissemination. Communication of findings that may be used directly to solve problems must be clear and facilitate putting the findings into practice. Results must be written in a way that allows the general public to understand them and translation into local language should take place, if applicable. Transfer of knowledge may also take place in ways other than written publications, such as lectures, exhibitions, drama, etc.

8. Apply the results

Simple dissemination of the results is not enough. The research team is obliged to ensure the results are utilized to the benefit of the target group as much as possible. In many cases, the group has expectations that participation in the research will help their disadvantaged community, and it is unfair for researchers to not work to apply the results. This process may be complex and working with people or institutions who have good contact with the target community is usually best.

9. Share profits equitably

All partners should share in any intellectual and commercial value of the research results. When results are disseminated, all those who were involved in a significant way should appear. Rights to publish should

be determined and committed to writing in advance. When considering legal matters, such as patent creation, both international law and national regulations of the country in which the research took place must be considered.

10. Increase research capacity

Improving research capacity should be a priority throughout the research activities. In addition to increasing a capacity to conduct effective research independently, research partnerships between target groups should be promoted. Such relationships may even be helped with the simple provision of names and address as visiting researchers often have more complete information than is available to the target community.

11. Build on the achievements

New knowledge and skills are only valuable if they are put to use. Successful projects will produce: (1) new knowledge that will be recorded in publications; (2) a contribution to sustainable development; and (3) new or more highly developed research capacities which must be maintained by the continued success of new or existing institutions to promote research and employment of the individuals who participated in the research in sustainable jobs. Too often good scientists from the target group are lured away from their community by better opportunities offered elsewhere, contributing to a "brain drain" situation. Increased respect is needed for this type of research and this respect must be earned via recognizable achievements and good public information. Frequent personal communication between partners should continue after the project has ended. When possible, advocacy with organizations that would provide further employment opportunities in research should be undertaken.

Principles for Research with Indigenous Populations

Participatory research is often conducted with indigenous populations and principles of collaborative research can be applied directly to research with indigenous populations. Indigenous populations, however, are unique in some ways to other groups that may be involved with participatory research. Principles for conducting research with Canadian First Nations populations have been put forth which can be applied to indigenous populations internationally.²⁸ First of all, the indigenous group has ownership of the cultural knowledge, data and information that is obtained or compiled during research. Secondly, the indigenous population is within its rights to seek control of all aspects of research. Control is particularly important to many indigenous populations due to the lack of control often experienced in the past. Thirdly, indigenous populations must have access to the information regarding individuals and groups involved in the research, as well as be involved in decisions regarding who receives access to the data. Fourth and finally, the indigenous group must be in literal possession of the relevant data.

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