



CAPTURE

Canadian platform to increase usage of real-world evidence

Plateforme canadienne pour accroître l'usage de données probantes du monde réel

ANNOTATED BIBLIOGRAPHY ON CONDUCTING RESEARCH WITH ABORIGINAL COMMUNITIES

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ABOUT THE ANNOTATED BIBLIOGRAPHY

This annotated bibliography was produced to inform the development of a survey of the challenges experienced by Aboriginal, Northern, and Remote communities involved in evaluation and to create a data collection tool adaptation framework for Aboriginal, Northern and Remote communities. This work was undertaken by Reciprocal Consulting on behalf of the CAPTURE Project. The CAPTURE Project is a strategic initiative funded by the Canadian Partnership Against Cancer. CAPTURE is creating a knowledge exchange platform to facilitate the collection, sharing and using of real-world knowledge on health promotion programs (www.thecaptureplatform.ca). Funding for this work was provided by the Public Health Agency of Canada.

The annotated bibliography consists of a review of 25 peer-reviewed and grey literature articles. The articles addressed historical factors for research with Indigenous communities, participatory research, the community-based research approach, guidelines or ethical protocols for working with indigenous peoples, and survey adaptation: specifically cross-cultural survey adaptation guidelines.

The articles were reviewed for information on the unique challenges or barriers to doing research with Aboriginal communities, as well as suggestions for working with or researching with Aboriginal communities. Information on mechanisms for knowledge translation was also noted to provide further context for making research and evaluation useful for communities. When possible, information from the articles was organized according to the Four R's framework of respect, relevance, reciprocity and responsibility developed by Kirkness and Barnhardt (1991). Kirkness and Barnhardt (1991) propose that these principles should be the core of conducting research with Aboriginal peoples. *Respect* means valuing and building on the diverse knowledge of the individual, culture and community. *Relevance* means involving the community in all stages of the project to make sure the research is relevant to the needs and dreams of the community and culture. *Reciprocity* means when the researcher and community both benefit from the project/evaluation, and learning and research is a two-way process. *Responsibility* means an overarching concept of the previous three R's, and the researcher/evaluator is mindful of all perspectives during the process. Once all of the articles were reviewed, four researchers discussed the content of the articles and grouped them into thematic topic areas. The summaries of articles presented below are organized into the thematic topic areas.

COMMUNITY-BASED RESEARCH APPROACH

Delormier, T., Cargo, M., Kirby, R., McComber, A., Rice, J., & Potvin, L. (2003). Activity implementation as a reflection of living in balance: the Kahnawake Schools Diabetes Prevention Project. *Pimatzwin*, 1, 145-163.

Respect

- The program activities were structured around the Kanien'kehaka people's cultural values (151)
- The intervention staff was highly open and responsive to community requests (152)
- Activities were designed to be "familiar, pertinent, and appeal to participant tastes and interests through tradition...and socially based practices" (157)

Relevance

- Ecological models for health promotion programs suggest to direct interventions at multiple levels/sectors in the community (146)
- This approach attends to the complex interdependence of factors that influence behaviour and the environment (146)
- Community-based theories for the primary prevention of diabetes have been accepted in some Aboriginal communities (147)
- Researching community-based approaches and developing culturally sensitive theory can help community development and scientific knowledge (147)
- Kahnawake Schools Diabetes Prevention Project (KSDPP) takes a holistic approach of embedding intervention activities into the overall goal of living in balance (149-50)
- Activities focused in the domains of eating in balance, active living, and diabetes awareness (150)
- The intervention staff knew the community well, being from and living in the community (151)
- The intervention plan took participant feedback, community responses and situational circumstances and was adapted accordingly (152)
- They carried out intervention activities where the intended target groups would be present, therefore facilitating "getting living in balance" messages to them (156)
- KSDPP capitalized on existing important occasions in the community, such as special occasions, cultural events, etc. by networking- simultaneously supporting the activities of other organizations (156)

Reciprocity

- Priority for Aboriginal research is to develop knowledge for the primary benefit of the community, and the potential benefit of sharing this knowledge with other communities (including the scientific community) (147)
- Collaborated with community organizations which created reciprocal support for the activities (157)

Responsibility

- Planning was mainly done collaboratively, through meetings with partner organizations (153)
- Intervention staff listened to feedback on their activities from community partners, parents, teachers and other professionals (156)

Israel B. A., Schulz A. J., Parker E. A., & Becker A. B. (1998). Review of community-based research: Assessing partnership approaches to improve public health. Annual Review of Public Health, 19, 173-202.

Respect

- Incorporating the partners' "unique strengths and shared responsibilities" enhances the understanding of a given phenomenon and a community's social and cultural dynamics (177)
- The community is recognized as an aspect of individual and collective identity (178)
- Community-based research has the potential to "bridge the cultural gaps that may exist" between the project partners (181)
- Barriers in partnerships during research can stem from differences in perspective, priorities, values, beliefs, language, or assumptions (184)

Relevance

- The terms "community-based research", "community-wide research", "community-involved research", and "community-centered research" are at times used interchangeably (177)
- The distinction comes from the extent to which the community is involved, whether it is simply where research is conducted or if community members share active engagement in the research process (177)
- In public health community-based research is a collaborative approach, involving community members, organizational representatives, and researchers equally in all parts of the research process (177)
- The research process includes a cyclical and iterative process (180)
- The research addresses health from a positive model (emphasizing physical, mental and social wellbeing) and an ecological model (emphasizing biomedical, social, cultural, historical, economic and political factors as health determinants) (180)
- Community-based research operates on a more informed and effective theory that is grounded in social experience (181)
- The involvement of support staff/team can maintain the partnership's cohesiveness (186)

Reciprocity

- The research builds on strengths, resources, and relationships within the community (178)
- The research combines knowledge and action for the benefit of all partners (179)
- The research process encourages a co-learning and empowerment process that facilitates the reciprocal transfer of knowledge, skills, capacity and power (179)
- The researchers disseminate findings and knowledge gained to all partners in a language that is understandable and respectful to all, and the "ownership of knowledge is acknowledged" (180)
- Community-based research acknowledge the concept of "knowledge is power" and thus the partners' knowledge gain can be used to benefit the community (181)
- It also provides funds and potential employment opportunities for community partners (181)
- Identifying common goals and objectives and having a democratic leadership is important for the entity of the partnership (186)
- A goal of this type of research is to improve the health and wellbeing of the communities involved, both directly (identifying needs) and indirectly (increasing their power/control over research) (181)

Responsibility

- The research process facilitates collaborative partnerships in all of its stages (178)
- Community-based research strengthens the quality of the research and the program development capacity of the partners (181)
- Barriers may exist in the partnerships created: lack of trust and respect, inequitable power/control (183)

- Conflicts over funding may also arise (184)
- Because of the time-consuming nature of this type of research, conflicts may arise due to the expenditure of time (184)
- Conflicts may also arise over different emphases on task and process (184)
- May encounter challenges when deciding who will represent the community and how it is defined (185)
- Important to develop consistent operating norms to facilitate partnerships (185)
- Also critical to the success of the partnership is the presence of a community organizer, who has a history with the community and can bring people together (186)

ETHICAL ISSUES IN RESEARCH WITH FIRST NATIONS COMMUNITIES

Castellano, M.B. (2004). Ethics of Aboriginal Research. Journal of Aboriginal Health, 98-114.

Respect

- When Aboriginal Peoples speak of maintaining and reviving their cultures, they are referring to “restoring order to daily living in conformity with ancient and enduring values that affirm life (100)
- Canadians must recognize that even today, Aboriginal cultures are vibrant and distinctive (102)
- Despite the struggle of its expression, Aboriginal Peoples continue to have a fundamentally different worldview (102)
- This struggle extends to applying their cultural ways to manage economic issues, governance issues, human services, and relations with the country and world (102)
- In describing the encounter of Aboriginal philosophy and positivistic science, the phrase “jagged worldviews colliding” was coined by Leroy Little Bear (103)
- Aboriginal worldviews incorporate the need for positive human action to be embedded in an ethical, spiritual context (in addition to its physical/social context) (103)
- Because of the difference in knowledge creation between cultures, there is a need for different methods of collecting and validating information- cannot be done through Western methodologies (106)

Relevance

- History: “If we have been researched to death...maybe it’s time we started researching ourselves back to life” (98)
- History: The associations Aboriginal Peoples make with research are negative due to past purposes and meanings for its practice- the outcomes were often misguided and harmful (98)
- The act of “researching ourselves” can be either Aboriginal directed research or the making of successful partnerships (98)
- The West Coast nations’ potlaching ceremonies were a means to validate ethical issues, such as family responsibilities and land tenure (101)
- Many other nations orally and non-verbally transmitted their ethical codes through their relationships with family and the community (101)

- Aboriginal Peoples have an interdependent relationship with the natural elements, and industrial development that compromises the environment directly violates their wellbeing (103-4)
- Consult with the community while developing research protocols (108)
- Drafts of research reports should be given to the community in advance to hear their views (108)

Reciprocity

- Important to reframe ethical codes and practices for the mutual benefit of the Aboriginal world being studied (100)
- Researchers and those who are researched have aligning views of what constitutes “social benefit”, research is more likely to satisfy the needs of both sides (103)
- “Holistic awareness and highly focused analysis are complementary, not contradictory” (104)
- Research where there is objectivity through distance between the researcher and community violates Aboriginal ethics of a reciprocal relationship (105)
- Aboriginal Peoples have an increasing desire for community control, whether through assuming full responsibility or collaborative research (in which responsibilities are outlined by contract) (105)
- Many Aboriginal Peoples feel an imbalance in power with the researchers, and fear that non-compliance with research may lead to loss of funding (105)
- Maintain communication with the community during implementation (108)
- Involve the community in the conducting research, while transferring skills/expertise to the community (108)

Responsibility

- Along with identifying research concerns (such as irrelevancy and inaccuracy), it is imperative that Aboriginal Peoples suggest solutions to these problems that have affected them (100)
- Elders want to ensure that before divulging their knowledge, the seeker is compliant with ethical obligations that prevent them from doing ill to the knower or community (104)
- Obtain informed consent from community leaders before approaching individuals (108)
- Principles when devising an ethics regime for Aboriginal Peoples (109):
 - Principle 1: “*Aboriginal Peoples have an inherent right to participate as principals or partners in research that generates knowledge affecting their culture, identity and well-being. This right is protected by the Canadian Constitution and extends beyond the interests that other groups affected by research might have.*” (109)
 - Principle 2: “*The Government of Canada has a fiduciary obligation to guard against infringement of Aboriginal rights in research activities, particularly in institutions and activities for which it is responsible. The appropriateness of particular safeguards must be endorsed by Aboriginal Peoples through their representative organizations.*” (110)
 - Principle 3: “*Action by the Government of Canada to establish ethical standards of research should strike a balance between regulations that restrict infringement of Aboriginal rights and those that respect the primary of ethical codes originating in affected communities, including Métis communities.*” (110)
 - Principle 4: “*Ethical regulation of research affecting Aboriginal Peoples should include protection for “all knowledge, languages, territories, material objects, literary or artistic creations pertaining to a particular Aboriginal Peoples, including*

objects and forms of expression which may be created or rediscovered in the future based upon their traditions” as cited in the emerging international norms.” (11)

- Principle 5: “*The federal government, in collaboration with Aboriginal Peoples, [should] review its legislation on the protection of intellectual property to ensure that Aboriginal interests and perspectives, in particular collective interests, are adequately protected.*” (111)
- Principle 6: “*Development and implementation of ethical standards for Aboriginal research should be in the hands of Aboriginal Peoples, as experts in devising minimum standards for general application and as majority members on Aboriginal-specific research ethics boards serving local, regional and national communities.*” (111)
- Principle 7: “*The costs of community consultation, development of research plans, negotiation and implementation of ethical protocols, and skills transfer should be recognized in budget formulas for research grants and project planning whether conducted by researchers internal or external to Aboriginal communities.*” (112)
- Principle 8: “*Responsibility for education of communities and researchers in ethics of Aboriginal research rests with Aboriginal communities and organizations, government funders, granting agencies, professional associations, research institutions, and individual researchers working collaboratively.*” (112)

Ludwig, K. (2009). Culturally safe and ethically relevant. BC: The Network Environments for Aboriginal Health Research BC, 1-28.

The Unique Challenges/Barriers to doing Research with Aboriginal Communities

- (1) Barriers (19):
 - Mistrust of systems or programs
 - Lack of access
 - Stigmas, lack of awareness
 - Lack of support systems
 - Poverty, crime, violence
 - Drug abuse, risk behaviours
 - Clinician bias, lack of objectivity
 - Stereotyping, racism, “isms”

Suggestions for Working and/or Researching with Aboriginal Communities

- Cultural competence (9)
- Cultural competence requires that organizations (9):
 - Have a defined set of values and principles, and demonstrate behaviours, attitudes, policies and structures that enable them to work effectively cross-culturally
 - Have the capacity to (1) value diversity (2) conduct self-assessment (3) manage the dynamics of difference (4) acquire and institutionalize cultural knowledge and (5) adapt to diversity and the cultural contexts of the communities they serve
- Should include all aspects of policy-making, administration, practice, stakeholders, and communities (9)
- Recognize the impacts of colonization (12)
- Address communication challenges (12)
- Respect culture and traditional knowledge (12)

- The National Minority AIDS Education and Training Centre (NMAETC) developed the BESAFE Model that has 6 core elements of practice (19):
 - o (1) Barriers – see barriers section above
 - o (2) Ethics – providers must give priority to professional duty, valuing different cultures, and issues relevant to honesty, confidentiality, and research
 - o (3) Sensitivity – need providers to examine their own prejudices and biases toward other cultures and determine where they are along a continuum that ranges from unconscious to conscious competence. Conduct an in-depth exploration of their own cultural background and work to avoid engaging in the phenomena of cultural imposition
 - o (4) Assessment – collect relevant data ... within the context of the patient’s cultural background, they have the right to hold their specific cultural beliefs, values and practices
 - o (5) Facts – understand perceptions to provide assessment
 - o (6) Encounters – achieve effective encounters with all people. Discuss the following when unsure how to move forward: language, cultural norms, the role of spirituality, and concepts of personal space (19)

Good Knowledge Translation with Aboriginal People

- No information

van der Woerd, K. A., & Cox, D. N. (2006). From theory to practice: Methodological and ethical issues for research with First Nations communities. Pimatisiwin, 39-48.

Respect

- Aboriginal scholars are now adapting methodologies that are culturally sensitive and appropriate for the communities they are working in (41)
- The substance abuse treatment centre project aimed to “bestow education, life skills, and Aboriginal traditional knowledge and spirituality to clients” (41-2)

Relevance

- History: Social science research often tries to quantify social issues, maintaining “objectivity” as per a scientific research approach (40)
- Many Aboriginal communities have reported dissatisfaction with this imbalance in power, and how the research mainly benefits the researcher (40)
- Rather than a positivist approach, there is now types called community action research, participatory research, or partnership research approach (community is fully engaged during the research process) (41)
- Project objectives were determined in partnership between treatment centre staff and community members (42)
- Staff felt a sense of ownership and commitment to the study results (42)
- Groups that collaborated in the survey development included the treatment centre staff, the Band Council, and the ‘Namgis Health Board (42)
- Survey was piloted tested on three individuals, and revisions were made before its final distribution (42)
- Advantages to using a participatory approach: looked at relevant issues, increased understanding of diverse points of view, enhanced a shared commitment to the program, team-building, recognized shared interest between different groups (42)

- A meeting was held to discuss an additionally relevant project in the community- decided on issues related to health and education in Aboriginal youth (43)
- A survey was distributed to all youth in Alert Bay between the ages of 12 and 25, received \$10.00 for compensation of its completion, and all results were anonymous (43)
- The second project also maintained a community-based approach (44)
- Many Band Council members, elders, and teachers promoted the project (44)
- Many youth took interest and investment in the project, referring to it is “our project” (44)

Reciprocity

- The first project - a First Nations substance abuse treatment centre- was done as per community needs (40)
- The second project- on health compromising and health promoting factors related to Aboriginal youth education- was also community driven (40)
- The participatory approach increased the likelihood that results would be used to improve the program’s performance in the future (42)
- Participating groups met at the completion of the project to discuss findings, problems and make improvements (42)
- Upon project completion, the results were disseminated to interested community members in meetings (44)

Responsibility

- Before research began on either project, a “Namgis First Nation Guidelines for Visiting Researchers/Access to Information Contract” was signed, which included “rules of conduct” and “ethical guidelines for research with human subjects” (41)
- Researchers agreed not to publish anything without consent from the ‘Nanaimo band (41)
- Two papers were reviewed and approved by the Band before they were submitted for publication (44)

GUIDELINES FOR WORKING WITH INDIGENOUS PEOPLE

Atkinson, D.L. (2008). Aboriginal health promotion: A literature review and environmental scan. BC Initiatives for Aboriginal Health, 1-55.

The Unique Challenges/Barriers to doing Research with Aboriginal Communities

- Low self-esteem, lack of encouragement, motivation, consistency, issues around exclusion and addiction (16)
- Inadequate time and resources (24)
- Lack of Aboriginal specific health data (24)
- Misunderstandings when worldviews and knowledge systems come together (24)

Suggestions for Working and/or Researching with Aboriginal Communities

- Holistic, community based, culturally appropriate and strength based (14)
- Build capacity and address social determinants of health (14)
- Holism – interconnectedness and everything is related (14)
 - Medicine wheel as a symbol of balance and interdependence across the lifespan and between domains (14)
 - Use traditional knowledge and healing practices (15)
- Community based
 - Helps increase control over the determinants of health and improve health and wellbeing (15)

- Not something done *to* people, it is done *with* people (15)
- Participatory and collaborative (15)
- Engage community at all levels (15)
- Set priorities, strategic planning, decision-making, implementation, and evaluation (15)
- OCAP – ownership, control, access, and possession (15)
- Supportive environment (17)
- Working closely with community members (17)
- Culturally appropriate
 - 5 strategies for enhancing cultural appropriateness in mainstream health promotion:
 - Peripheral Strategies – seek to give programs the appearance of cultural appropriateness by making the program appealing to certain groups (i.e. using the image of a medicine wheel; 18)
 - Evidential Strategies -- enhance perceived relevance of the health issue for a certain group by giving evidence on how it will impact that group (18)
 - Linguistic Strategies – make the programs and materials accessible by providing them in the dominant language of the group of interest (18)
 - Constituent-Involving Strategies -- draw directly on the experiences of the target group members (18)
 - Socio-Cultural Strategies – frame the issues in the context of broader social/cultural values (18)
- Strength based
 - Emphasis on solutions, strengths, resources, resilience, capacity to transform and change (19)
 - Promote Aboriginal people and their communities – who have been stereotyped (19-20)
- Involve Elders and Aboriginal health workers (24)
- Adhere to community protocols and ethical guidelines (24)

Good Knowledge Translation with Aboriginal People

- Holistic, community based, culturally appropriate and strength based (14)
- Build capacity and address social determinants of health (14)
- KT that encompasses Indigenous knowledge, knowledge holders, and cultural practices and protocols that support transmission between generations (24)
- Sharing culturally relevant and useful information (24)
- Purpose of KT is to improve health status, policy, services, and programs (24)
- Successful KT = cultural appropriateness, respect for diversity and distinctiveness, including Elders, being aware of historical happenings, empowerment, equality, partnership, respecting Indigenous knowledge, cross-cultural communication, ,building relationships (25)
- Take participatory action, emphasize visual and oral strategies, use many forms of media, and innovative communication practice in knowledge exchange (25)
- Use community gatherings, talking circles, storytelling as ways for KT(25)

Barnes, H. M. (2000). Collaboration in community action: a successful partnership between indigenous communities and researchers. Health Promotion International, 15, 17-25.

Respect

- Collaborative project between researchers at the Alcohol & Public Health Research Unit and two Maori organizations, Te Whanau o Waipareira Trust in West Auckland and the Huakina Development Trust in South Auckland (17)
- Evaluated two community action programs for prevention of alcohol-related traffic crashes (17)
- Until this project, partnerships between researchers and communities were rare (17)
- Programs preferably need to be “based on Maori social structures, Maori delivery systems and a Maori cultural context” (18)

Relevance

- Maori's are consistently identified at most at risk, yet few studies/projects have included Maori solutions or community action in dealing with this problem (17)
- There have been few alcohol studies internationally that have taken ethnicity into consideration (18)
- Evaluations needed to demonstrate the Maori participation and ownership (18)
- Used a naturalistic evaluation approach (focused on describing social phenomena, rather than manipulating independent variables) (19)
- The Huakina Development Trust ran a program called Whiriwhiri te Ora (Choose Life)- it built upon the tribal (Tainui) history of opposition to alcohol (22)
- This provided context for strategies to reduce drinking and driving, emphasizing that such prevention strategies could be part of their tribal identity (22)

Reciprocity

- Aimed to include the Maori in both the program development and the evaluation of it (19)
- There was positive and constructive communication between partners in this project (22)
- Both the providers and researchers felt a “strong sense involvement and shared investment” (22)
- Community members were enthusiastic about the program and subsequent evaluation (23)
- The building of alliances was time consuming yet a crucial (laid foundations for the program's acceptance) and lasting component of the project (23)
- Since people felt included in the process, they were more willing to accept and support the program implementation (23)
- Alliance building facilitated the cohesion of diverse groups, such as the community, police, education, councils, etc. (23)

Responsibility

- Issues of empowerment and ownership are important for Maori during community action program (18)
- Negotiations occurred during the evaluation about identifying stakeholders and methods of respectful dissemination (that met the diverse needs/interest) (19)

Canadian Institute for Health Research. (2007). CIHR guidelines for health research involving Aboriginal people. Ottawa, ON: Canadian Institute of Health Research, 1-46.

The Unique Challenges/Barriers to doing Research with Aboriginal Communities

- Concerns about anonymity when in small communities (4)

Suggestions for Working and/or Researching with Aboriginal Communities

- Understand and respect Aboriginal worldviews, including responsibilities to the people and culture that flow from being granted access to traditional or sacred knowledge. These should be incorporated into research agreements (3)
- Researchers should understand the broader senses of accountability in order to understand the responsibility they have when entering into a research relationship with Aboriginal people (3)
- A community's jurisdiction over the conduct of research should be understood and respected (3)
- The researcher should comply with any by-laws, policies, rules or procedures adopted by the community (3)
- Communities should be given the option of a participatory –research approach (3)
- Genuine research collaboration (3)
- Mutual trust and cooperation (3)
- Culturally sensitive, relevant, respectful, responsive, equitable and reciprocal, with regard to the understandings and benefits shared between the research partners and Aboriginal communities (3)
- If the research involves traditional or sacred knowledge, the researcher should consult with the community leaders to obtain consent before approaching the community members individually (4)
- Once consent is obtained, the researcher still needs free, prior informed consent
- Process of obtaining free prior informed consent should involve advance notice before the start of the research project and it should consider the community's decision making processes in planning, implementation, monitoring, assessment, and evaluation (4)
- Concerns about anonymity, privacy, and confidentiality should be respected and addressed (4)
- If anonymity is not possible, or if there are limitations, these should be made clear and communicated (4)
- Research should be guided by community knowledge holders (4)
- Research should address the use of the community's cultural knowledge and sacred knowledge (4)
- Aboriginal people and communities retain inherent rights to cultural knowledge, sacred knowledge, cultural practices, traditions, when they are shared with the researcher (4)
- Disseminating any cultural practices, knowledge, traditions, etc must be consented to and permission must be obtained (4)
- Concerns over intellectual property should be addressed at the start of the project (4)
- Research should benefit the community as well as the researcher (5)
- The researcher should support capacity building, education and training of Aboriginal people to enhance participation in the research (5)
- The researcher should learn about Aboriginal cultural protocols and apply them (5)
- The researcher should translate all reports, publications, and documents into the language of the community (if at all possible; 5)
- Ensure there is accessible understandable communication within the community (5)
- Recognize and respect the interests of individuals and community in data and biological samples generated during the research (5)
- Transfer of data/biological samples to a third party requires consent (5)

- Secondary use of data/biological samples requires consent (5)
- If the data/biological sample is known to originate from Aboriginal people, the researcher should consult with the appropriate Aboriginal organization before secondary use (5)
- Aboriginal communities should have the opportunities to participate in data interpretation, review of conclusions, and ensuring cultural sensitivity, and cultural accuracy (6)
- An Aboriginal community should be able to decide how its contributions to the research should be acknowledged, they are entitled to credit for participating in the dissemination of results (6)
- Publications should recognize the contribution of the community and its members while conforming with confidentiality (6)
- In the NWT, there is the Scientists Act with requirements for obtaining a license for research for western scientific knowledge and/or Aboriginal knowledge (11)
- Need to balance individual and collective interests (12)
- Respect Aboriginal values, knowledge, methodologies and decision making processes (12)
- Commit to an inclusive, participatory process that engages Aboriginals in research (12-13)
- It would be good to reconcile differences among ethical spaces (the community's principles, values, and beliefs) that protect and respect the validity of each (17)
- It's important that western trained researchers understand Aboriginal ethical space, as well as respected (17)
- The process of protecting Aboriginal ethical space includes stages of dialogue – talking before the research begins all the way until the research is disseminated (17)
- Address expectations by both researcher and communities with a memorandum of understanding and then a binding agreement (26)
- Negotiate and set out the terms of the research project before hand (27)
- Figure out details of data ownership, use and interpretation/analysis, rights to intellectual property, content and authorship of publications (27)
- Maintain a relationship with the Aboriginal community (30)
- All parts of the funding should be explained to the Aboriginal leadership to ensure a clear understanding of limits, time, requirements:
 - o Requirements of eligibility
 - o Timeframe from announcement to submission
 - o Pre-determined focus of announcement
 - o Involvement of experienced grant writer
 - o Lead project person
 - o Duration of the announcement
 - o Amount of money available (33)
- All approvals should be sought with adequate time because there may be many levels of approval (institutional ethics, Aboriginal community ethics, health services approval, band approval, etc; 34)
- A clear project timeline should be established (34)
- Outline how Aboriginal personnel/programs will be involved (34)
- Provide regular status updates to Aboriginal leadership (34)
- Regular and final reports should be made available to Aboriginal group, band, and council (35)

- Capacity building, training of Aboriginal personnel for data entry, analysis and interpretation (35)
- Recommended to include Aboriginal group members (35)
- Take into account and allow for dissenting views to be expressed in publications if not resolved earlier (35)

Good Knowledge Translation with Aboriginal People

- Information gathered during the study should be relayed to the Aboriginal group, band, council, to the research community and to the public (35)
- Numbers and statistics should be explained in lay terms so it's easily understood (35)
- The Aboriginal group should be consulted with on the findings and descriptions of Aboriginal identity (35)
- Community leaders should vet final reports, manuscripts, and any disseminating materials to ensure cultural accuracy (35)
- Share results with participants/community via newsletter, mail, public forums (35)

Cochran, P.L. (2003). Ethical guidelines for the use of traditional knowledge in research and science. Retrieved February 24, 2011, from <http://www.cyfn.ca/index.html>

Respect

- Traditional knowledge is “practical common sense”, implies “knowing the country”, is holistic in its spiritual and cultural roots, and is a way of life (What is Traditional Knowledge?)
- Traditional knowledge is also an authority system, in governing the use of resources, and gives “credibility to the people” (What is Traditional Knowledge?)
- Native people have historically/still presently use traditional knowledge as a decision-making process (The Purpose for Traditional Knowledge Research Guidelines)
- Ensure that the sacred knowledge and cultural or intellectual property of Native people is protected (AFN Adopts Policy Guidelines for Research)
- Use Native tongue when English is the second language (AFN Adopts Policy Guidelines for Research)
- Incorporate Native viewpoints into the final study (AFN Adopts Policy Guidelines for Research)
- “Culturally Sensitive: Acknowledge the holistic nature of traditional knowledge within its spiritual and cultural context” (Principles of Traditional Knowledge Research)
- Researchers must show respect to the Elder, or tradition knowledge holder, at all times (Collection of Traditional Knowledge)
- Researchers should consider culturally-sensitive methods of interviewing traditional knowledge holders (Collection of Traditional Knowledge)
- Communities should clarify culturally sensitive ways to approach traditional knowledge holders, and how respect for them can be identified (Collection of Traditional Knowledge)

Relevance

- The Alaska Federation of Natives (AFN) created a series guidelines for scientists and researchers doing work with Alaska Natives (AFN Adopts Policy Guidelines for Research)
- Ensure to inform the Native people who may be affected exactly what the purpose, goals, and timeframe of the research process, data gathering techniques, etc. (AFN Adopts Policy Guidelines for Research)

- Traditional knowledge and scientific knowledge originate from different frameworks (The Purpose for Traditional Knowledge Research Guidelines)
- “Comprehensive: Consider all current and planned initiatives involving traditional knowledge research” (Principles of Traditional Knowledge Research)
- “Equitable: Recognize the need for balance in substantive weight between traditional knowledge and western science” (Principles of Traditional Knowledge Research)
- Researchers should discuss how control of the project can be improved by a Community Research Committee (Access to Traditional Knowledge)
- Communities should collect information at a community level (Collection of Traditional Knowledge)
- The intent and benefits of the collection should be communicated (Collection of Traditional Knowledge)

Reciprocity

- Hire and train Native people so they can assist in the study (AFN Adopts Policy Guidelines for Research)
- Supply the local library with copies of the studies (AFN Adopts Policy Guidelines for Research)
- “Collaborative: Advocate for effective partnerships in planning, implementation, and communication” (Principles of Traditional Knowledge Research)
- “Capacity Building: Provide a framework that nurtures community responsibility and accountability” (Principles of Traditional Knowledge Research)
- Communities should discuss if the proposal addresses the community’s research priorities (Access to Traditional Knowledge)
- Researchers should consider how the project will build the community’s capacity (Access to Traditional Knowledge)
- Researchers are responsible for their research results and must bring them back to the community (Collection of Traditional Knowledge)
- Any benefits, including monetary, stemming from the research must be shared equally with the community (Collection of Traditional Knowledge)
- Researchers should address the necessity of training community-based researchers, and communities should identify the criteria for selecting them (Collection of Traditional Knowledge)
- Community should clarify methods to sustain community support for the project (Collection of Traditional Knowledge)
- Communities could consider what existing capacity there is for holding traditional knowledge or how to establish that local capacity (Storage of Traditional Knowledge)

Responsibility

- Obtain the informed consent from who will be governing the project (AFN Adopts Policy Guidelines for Research)
- Fund the support of a Native Research Committee, formed by the local community, who will continually assess/monitor the research project and its adherence to Native wishes (AFN Adopts Policy Guidelines for Research)
- Assure the confidentiality of surveys and sensitive material (AFN Adopts Policy Guidelines for Research)
- Acknowledge Native resource people’s contributions (AFN Adopts Policy Guidelines for Research)

- Provide the Native Research Committee with a non-technical summary of the study's findings (AFN Adopts Policy Guidelines for Research)
- Helps build a respectful, trusting and cooperative working relationship (The Purpose for Traditional Knowledge Research Guidelines)
- Researchers should consider with whom they will negotiate a research agreement, and the community should discuss who will negotiate on the community's behalf (Access to Traditional Knowledge)
- Researchers and communities should consider/discuss which aspects of research are necessary to negotiate (Access to Traditional Knowledge)
- Communities should discuss what constitutes "confidential" information, and researchers should identify how that information will be protected (Access to Traditional Knowledge)
- Communities should discuss procedures for conflict resolution (Access to Traditional Knowledge)
- Must reference the traditional knowledge information sources in any works being done (Collection of Traditional Knowledge)
- Traditional knowledge holders should be compensated (Collection of Traditional Knowledge)
- When proposing to do traditional knowledge work, researchers must contact the community prior to working with Elders or other community members (Collection of Traditional Knowledge)
- Researchers and the community should clarify appropriate options for compensating project participants (Collection of Traditional Knowledge)

Estey, E., Smylie, J., & Macaulay, A. (2009). Aboriginal knowledge translation: Understanding and respecting the distinct needs of Aboriginal communities in research. CIHR Institute of Aboriginal Peoples' Health, 1-5.

The Unique Challenges/Barriers to doing Research with Aboriginal Communities

- Using mainstream/Western approaches can result in marginalization of Aboriginal ways of knowing and can also contribute to perpetuating the inequities between Aboriginals and non-Aboriginals (p4).

Suggestions for Working and/or Researching with Aboriginal Communities

- It is suggested that if researchers/policy makers are interested in Aboriginal health matters, they could use the history of KT in Aboriginal communities (e.g., oral traditions, experiential knowledge) as a framework to guide their work (p3).
- Research with Aboriginal people should involve (p3):
 - CIHR Guidelines for Health Research involving Aboriginal People (which includes a participatory research approach; p4)
 - The new version of chapter 9 of the Tri-council Policy Statement "Research Involving Aboriginal Peoples"
 - The 4 R's of research: respect, reciprocity, relevance, responsibility
 - Ownership, Control, Access, Possession (OCAP) principles
 - Inclusion of Aboriginal People in the research and policy-making efforts
 - A focus on both knowledge that's used and knowledge that's gathered, in addition to the process of translation (p3).
- When research is in collaboration with an Aboriginal community, it is suggested that the partnership use the existing channels for dissemination in Aboriginal contexts (p4)

Good Knowledge Translation with Aboriginal People

- Definition used to describe KT in Aboriginal contexts is: ***sharing what we know about living a good life*** which differs from CIHR's definition of KT as: ***a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system*** (p3).
- In Western mainstream science, KT is about reducing the "know-do gap" where knowledge and action are separated. On the other hand, in Aboriginal communities, knowledge is practical, we do and apply our own science and have been for centuries with oral traditions, and experiential knowledge (p3).
- KT approaches by Aboriginal communities using their knowledge can result in the most effective ways to address health disparities (p3).
- Many Aboriginal knowledge traditions include components that respect for multiple perspectives, and different types/sources of knowledge, whereas this is not the case in non-Aboriginal settings. Rather, in non-Aboriginal settings there is an emphasis on research methods (e.g., RCTs; p3).
- Due to the complexities of Aboriginal health interventions, they are not easily evaluated by the standard RCTs – the multiple knowledge sources requires multiple evaluation approaches (p4).
- The "T" of KT should involve community input/support from the beginning (p4).
- Involve Aboriginal Peoples in all research and action (e.g., data collection, policy-making, program development; p4).
- Engage the community to increase effectiveness, relevance, support, knowledge, capacity and encourage sustainability (p4).
- Contextualize results and knowledge, as well as have the message developed and communicated by community members, peers, community based organizations and/or Aboriginal leaders (p4).

Estey, E.A., Kmetz, A.M., & Redding, J.L. (2010). Thinking about Aboriginal KT: Learning from the network for Aboriginal health research British Columbia (NEARBC). Canadian Journal of Public Health 101(1), 83-86.

The Unique Challenges/Barriers to doing Research with Aboriginal Communities

- Communities not viewing research in a positive light, not seeing research as positive (84).
- Challenge of bringing together diverse groups (researchers, communities, policy-makers; 84).
- Challenge – researchers and community members often don't have skills, time, and/or resources to take on the roles/responsibilities of Aboriginal KT (85).
- Sometimes time is a challenge for communities – they are interested in the research, but other crises take priority (85).
- Policy-makers can experience problems with convincing communities of the benefit of their involvement in the research (85).
- Community costs for participating in KT (85).
- Challenge of "bringing diverse voices to the table, and getting them to talk to and mutually respect one another (85)."

Suggestions for Working and/or Researching with Aboriginal Communities

- Engage with policy-makers, health practitioners, health professionals to get the desired changes/results (85)

- Engage stakeholders (85)
- “In Aboriginal health research, the benefits of creating equality between researchers and communities are twofold: first, communities are empowered to take more control over the research, and second, researchers are enabled to do work that is productive (scholastically) and meaningful (contextually; 85).

Good Knowledge Translation with Aboriginal People

- “Aboriginal KT is used to denote participants’ descriptions of the unique features of KT in Aboriginal health research contexts; namely, the distinct history and purpose of KT ... storytelling, tattoos, totems, and the role of Elders as carriers and translators of wisdom are traditional methods of KT in Aboriginal communities (p84).”
- Including these traditional methods (storytelling, tattoos, totems, Elders) into research is practical in using all skills and resources available, and it is ethical because it involves the people it will ultimately affect (84).
- KT in Aboriginal health is often research-community collaborations (85).
- “For researchers, taking responsibility for KT often requires changing the way they consider their role, the role of their research, and the way research is framed and perceived in Aboriginal communities (85).”
- Researchers should start to see themselves as resources for communities (85).
- Community involvement/engagement in KT – a shift towards a community based, context dependent approach (85).
- Use “integrated KT” rather than “end of grant KT” (1) the integrated KT involves using the end-users in the research process, it’s collaborative, and (2) end of grant KT focuses on traditional dissemination via academic channels (85)

Henderson, R., Simmons, D. S., Bourke, L. & Muir, J. (2002). Development of guidelines for non-Indigenous people undertaking research among the Indigenous population of north-east Victoria. Medical Journal of Australia, 176, 282-485.

Respect

- Key concern of cultural appropriateness since mainly non-Indigenous researchers are involved in Indigenous research (482)
- History: Indigenous communities in these areas have had negative research experiences, namely because of lack of community control/benefits, and the data was analyzed without social context (482)
- Cultural protocols must be followed when doing recording in the communities (483)
- Recommended to employ a Koorie worker to ensure culturally appropriate research and accompany non-Indigenous workers in community/supervise their work (484)
- It became department policy that all research-oriented activities follow the guidelines, be sensitive to the community’s culture and history, and aim to improve Koorie health outcomes (484)
- The framework used in this project reflects the Indigenous holistic view of health (485)
- It also respects the integrity of each Indigenous community (485)

Relevance

- High-quality participatory research is needed in working with Indigenous people in Australia (482)
- Approach that developed a partnership between researchers and Koorie communities (northern Victoria and southern New South Wales (482)

- Objective of the Department of Rural Health (DRH) at the University of Melbourne is to reduce the health discrepancy between Indigenous and non-Indigenous people (482)
- The DRH established a Koorie Team which aims to work with researchers for the benefit of the communities (483)
- Prior to generating a proposal, the project group should seek approval from the Koorie community organization's Board of Directors (483)
- Project outcomes should be discussed and agreed upon before research begins (483)
- The Koorie community and organizations should be a part of the entire research project, from its design to implementation (483)
- Local political issues and family histories within the community can provide difficulties during this work (485)
- The guidelines are flexible in that they can be negotiated and adapted to each individual project and reform stages of previous projects (485)

Reciprocity

- The Koorie Health Partnership Committee (established in 1999) meets bimonthly and identifies health priorities, design projects, and reviews the initiatives of the DRH, communities and other organizations (482)
- The committee recognized the need for written protocols and created guidelines for trust, integrity, and maintain strong relationships with the communities (483)
- The publication acknowledgments should properly accredit the Koorie community members and organizations for their assistance participation in the project (484)
- It is departmental policy for the priority of research to be the benefiting of Koorie communities rather than researchers (484)

Responsibility

- It may be necessary for a local Koorie ethics committee (483)
- All reports/research material/data remain property of the community (484)
- Results must remain anonymous unless community members consent to their release (484)

Jack, S., Dobbins, M., Furgal, C., Greenwood, M., & Brooks, S. (2010). Aboriginal environmental health issues researchers' and decision-makers' perceptions of knowledge transfer and exchange processes. Prince George, BC: National Collaborating Centre for Aboriginal Health, 1-36.

The Unique Challenges/Barriers to doing Research with Aboriginal Communities

- Suspicions about researchers (17)
- Knowing who and how to contact different people in the community (20)
- How to organize community meetings (20)
- Perceptions by researchers that they are genuinely trying to understand things from an Aboriginal point of view/world view but they don't perceive equal reciprocity from the community – the community doesn't try to understand the researchers view (i.e. deadlines, methodology boundaries) (20)
- Challenge for researchers – grants don't cover the costs of the frequent trips to remote communities that are required (20)
- Mismatch between what is cost effective for the researcher and what is preferred by the FN community - telephone interviews favoured by researchers in terms of cost, however this is not favoured by FN communities (20)

- Challenge with collaboration with FN communities – a desire to have research on politicized issues that researchers have no ability to influence or they simply don't have the skills or knowledge (i.e., residential schools) (20)
- History of exploitation by researchers (22)
- Community mistrust of researchers (22)
- Fatigue of being researched (22)
- Difficult to generalize between some communities as each FN community is unique and there is variation (22)
- Community refusal to disseminate results or have results exposed (22)
- Researchers expressed concern about OCAP principles saying that if they follow OCAP fully they have few rights to the data, this might effect the number of researchers wanting to do research with FN communities (24)
- Informed consent and confidentiality – some expressed that the concepts don't fit with cultural context (24)
- Problem where people consent to participate in research, but don't consent to having the findings released (24)
- The jargon used by researchers, technical language barriers, decreased comprehensibility (26)
- Not having access to the tools/skills needed for research – no internet (26)

Suggestions for Working and/or Researching with Aboriginal Communities

- Seek consent from community leaders (17)
- Engage community members (17)
- Build relationships, identify opportunities to develop community capacity (17)
- Understand that each Aboriginal community is unique and may have specific protocols and etiquette for research (17)
- Seek permission from the Chief or Band Council to conduct research (17)
- Important for researchers to physically travel to the community, meet face to face with community leaders and provide both personal and professional background (17)
- Be truthful and clear when talking about study objectives (18)
- Try to understand the worldview of the community (18)
- Understand the needs and concerns of the community (18)
- Identify strategies to help you get through conflict if it arises (18)
- Be genuine, listen genuinely, be genuine in learning about local concerns (19)
- Value different types of evidence (19)
- Empower the community to develop skills, knowledge and capacity to conduct research (19)
- Involve community members in the research (19)
- Maintain stability as a research team – don't continually change research members working with the community – be consistent (19)
- Meet with Aboriginal leaders several times (19)
- Attend social events, feasts so the community can gain trust in you and you can get to know them (19)
- Actively involve community members (20)
- Collaborative research (21)
- Talk in great detail about confidentiality and informed consent (24)
- Genuine, honest, good intentions, respect for all members (29)
- Translate findings for target audience, use concepts they will understand (29)
- Be clear on your limitations (29)

Good Knowledge Translation with Aboriginal People

- Most KTE models focus on effective/efficient ways from research results to policy - these are thought to be influenced by 2 communities theories that collaboration is between 2 culturally different communities that sometimes have conflicting ideas, values, beliefs (11)
- 2 elements needed to facilitate successful KTE at all levels (17):
 - o Relationships characterized by trust, respect, empowerment and equity must be initiated and nurtured
 - o KTE activities need to be negotiated and implemented throughout the entire course of the research process
- Initiate and nurture relationships at all levels throughout the entire research project (17)
- Be sure to negotiate at the start of the project the strategies for KTE, this shouldn't be an add-on at the end (20)
- Providing a communication plan and contract how the information will be shared back with the community (23)
- Report results back to the community first (23)
- Talk about data ownership in the beginning (24)
- Develop skills in crafting key messages from study results (27)
- Identify what specific findings will be communicated to which audiences (27)
- Include different perspectives (27)
- Include community concerns as key messages when disseminating results (27)
- Key messages need to be relevant and resourceful to the (27)
- Messages about risk need to be carefully talked about to avoid alarming the community (27)
- Include community partner in crafting key messages (27)
- Identify credible messengers to deliver the message (27)
- In some communities, have the researcher present results and a community member present to answer specific questions and support translation (28)
- Find effective communication channels to disseminate (27)
- Use many strategies and ways to communicate findings (28)
 - o Radio ads
 - o Radio call-in shows
 - o Attend community presentation
 - o Conduct community tours/workshops
 - o Community meetings
 - o Prepare and distribute newspaper/article/newsletter/poster/flyers (29)

King, M. (unknown). Community-based intervention research as a pathway to health equity for First Nations, Inuit and Metis. CIHR Institute of Aboriginal Peoples' Health, 1-24.

The Unique Challenges/Barriers to doing Research with Aboriginal Communities

- Challenges to FN, Inuit, Metis wellness – infectious disease, chronic disease, mental disease, emotional trauma, addiction, injuries, violence, barriers to health care access, primary care, reconciliation and healing (1)
- Reducing health inequities can only be made if Indigenous communities are engaged in the process of healing and revitalization (21)

Suggestions for Working and/or Researching with Aboriginal Communities

- CIHR Health Research Roadmap includes:
 - o Promote patient-oriented research and target science and technology innovations to improve health outcomes and health systems (6)
 - o Support high quality, accessible and sustainable health care systems (6)
 - o Decrease health inequities in Aboriginal Peoples (6)
 - o Promote health and reduce the burden of chronic disease and mental illness (6)
- Good Practices in Indigenous Health Research
 - o Good practice in training/capacity building (8)
 - o Good practice in community engagement (8)
 - o Good practice in research team development (8)
 - o Good practice in intervention research (opportunistic & designed interventions; 8)
 - o Good practice in knowledge translation (8)
- Good Practices in Indigenous Research methodology
 - o Indigenous control and leadership (9)
 - o Located within Indigenous worldviews (9)
 - o Knowledge translation is a critical element (9)
 - o Evolve Indigenous research approaches and build our capacity (9)
 - o Critical approaches preferred – examine nature of power relationships (9)
 - o Researchers as “boundary walkers/bridgers” (9)
 - o Maintenance of research team wellbeing (9)
- Foster broad coalitions of researchers and knowledge users (20)
- Indigenous communities need to lead the process (21)
- Interventions should benefit not only the social development of Indigenous peoples, but also their health (21)

Good Knowledge Translation with Aboriginal People

- No Information

National Collaborating Centre for Aboriginal Health. (2007). Exploring evidence in Aboriginal health: Proceedings from the Indigenous knowledges dialogue circle, Vancouver BC. Prince George, BC: National Collaborating Centre for Aboriginal Health, 1-6.

The Unique Challenges/Barriers to doing Research with Aboriginal Communities

- Challenge – systematic reviews (specific and detailed summaries) insist on objectivity and that it remains context free, but this leaves no room for and no acceptance of peoples experiences (2)
- “My nursing professors told me you don’t have any evidence – except that I just lived it for 18 months.” (2)
- Challenge of how to meet research mandates while also acknowledging lived experiences (2)
- “We have been researched to death.” (2)

Suggestions for Working and/or Researching with Aboriginal Communities

- Empower communities to help themselves (2)
- Use many types of knowledge as well as many knowledge bearers because each type of evidence requires different approaches and different skills (2)
- Develop fresh approaches to evaluation to help with balance (3)
- Be aware of and appreciate that Indigenous context is important (3)

- Elder Andrew Tagak Sr. from Nunavut has 8 traditional Inuit Qaujimajatuqanginnut principles to harmonize the ways Inuit and non Inuit work together (3):
 - o Inuuqatigiitsirniq – respecting others
 - o Tunnganarniq – fostering good spirit by being welcome, open and inclusive
 - o Aajiiqatigiinniq – decision-making through discussion and consensus
 - o Piliriqatigiinniq/ikajuqtigiinniq – working together for a common cause
 - o Qanuatuurniq – being innovative and resourceful
 - o Avatittinnik kamatsiarniq – respect and care for the land, animals and environment (3)
- Focus on optimum well being rather than ailments (4)
- Research *from within* Indigenous worldview (4)
- Promote “two-eyed seeing” – combine Indigenous heritage the best of western science, knowledge and technology (4)
- Acknowledge that Indigenous ways of knowing are valid evidence (not just numbers; 4)
- Incorporate Indigenous ways of knowing into public health decision-making (4)
- Evidence needs to be relevant to the community (4)

Good Knowledge Translation with Aboriginal People

- No information

Objective 3: Information Re: Expansion of indicators/Tools for Nutrition/Physical Activity Interventions to be Implemented in Remote, Northern, and Aboriginal Communities

- There is value in incorporating understanding of what traditional knowledge has to offer into health promotion tools/interventions (3)
- Example by Michael Bird, past president of the American Public Health Association – “His Windrunner video has affected many viewers by showing that running was a spiritual and mental practice as well as health-promoting physical activity, with roots anchored deep in American Indian history and culture (3).”

Norton, I. M., & Manson, S. M. (1996). Research in American Indian and Alaska Native communities: Navigating the cultural universe of values and process. *Journal of Consulting & Clinical Psychology*, 64, 856-860.

Respect

- As a culturally relevant form of acknowledgement and gratitude, employees have planned honoring ceremonies and dinners to recognize project participants (859)

Relevance

- American Indians and Alaska Natives can participate in research on a multitude of levels, such as communication with tribal leaders/councils (858)
- When approaching a tribe for research consent, they may request to have input in the study questions, implementation, result presentation and publications- if a researcher denies this it may jeopardize their research capabilities (858)
- Community members will be more motivated to participate in research if it addresses issues that are relevant to the tribe (859)
- There may be concern when issues are researched that have value to the larger society, but minimal interest to the American Indians and Alaska Natives communities (859)

Reciprocity

- American Indians and Alaska Natives may be employed to work on the research project (858)

- Employment of local community members on the project can increase their perceived benefit of the research (859)
- The community may also perceive the research as beneficial if they are working with local service providers, translating results into action (859)
- Research results should be presented to the tribal councils and communities in an interpretable and meaningful way- it may then be used for lobbying for program funding (859)

Responsibility

- Necessary for the investigator to obtain permission from the tribe(s) as well as the individual for research participation (857)
- Adequate compensation can influence the willingness of the individual and tribe to participate in the research (858)
- If there are high poverty rates in the community of study, compensation can potentially be viewed as coercion (858)
- Community and individual confidentiality are integral components in research with American Indians or Alaska Natives (858-9)
- The identity of specific communities should remain anonymous in publications (859)
- Confidentiality is an issue particularly with the small and close-knit nature of this population (859)
- In every project, employees must sign confidentiality agreements, as well as undergo extensive training regarding confidentiality in their communities (859)
- Study participants may be more comfortable being interviewed by a member of a tribe other than their own (859)
- Researchers that demonstrate a long-term commitment to the community and a willingness to work in collaborate partnerships will receive greater participation/support in their work (859)

Reading, J. (2010). The crisis of chronic disease among Aboriginal peoples: A challenge for public health, population health and social policy. Victoria, B.C.: Centre for Aboriginal Health Research, 1-185.

The Unique Challenges/Barriers to doing Research with Aboriginal Communities

- Concern that there is no amount of risk assessment or health recommendations that will reduce the burden of disease without a parallel understanding of the importance of social change (8)
- Decreased health care access in rural areas (26)
- Accessibility of health services (29)
- Lack of local services, lack of access to a physician, need to travel to get to health facilities are barriers/challenges faced by those on reserves in northern and rural areas (29)
- Economic challenges – transportation, child care, cost of services (29)
- Cultural barriers – lack of culturally relevant services and care, access to traditional care (29)

Suggestions for Working and/or Researching with Aboriginal Communities

- Take a life course approach - this approach provides researchers with tools to integrate scientific, cultural and sociological knowledge and it satisfies both scientific and cultural requirements (7)

Good Knowledge Translation with Aboriginal People

- No information

Objective 3: Information Re: Expansion of indicators/Tools for Nutrition/Physical Activity Interventions to be Implemented in Remote, Northern, and Aboriginal Communities (examples of tools developed, identify any factors that should be known for making tools culturally relevant)

- Rural locations associated with poor nutrition, inactivity, high smoking rates (26)
- Different environments for Aboriginals in rural/northern areas versus urban/suburban areas (26)
- There are differences between on and off-reserve living (26)
- Diabetes is the most reported and documented chronic diseases in Aboriginal health (79)
- Geographical differences in rates of diabetes – lowest rates in NWT and highest rates are in the Maritimes (81)
- In all provinces except BC, Yukon and NWT the prevalence of diabetes was higher in Aboriginal peoples versus non-Aboriginal (81)
- Prevalence varies along a north-south gradient – it's lower in the north and higher in the south (81)
- There are differences among Inuit and FN people in terms of cancer. Inuit are high risk for rare cancers (nasopharyngeal, salivary gland, esophageal cancer) but this has declined since the 70's (109)
- Cancers among the non-Inuit population (lung, cervical, colon, breast cancer) has increased
- Circumpolar Inuit are at lower risk for cancer of the bladder, breast, endometrium, prostate, lymphomas, Hodgkin's, leukemia, myeloma, melanoma (110)

Smylie, J. (2009-2010). Achieving strength through numbers: First Nations, Inuit, and Metis health information. Prince George, BC: National Collaborating Centre for Aboriginal Health, 1-4.

The Unique Challenges/Barriers to doing Research with Aboriginal Communities

- There are differences in health determinants and outcomes between FN, Metis, and Inuit, as well as differences between geographic locations, status versus non-status (p2).
- There has been systematic exclusion of Aboriginal people from data collection based on geography, ethnicity, status, and residence (e.g., Aboriginals living in urban areas have been excluded from Aboriginal health initiatives; p2).
- Challenge – absence/inconsistency of ethnic identifiers in vital registration systems, primary care and hospital administrative datasets, which results in Aboriginal people being invisible in provincial/territorial health data (p2).
- Challenges of data quality – has been linked to substandard data sources, application of substandard methods, double standards with Aboriginal data quality versus mainstream data (p3).
- Depending on Aboriginal ethnicity (FN, status, etc) and geography (remote, on-reserve, urban, etc) the health systems can vary (federal, provincial, Aboriginal, combination; p3).

- There is a lack of infrastructure to support collection of Indigenous specific health indicators (p3).
- Disseminating the results of health assessments back to Aboriginal decision makers at local and small levels has been identified as a gap (p3).

Suggestions for Working and/or Researching with Aboriginal Communities

- Datasets need to be inclusive of all who self-identify as First Nations, Inuit, Metis if the population of interest is Aboriginal (p2).
- Be clear about which Aboriginal groups are included and excluded from the dataset (p3)
- Be sure you are striving to include all of the Aboriginal people in your area (p3)
- Amend the systematic exclusion of certain Aboriginal subpopulations (p3)
- Identify who the relevant FN, Inuit, Metis stakeholder groups are at your level (federal, provincial, community level) and seek them out as partners – get to know their needs and priorities (p3)
- Try to work through cross-jurisdictional barriers that prevent excellence (p3)
- Support the articulation and development of Indigenous specific health measures and frameworks (p3).

Good Knowledge Translation with Aboriginal People

- No information found

Objective 3: Information Re: Expansion of indicators/Tools for Nutrition/Physical Activity Interventions to be Implemented in Remote, Northern, and Aboriginal Communities

- “Indigenous models of health are diverse and can differ from non-Indigenous models. [There is a need for] indicators to reflect Indigenous ideas and systems of health ... several Aboriginal groups in Canada have started to develop culturally specific health measurement models. There is a need for locally relevant and customized First Nations, Inuit, and Metis health indicators (p3).”
- *see Smylie & Anderson (2006) for more information on the culturally specific health indicators that have been developed.

OCAP PRINCIPLES

Schnarch, B. (2002). Ownership, control, access and possession (OCAP) or self-determination applied to research. A critical analysis of contemporary First Nations research and some options for First Nations committees. Ottawa: National Aboriginal Health Organization.

Respect

- History: Cultural property/human remains have been put on display in museums, storage or sold (5)
- New ethical guideline: Local and traditional knowledge should be included in the process (13)
- New ethical guideline: Community protocols should be respected during research (13)
- Benefits of OCAP: Assists in building community trust (32)
- Benefits of OCAP: Promotes a more holistic, and thus First Nations, approach to health (32)

Relevance

- History: First Nations have been treated just as a source of data (5)

- History: They have been told that research participation is the only way to sustain health services (5)
- New ethical guideline: Researchers should continually communicate in regards to all aspects of the research process (i.e. its purpose) (12)
- New ethical guideline: Support community interests and maximize benefits, while avoiding/reducing harm (13)
- Benefits of OCAP: Improves the quality and accuracy of information, as First Nations will invest more in the project (32)

Reciprocity

- History: They have been treated as “informants” in research rather than “colleagues” (5)
- History: Research focuses on negative aspects within a population rather than considering the positives (7)
- History: The benefits to First Nations people/communities have not been made clear (7)
- New ethical guideline: Researchers should make the involvement plan of the research process and anticipated benefits clear to the community/partners (12)
- New ethical guideline: Meaningful capacity development for Aboriginal Peoples should be included in the research project (13)
- New ethical guideline: All reports/summaries should be returned to the community in an appropriate language format (13)
- Important to define what constitutes a benefit for an Aboriginal community (be culturally relevant)- increasing the number of PhDs, for example, actually benefits the government/universities (18)
- Benefits of OCAP: Encourages capacity building in the community (33)
- Benefits of OCAP: Produces results that are more useful which can lead to change (33)

Responsibility

- History: Study results have not been confidential as they would be for a non-First Nations person (5)
- History: After establishing a rapport with the community, new researchers come in who are unknown to community members (5)
- The problem with research is stem from who is in control and who knows about it (9)
- New ethical guideline: all standard ethical requirements for research apply, such as informed consent (12)
- New ethical guideline: The research agreement must be negotiated by the parties involved, ideally written in the form of an agreement or contract (13)
- Important to define that communities are not researchers- they are involved/supportive/consultants (15)
- The essence of the OCAP principles is self-determination (23)
- Benefits of OCAP: Contributes to the empowerment and self-determination within a First Nations population (33)

PARTICIPATORY RESEARCH

Davis, S., & Reid, R. (1999). Practicing participatory research in American Indian communities. *American Journal of Clinical Nutrition*, 69, 755-759.

Respect

- Through the establishment of laws, policies, and protocols for research on reservations, tribes have asserted their sovereignty (755)
- Consequently, researchers have been more aware and sensitive to their wishes (755)
- Many researchers have yet to develop cultural sensitivity (755)
- Researchers assume that when American Indians are uncooperative, they are being unreasonable- rather than considering there clashes in culture and belief systems (756)
- Everyday interactions between American Indians and non-Indians can be complicated with thoughts of the past (756)
- “American Indians remember constantly that they once controlled all lands on this continent” (756)
- Many non-Indians fail to recognize uniqueness of tribes and their cultures, categorizing them all under the term “Indian” (756)
- American Indians do overlap viewpoints, such as their respect for the entire biota (whereas the dominant Western culture views humans as being a superior species) (756)
- Since religion has little place in the scientific world, many researchers fail to understand the importance of religion to American Indians and their strong adherence to it (756)
- Comprehending the language and religion of American Indians is essential to understand their origins, beliefs, their evolution (physical and spiritual), and their lifestyles (756)
- Recommendation: Before approaching Indian communities, make an effort to learn and understand the peoples’ religion, beliefs, and culture to ensure the project’s cultural compatibility (758)
- Recommendation: To enhance cultural diversity and increase intercultural communication skills, participate in cultural sensitivity workshops/training (758)
- Recommendation: Respect diverse philosophies regarding time and decision-making. Many American Indians do not regard time as a linear process, but rather a comprehensive continuum including myth and memory (758)

Relevance

- Investigators were unaware of their attitudes toward and consequent effect on the participants (755)
- Participants perceive that researchers are ignorant of the wishes and beliefs of American Indians (755)
- Investigators must work in partnership with communities to respond to their needs (755)
- History: An epidemiologic study was done on a syphilis outbreak in an American Indian reservation. There was no anonymity in results or reporting and community members felt betrayed, and were ostracized by neighboring non-Indian communities (755)
- History: A study on alcoholism led to adverse credit rating by lenders for a native community (755)
- Multiple accounts of trust violations have deterred American Indians from agreeing to participate in research projects (755)
- Ethnocentrism can pervade the interactions between nonnative researchers and American Indian advisors (755)

- Feeling like a subject rather than a collaborator in the research process leads to the objectification of participants (757)
- Green et al defines *participatory research* as “systematic enquiry, with the collaboration of those affected by the issue being studied, for the purposes of education and taking action or effecting change.” (757)
- Particularly in minority populations, investigators need to take the community’s culture into account when designing the research question, the methods of study, and the results (757)
- Recommendation: Before approaching Indian communities, determine how the study’s results could truly benefit them (758)
- Recommendation: During negotiations with American Indian communities, involve the members in the research development and execution (758)
- Some cultures make decisions through consensus rather than majority (758)
- Tribal elders may need to be consulted in the decision-making process (758)

Reciprocity

- Findings often benefited the researcher’s academic communities more than the American Indian groups (755)
- Research can be exploitive (755)
- Researchers rank the needs of Euro-American science more important than the wishes/needs of American Indian communities (755)
- American Indians see the importance and appreciate research among their people when it is appropriately done and they can participate in a project’s development and execution (757)
- They view research as meaningful when they can live “healthier, fuller lives” as a result (757)
- Recommendation: During/after research, schedule feedback sessions with community members to make sure data collection/interpretation/project evaluation is correct (758)
- Recommendation: During/after research, establish a value exchange program with representatives for their investment in time and knowledge sharing (i.e. skills, training, employment, etc.) (758)

Responsibility

- Participatory research needs to establish and maintain trust with residents (755)
- In some accounts, researchers disregard tribal authorities’ requests for privacy (755)
- Promote active involvement such as self-study, learning and action to revive interest in community development and empowerment (public health education and promotion) (757)
- Recommendation: Conceive the study between an American Indian community and the investigators as a partnership project (758)
- Recommendation: Make an opportunity for American Indian professionals in the field of study/discipline to contribute in peer review (758)

Fletcher, C. (2003). Community-based participatory research relationships with Aboriginal communities in Canada: An overview of context and process. Pimatziwin, 1, 27-61.

Respect

- Community-based participatory research (CBPR) respects and gives equal weight to the different forms of knowledge, scientific and traditional/cultural expressions of knowledge (28)
- Traditional Ecological Knowledge (TEK) is a term for “cultural knowledge of people living within a particular environment” (28)
- TEK does not involve scientific terms, but is gained through living experience (29)
- Work with Aboriginal communities in Canada has surrounded TEK and involves collecting knowledge from individuals about their culture and firsthand experience with their environment (28)
- CBPR incorporates diverse perspectives of viewing the world (32)
- History: The Berger Inquiry of the Mackenzie Valley Pipeline demonstrates a landmark project where Aboriginal perspectives were incorporated into a political/developmental context (33)
- The Berger Inquiry helped close the distinction between social and ecological frames of reference, and helped build awareness that the north is a homeland for Aboriginal people (33)
- It is a principle of CBPR to accept the various ways of seeing/understanding the world (38)
- Respect the ethical guidelines present in the Aboriginal community (38)
- When discussing research, meet in the community- shows genuine interest in working together (46)
- Respect the uniqueness of each community and project (46)
- Adhere to the community’s political structures/process (46)
- Listen closely to the voices in the community (48)
- Use research tools that are culturally appropriate (48)

Relevance

- As Aboriginal people have exerted more authority over the happenings in their own communities, CBPR has developed as a research method (28)
- Collecting non-scientific information and applying it to contemporary issues requires strong communication networks that allow information to “flow” between the scientific and local communities (29)
- CBPR emphasizes how context must be taken into account and incorporated into research question development, project design, and the dissemination process of results (30)
- History: in the past, research was done on Aboriginal people, whereas CBPR’s philosophy is do research for and with Aboriginal people (31)
- CBPR seeks to engage the people of communities in all phases of research, from conceptualization to dissemination (32)
- Focus on issues that are important to the community members (38)
- Engage community members as equal stakeholders (38)
- In CBPR, establishing contact in the community is a crucial stage that sets the tone for the working relationship (39)
- Important in early phase to identify areas of mutual interest (39)
- Include as many opinions as possible during the research process and ensure the collaboration of community members who will be the most directly affected (41)
- To maintain a constructive research relationship, it can be highly beneficial to have a local advisory committee (LAC)- assign clear responsibilities, give them progress reports, and ensure their authority in the process (43)
- Take the time to structure a reasonable and locally relevant timetable for the project (47)

- The researcher must make the objectives clear to the community- otherwise can be threatening/damaging to the relationship (47)

Reciprocity

- Indigenous people are concerned about the effects of the transmission of knowledge on their home environments (29)
- When research is properly conducted and organized, it has the potential to benefit everyone (30)
- CBPR encompasses the view of sustainable development, with “grassroots political organization and local empowerment” (31)
- CBPR aims to identify types of change that are applicable to local communities and giving them tools to help themselves (32)
- Foster the development of the community’s autonomy, and capacity building within the community that help self-sufficiency (38)
- Consider ways to frame research questions for mutual benefit of the community and researcher (40)
- Ensure that the community knows when research is finished and receives results they can use (44)
- It is important to leave something behind in the community, such as the researcher offering their skills/consulting for the community (52)

Responsibility

- CBPR is critical in building relationships between research communities and Aboriginal ones (29)
- Aboriginal communities/organizations are exercising varying levels of control and ownership over research processes, including data collection, the interpretation and dissemination (37)
- A basic principle of CBPR is acknowledging the imbalance of power between Aboriginal communities and the researcher/institution/organization (37)
- Approach CBPR as an opportunity to provide public education about research (broadly and about the specific issue) (38)
- During the interpretation and communication of results, incorporate the community members’ personal interpretations in the final results (43)
- After finishing research, maintain a relationship with the community (45)

Hoare, T., Levy, C., & Robinson, M. P. (1993). Participatory action research in native communities: cultural opportunities and legal implications. Canadian Journal of Native Studies, 13, 43-68.

Respect

- The Indigenous knowledge, once maintained orally, of many Canadian Native communities is being rapidly lost (44)
- In order for Native communities to participate in non-Native society, research should be more aligned with cultural values (46)
- Define Indigenous knowledge as “knowledge that derives from or is rooted in the traditional way of life of Native people” (48)
- Participatory Action Research (PAR) integrates well with Native culture and is able to document oral history (51)

Relevance

- Hoare, Levy and Robinson (1993) argue that there is a critical need for involving Native community members as principle researchers (44)
- “If knowledge is fundamental to understanding, interpreting and establishing values within a society, then control over its production becomes an integral component of cultural survival” (46)
- When discussing the validity of oral history, Native people are careful in making assumptions and only offer information when it is known personally to the individual (49)
- It is difficult to integrate Indigenous knowledge with western knowledge because the systems do not translate (stories, legends and songs cannot be interpreted in scientific form) (50)
- Hoare, Levy and Robinson (1993) advocate the use of Participatory Action Research (PAR) as an important mechanism for collecting Indigenous knowledge and encouraging social change in Native communities (51)
- PAR increases the potentiality for a project’s effectiveness, longevity, and that it continues having an active role of the community’s development (53)

Reciprocity

- PAR is dependent on the people’s experience, values the culture, and builds human capacity in the community (51)
- Key objectives of PAR are to build people’s capacity through education, and to change/eliminate forms of oppression (51)
- In order to identify research needs, PAR involves seven main steps (51):
 - Community identifies problems, then investigates the problem and isolates its components (51)
 - Through research tools and analysis, adult trainees determine the social, political and economical structures that contribute to the problem (52)
 - To potentially resolve the problem, alternative actions are identified (52)
 - The alternatives are evaluated (52)
 - The preferred alternatives are incorporated into a program to be implemented (52)
 - Raise community awareness of the potential for change and to nurture a deeper commitment to resolve community problems (52)

Responsibility

- PAR methodology advocates the signing of a project agreement with all participants, outlining the following principles (62):
 - 4.1 a commitment to the community controlling the process, from setting the research agenda, through PAR consultant trainee selection and project development, to budgeting the annual project review (62);
 - 4.2 a commitment to community ownership and control of all research products and their use. This means that copyright is obtained by the community (62);
 - 4.3 a strong and continuing reliance on the capability of community adults as trainee researchers, teachers, writers and project advisors (62);
 - 4.4 a shared commitment to advocacy on behalf of the community on issues of its choosing (62);
 - 4.5 a commitment to a group dynamic and consensual process of decision-making and a feminist interrelational approach (62);
 - 4.6 a commitment to the PAR consultant working him/herself out of a job within a specific time (62); and

- 4.7 a commitment to regional adoption of the above principles if a multi-community project is contemplated so that a regional PAR standard is achieved (62).

Lantz, P. M., Israel, B. A., Shultz, A. J., & Reyes, A. (2005). Community-based participatory research: Rationale and relevance for social epidemiology. In J. M. Oakes & J.S. Kaufman (Eds.), Methods for social epidemiology. San Francisco, CA: Jossey-Bass Press.

Respect

- A major strength and a major challenge of a CBPR approach is the diversity of partners involved- includes cultural backgrounds, academic discipline, values, perspectives, beliefs, language, etc. (254)
- Although these differences may produce a lack of trust, common goal or common language, it also provides a wide range of viewpoints, skills and experiences that can be drawn from during the CBPR project (254)

Relevance

- Community-based participatory research (CBPR) is a type of research in which the lines are blurred between the researchers and the “researched” (239)
- Lantz et al defines CBPR as “a partnership approach to research that equitably involves diverse partners (for example, academic researchers, health professionals, community members) in all steps of the research process, with all partners contributing their expertise, and in which influence, decision making, and ownership is shared” (241)
- Important to distinguish that CBPR rather than being a specific research method or design, it is an approach (244)
- Four key types of social epidemiological research in which CBPR is applicable to (244):
 - CBPR can be usefully applied to descriptive research, attempting to identify social determinants of health (244)
 - CBPR can also be a productive approach for research attempting to identify disparities in health status/health-related risk factors (245)
 - CBPR has been used when research attempts to define needs, problems and assets in particular communities (246)
 - CBPR is an effective approach when designing, implementing, and evaluating interventions and policies whose goal are to reduce the negative impact of particular social determinants of health/reducing social inequalities of health (246)
- CBPR can be an effectively applied when research involves a needs assessment for the community (248)
- Partners in the project must work together to define the research questions that will be addressed- key is to have partners involved from a variety of perspectives and social locations (251)

Reciprocity

- Collaborative approach to research that with partners from the community, works toward the goal of producing knowledge that can be used to benefit of the community by positive social change (239)
- In the scope of public health, CBPR aims to improve the health status of the community and/or reducing social disparities in health (239)

- It is also beneficial when research focuses on developing interventions to address health concerns in a particular community- able to have an insider look at the community dynamics/structures that may underlie and affect health (248)
- Participatory research involves the mutual commitment to actively address health concerns that have been identified (i.e. designing individual or group interventions, promoting community change, disseminating results at local/state/regional/national venues, or efforts to change any level of health policy) (251)

Lasker, R. D., Weiss, E.S., & Miller, R. (2001). Promoting collaborations that improve health. *Education for Health*, 14(2), 163-172.

Respect

- By bringing people with diverse perspectives together, partnerships can find new and better ways of thinking about health issues (165)
- It is highly challenging to

Relevance

- Health partnerships can be difficult to maintain because collaboration requires relationships, structures and procedures that are different from how they worked individually in the past- many cannot get past the planning phase (164)
- Many communities have fragmented clinical care and health services, which creates problems for the community members- collaboration can connect these services in ways such as “one stop” centers or coordination offices to link a variety of organizations in the community (166)
- Community partnerships that involve government agencies can obtain the widespread information they need to conduct certain types of health assessments (167)
- Partnerships between individual-level services and population-based strategies can strengthen their ability to identify the underlying causes of health problems and consequently take action on them (167)

Reciprocity

- By engaging people/organizations not typically involved in population-based health strategies, collaboration can increase a community’s capacity to improve health (166)
- For sustainable partnerships, it is important to establish procedures/structures that incorporate a wide array of stakeholders- including community members- in collaborative decision-making and action. The involvement of community members ensure addressing local problems and generating more responsive programs (169)
- Necessary to develop more effective methodologies for assessing the impact of partnership actions on the community’s health and the functioning of the health system (169)

Responsibility

- Thousands of partnerships in today’s world recognize that most objectives related to health and health care cannot be accomplished by any single person/organization alone (164)
- Many health professionals/organizations are being held responsible for making changes that are beyond their direct control (164)
- Since there is a lack of connectivity in the health system [of the United States], many people/organizations within it have difficulty supporting each other- despite their complementary goals and skills (164)

- Collaboration has a unique advantage in that the whole of a partnership is greater than the sum of its parts (165)

Responsibility

- Cyclic nature of CBPR- involves forming and maintaining a partnership over time- includes documenting/evaluating the effectiveness of the partnership and the actions it took to address health issues (249)
- Process involves an ongoing evaluation to see what extent CBPR is successful obtaining research, intervention and policy goals (252)
- A challenge in conducting CBPR is defining the community, who will represent it, who decides the community partners, how “grassroots” are community members, and to what extent do community partners reflect and represent the community on a broad scale? (254)

Trust is a critical factor for CBPR (255)- helps to build upon a prior history of collaboration work with a community/an existing positive relationship (257)

Quigley, D., Handy, D., Goble, R., Sanchez, V., & George, P. (2000). Participatory research strategies in nuclear risk management for Native communities. *Journal of Health Communication*, 5, 305-331.

Relevance

- The Nuclear Risk Management for Native Communities (NRMNC) project is a collaborative tribal project based in the community (305)
- The project conducts 3 crucial aspects of participatory research: research, education and community action (305)
- Relationships between the community members and researchers were unethical and inequitable (306)
- Communities were frustrated by the assessments (risk and health) and studies done by external agencies (306)
- This “positivistic science” fails to make accounts of other important factors going on in the communities (306)
- Community participation is essential in all aspects of the research process, from the design to the dissemination of results (307)
- The knowledge and experiences of community members must not be disregarded in the process (307)
- Quantitative research alone is not sufficient for the health assessment (308)
- NRMNC wanted to develop a “community exposure profile” that contained a summary of all studies conducted on the site’s contamination, including a narrative of the holistic impacts the contamination (314)
- The “community exposure profile” included interviews/meetings with affected community members regarding their personal accounts and perceived impact on community life (316)
- The NRMNC recruited and trained a community advisory committee (CAC) to share power and decision-making (314)
- They prioritized recruiting Native elders because of their first-hand accounts and extensive experience in the community (314)
- The NRMNC and the CAC had shared management procedures, that involved approving grant applications/goals/budgets, approving project publications, progress reports, and establishing subcommittees in areas like education and research (315)

- A large challenge in the NRMNC project was overcoming problems of limited resources and distance (324)
- Community researchers were not comfortable with the time-consuming “electronic mail” or were remote reservations and did not have electronic mail set up- eventually it was installed for future work (324)
- Distance was a disadvantage for conducting interviews/attending meetings or events (325)
- Team members adapted to these challenges and managed to maintain very good communication (325)
- Another challenge was the competing institutional demands of team members and the CAC (325)
- The NRMNC’s success was partly attributed to the contributions of the established and trusted Native environmental organization, CANAP (326)
- The CAC’s skilled members also can be credited for their assurance of honest research- they maintained open communication between the researchers and community and ensured they were not being dominated by Western traditions (327)

Reciprocity

- There is a need for equitable relationships between researchers and communities (307)
- Community members must be educated on [the issue being studied] and trained to make decisions throughout community-based research (307)
- The NRMNC’s overall goal is to build capacity within the community to manage their potential health risks from nuclear contamination (311)
- NRMNC also sought to distribute the necessary resources and assistance to Native communities to build a community-based health infrastructure (313)
- NRMNC aimed at implementing an educational program on the site’s contamination with the use of educational modules (314)
- NRMNC also designed a community-based hazard plan for continual community health support in dealing with the contamination (314)
- Established a community research program called the “Local Knowledge Program” which provides a plethora of information/observations, along with skills training and empowerment to local Native staff (allows Native people to research their own people’s experience and culture) (318)
- The NRMNC used a participatory evaluation process in which the CAC evaluated the project over a period of four years (327)
- The NRMNC also incorporated feedback from workshops for their improvement (327)
- By the third and fourth year of its establishment, the CAC had a high investment in the project by obtaining their research goals, the greater likelihood for long-term funding, and the fact they enjoyed their meetings and were a strong group representative of diverse tribal communities- they also unanimously supporting the project’s continuation (315-16)

Responsibility

- Tribal support was also crucial in the project’s success, particularly for legitimacy and funding purposes (328)

Richmond, C.A.M, & Ross, N.A. (2008). Social Support, Material Circumstance and Health Behavior: Influences on health in First Nation and Inuit communities of Canada. *Social Science and Medicine*, 67, 1423-1433.

Respect

- In Indigenous communities throughout the world, balance, holism and interconnectedness are considered key concepts for healthy living (1424)

Relevance

- There is extensive literature on the connection between social support and health (1423)
- Researchers have suggested that “the health effects of our social relationships may be as important as established disease risk factors such as smoking, obesity and high blood pressure” (1423-4)
- First Nation and Inuit communities are geographically small and socially integrated, thus a unique population to research the link between social support and health (1424)
- Social support is reportedly high in this communities, yet there are continually patterns of mortality and morbidity largely influenced by social pathologies (such as family violence, sexual abuse, poverty and suicide) (1424)
- The notion of individual health is shaped by the social context around them, such as family, community, nature and the Creator (1424)
- An individual’s wellness is also dependent on the wellness of those around them (1424)
- Social embeddedness is a term describing “the connectedness of individuals to others in their social environments” (1424)
- Three units of analysis in measuring an individual’s social embeddedness: the micro-level (most intimate relationships), the mezzo-level (regular interaction/support), and the macro-level (most distant social ties/at a community level) (1424)
- Indigenous frameworks suggest that the larger social networks most significantly shape one’s health and wellbeing (1425)
- Social support has been identified as a constant dimension of health among Métis and Inuit populations in Canada (1425)
- Social support has also been identified as a powerful determinant in Indigenous women health (1425)
- In studying how social environments impact Canadian Aboriginal people’s health, this study drew from a narrative analysis of interviews with 26 First Nation and Inuit Community Health Representatives (CHRs) (1425)
- The CHRs were front-line community workers, which are especially critical services in remote and rural communities (1425)
- Qualitative research in health geography aims to understand the ‘situated’ experiences in health/health care (1426)
- Conducting face-to-face interviews with CHRs was not possible due to widespread geographic dispersion, thus only one was done face-to-face and the remaining 25 interviews were done by telephone (1426)
- Most advantageous aspect of telephone interviews is cost-efficiency, although it is difficult to establish trust over the phone which can greatly impact the information interviewees share (1427)
- Through narrative analysis (interpreting a story/conversation in context of the speaker’s community) of the interviews, researchers are able to understand the “contingent, the local, and the particular” (1428)
- The analysis drew from both cultural and epidemiological frameworks (1431)

Richmond, C.A.M., & Ross, N.A. (2009). The determinants of First Nation and Inuit health: A critical population health approach. *Health & Place*, 15, 403-411.

**Drew upon same study/interviews as above article, Richmond and Ross (2008)*

Respect

- Land is, a fundamental part of Indigenous culture, is crucial for the health and wellness of Aboriginal societies- the loss of land is arguably one of the most significant factors of culture stress within Indigenous communities (404)
- Little research has been done on the dimensions that link Aboriginal peoples and their physical environment, nor on the health consequences from the severed ties (404)

Relevance

- There are various, contextual determinants in understanding the health of First Nation and Inuit communities in rural and remote areas (many rooted in unequal power relations and colonization history) (405)
- A conceptual framework, *population health* refers to why some people are healthier than others (404)
- A critical population health approach is appropriate in this analysis, in which the goals are (405):
 - (1) A thorough examination of how historical social structures, economic relationships and ideological assumptions perpetuate conditions that undermine the health of specific populations (405); and
 - (2) A project that results in a deeper understanding, and thus aims for the reconstruction of social, economic and political relations (405)
- Richmond and Ross (2009) argue that environmental dispossession is at the centre of health and social inequalities of rural and remote First Nation and Inuit communities (405)
- Necessary that researchers ask critical questions in order to positively change Aboriginal health outcomes (410)
- The determinants of health in rural and remote communities identified by the First Nation and Inuit CHRs are “balance, life control, education, material resources, social resources, and environmental/cultural connections” (409)
- The only determinant that differs from the Canadian list is environmental/cultural connections- CHRs mentioned that environmental dispossession affects health both directly and indirectly (409)

Riecken, T., Scott, T., & Tanaka, M. T. (2006). Community and culture as foundations for resilience: Participatory health research with First Nations student filmmakers. *Journal of Aboriginal Health*, 3, 7-14.

Respect

- Students also reflected on the importance of cross-generational relationships and the concept of carrying cultural knowledge and traditions (11)
- Many students discussed and produced videos on the importance of culture and the practice of one’s culture as a means to stay healthy (12)

Relevance

- A crucial social factor identified as a health determinant is the amount of control people have over their lives and in their supportive relationships (7)
- A participatory community health project- Traditional Pathways to Health (TPH)- was designed to address the disconnection experienced by many urban Aboriginal youth (7)

- TPH involves students (as co-researchers) to choose a health or wellness issue that interests them, then plans, researches and develops a video entailing the message they learnt and later present it (7)
- Three First Nations teachers in Victoria were TPH partners- each run a different program at their schools which aim to increase the opportunities for academic success of urban Aboriginal students (8)
- Large and small group discussions and one-on-one conversations with teachers and the research team take place- helps students develop their ideas around health and how they could convey their message to an audience (8)
- The university (research) team provides the students with digital video cameras and instructions to work them- signing out equipment and logistical ideas issues (i.e. transportation) is dealt primarily by teachers, students and parents (9)
- 28 student videos have been produced in the first three out of five-year project (9)
- Students presented their videos in a variety of ways- Esquimalt Secondary School students held a potlatch, Victoria High School and the Westshore Centre for Learning students invite their friends, family, and community members to video screenings (9)
- 28 individual and collaborate student-produced videos, 29 interviews with the video makers, and interviews with the 3 teacher partners constituted the data (9)

Reciprocity

- The aims of the project were to facilitate students' exploration of topics they perceive to be important in health promotion/injury preventing, develop prevention strategies, develop leadership skills/research expertise, and develop an understanding of how participatory action research can be beneficial to the community and school (8)
- In reflecting on the project, students talked about the importance and value of the project through connecting with community members and building relationships (11)
- The themes of personal growth, self-confidence and relationship with oneself are consistent in reflections of the project (12)

Responsibility

- A site project typically begins with the researchers being invited into the three First Nations programs- the researchers can then explain participatory research, pitch the opportunity to the students (who can choose to take part in the health and wellness video) (8)
- "Nurturing, supportive positive connections and relationships are working for the students and their teachers" and the willingness of community members to participate in the project (in any level) spoke to the relationships they have with community researchers (13)

POLITICAL ACTION ON ABORIGINAL ISSUES

Indian and Northern Affairs Canada (1996). Highlights from the Report of the Royal Commission report on Aboriginal peoples. Available online. Retrieved February 25, 2011 from <http://www.ainc-inac.gc.ca/ap/pubs/rpt/rpt-eng.asp#toc>.

Respect

- Aboriginal peoples say that their ultimate right to be self-governing comes from the Creator, who placed each nation on its own land, giving people the responsibility to care for that land and each other (The Case for Self-Government)
- There are 11 Aboriginal language families and over 50 different languages in Canada-protecting language involves increasing the number of fluent speakers and using the language in everyday life, particularly within family (Living Languages)

Relevance

- In forming a health strategy, for both individual and social health, it is important to talk a holistic approach (A Strategy for Health and Healing)
- “Reorganization of existing health and social services into a system of health and healing centres and healing lodges, under Aboriginal control” (A Strategy for Health and Healing)
- “Adaptation of mainstream services to accommodate Aboriginal people as clients and as full participants in decision-making” (A Strategy for Health and Healing)

Reciprocity

- As part of a health strategy, “a crash program over the next 10 years to educate and train Aboriginal people to staff and manage health and social services at all levels, in Aboriginal communities and in mainstream institutions” will be implicated (A Strategy for Health and Healing)
- To build strength and capacity, it is important to target action in the following main areas: healing (of individuals, families, communities and nations), economic development, human resources development (10-year education/training initiative to foster skills of Aboriginal people), and to build Aboriginal institutions (Gathering Strength and Building Capacity)

Responsibility

- In the Highlights from the Report of the Royal Commission on Aboriginal Peoples, the following four concepts are principles that should serve as the basis of a renewed relationship (Renewal and Recognition):
 1. **Recognition**

“The principle of mutual recognition calls on non-Aboriginal Canadians to recognize that Aboriginal people are the original inhabitants and caretakers of this land and have distinctive rights and responsibilities flowing from that status. It calls on Aboriginal people to accept that non-Aboriginal people are also of this land now, by birth and by adoption, with strong ties of love and loyalty. It requires both sides to acknowledge and relate to one another as partners, respecting each other's laws and institutions and co-operating for mutual benefit.” (The Way Forward)
 2. **Respect**

“The principle of respect calls on all Canadians to create a climate of positive mutual regard between and among peoples. Respect provides a bulwark against attempts by one partner to dominate or rule over another. Respect for the unique rights and status of First Peoples, and for each Aboriginal person as an individual with a valuable culture and heritage, needs to become part of Canada's national character.” (The Way Forward)
 3. **Sharing**

“The principle of sharing calls for the giving and receiving of benefits in fair measure. It is the basis on which Canada was founded, for if Aboriginal peoples had been unwilling to share what they had and what they knew about the land, many of the newcomers would not have lived to prosper. The principle of sharing is central to the treaties and central to the possibility of real equality among the peoples of Canada in the future.” (The Way Forward)

4. Responsibility

“Responsibility is the hallmark of a mature relationship. Partners in such a relationship must be accountable for the promises they have made, accountable for behaving honourably, and accountable for the impact of their actions on the well-being of the other. Because we do and always will share the land, the best interests of Aboriginal and non-Aboriginal people will be served if we act with the highest standards of responsibility, honesty and good faith toward one another.” (The Way Forward)

- “During [20 years] time - and beyond it - we can look forward to a Canada that celebrates Aboriginal heritage and draws strength from Aboriginal peoples as full partners in a renewed federation” (Last Words)

PROTECTING ABORIGINAL CULTURE

Christie, G. (1998). Aboriginal rights, culture, and protection. Osgoode Law Journal, 36, 447-484.

Respect

- “Aboriginal culture” contains the “values, principles, and beliefs that inform the physical manifestations, which give them meaning, truth, and validity” (450)
- These are the “cultural property” in which Aboriginal people feel deserves protection and respect in terms of its preservation, development and transmission (450)
- Where do Aboriginal people locate value in relation to their intellectual property (454)

Relevance

- Highest Canadian court makes decisions to protect Aboriginal “rights” and “culture”, when in actuality they are protecting Aboriginal activities (like fishing in particular areas) (448-449)
- Aboriginal culture lies in expressive activities such as storytelling, music and dance (449)
- Focus on protecting activities that are manifestations of Aboriginal culture (450)
- The protection of Aboriginal “intellectual property” has been made available, although this is not considered a positive outcome for Aboriginal people (450)
- The underlying defining elements of an Aboriginal world deem protection from Canadian sources both unnecessary and unwanted (451)
- The Western idea of cultural property hinders the appropriate control of Aboriginal culture (451)
- Canadian law could supplement these Aboriginal institutions with mechanisms to prevent outside users from unauthorized use of Aboriginal intellectual property (453)
- A viewpoint: asking if the Aboriginal communities have any need for the intervention of Canadian law in terms of protection (454)
- The concept of “tradition” does not necessarily allude to the purity of pre-contact Aboriginal peoples (456)
- There is a distinct difference in views of “property” between Aboriginal and Western cultures (457)
- Aboriginal societies were historically structured by “conditions of sharing” (“the obligations that members of the group must meet in order to be entitled to a share in its resources”), whereas modern Western societies are structured around “conditions of choosing” (“the obligations all individuals must respect if they are to be left alone to pursue their own vision of the good life”) (462)

- Notion now that once Aboriginal peoples are exposed to conditions of choosing, there is no going back and they will be judged by their individual choices (463)

Responsibility

- Responsibilities the Aboriginal community has in terms of protecting a tradition is unlike the Western concept of control- the protection of the traditions lie in their sacredness and greater role in the community (457)

RESEARCH WITH ETHNIC MINORITIES

Okazaki, S., & Sue, S. (1998). Methodological issues in assessment research with ethnic minorities. In A. E. Kazdin (Ed.), Methodological issues & strategies in clinical research (2nd ed.). Washington, DC: American Psychological Association.

Respect

- Researchers and others often refer to ethnicity, race and culture interchangeable when identifying/categorizing people by their background- in actuality race and culture are termed ethnic “identifiers” (367)
- During sampling, ethnicity may be defined at a broad or specific level (369)
- Researchers may have difficulty classifying people who are of mixed race or ethnic backgrounds (369)
- “A researcher may choose to translate and adopt the instrument to the ethnic minority group of research interest” (371)
- Recommended to use a method in which translation is followed by back-translation, then comparison, make consequent revisions, and so forth (371)
- It has been criticized that the sole use of quantitative measurement methodologies in assessing ethnic minority populations is insufficient because it does not take cultural factors into account (372)
- Recommended that expert cultural or ethnic consultants evaluate the translation and “conceptual equivalence” of the measure prior to data collection or interpretation (373)

Relevance

- There has been great skepticism with the validity of study results with minorities, such as comparisons of cognitive/intellectual abilities, self-esteem and self hatred, psychopathologies (prevalence rates and degrees), etc. (367)
- There needs to be more informed decisions on the researchers part when handling ethnic issues (367)
- Identified fundamental problems in the areas of sample heterogeneity, how culture is measured, and the underlying assumptions regarding ethnicity (367)
- It is important for the researcher to ask which ethnic groups they want to include in their project and for what purpose (368)
- If the ethnic minority group is too small to be grouped with a majority one, the researcher may tend to exclude them from the analyses (368)
- Another dilemma is deciding whether to analyze the target ethnic minority group data in isolation, or to compare data with a control group (368)
- Collecting data in ethnic minority groups can be difficult, and thus college populations are a viable option because it is easy to access a large group of them (370)
- Having a dominantly college-based sample can question the representativeness of it (370)

- Despite the challenging nature of sampling from ethnic minority communities, it is the preference of many studies (371)
- Research with ethnic minorities has also been criticized for its lack of ecological and contextual considerations (371)
- There has been little empirical work that examines the advantages and disadvantages of collecting qualitative data from ethnic minorities (372)

Responsibility

- It is prioritized that assessment research with ethnic minority groups is reliable and valid, with less cultural or ethnic bias (371)
- During the interpretation of data, “differences tend to be evaluated in disfavor of ethnic minorities” (372)
- Suggested that research reports include more detail as to the sample and sampling methodology used (373)

RESEARCH WITH NORTHERN COMMUNITIES

Smith, H. S., Bjerregaard, P., Chan, H. M., Corriveau, A., Ebbesson, S. O. E., Etzel, R. A., Fabsitz, R. R., Hakonarson, H., Hild, C., Nobmann, E. D., Reading, J., Tereshchenko, L., Young, T. k., & Howard, B. V. (2006). Research with arctic peoples: Unique research opportunities in heart, lung, blood and sleep disorders. *International Journal of Circumpolar Health*, 65(1), 79-90.

The Unique Challenges/Barriers to doing Research with Aboriginal Communities

- View that research doesn't offer much benefit and there is potential for harming the community (80)
- Distrust of research – investigators take and never give back (80)
- Research results get shared with scientific community before Native community (80-81)
- Limited formal education, resulting in lack of understanding of research (81)
- Short supply of Native scientists, lack of educational programs to train students interested in research, minimal mentors to train and inspire (81)
- No roads between villages (81)
- Lack of infrastructure can be a barrier for research (82)
- Language barriers (82)
- Research costs are high because of the low density of population and high travel expenses (82)
- Time it takes for research project proposals to be reviewed by multiple institutional, community and governmental entities (86)
- Issue of data ownership (86)
- IN NWT, research licenses are required by the government (86)

Solutions to Barriers

- Create mentorships, develop advanced degree programs, simplify grant application/reporting process, emphasize community partnerships for research projects (81)
- Distance learning programs for those in remote, rural areas (81)

Suggestions for Working and/or Researching with Aboriginal Communities

- Support collaborations, partnerships (81)
- Increase research capacity within communities (81)

- Give weight to traditional knowledge when reviewing applications, establishing community based research and developing an integrated northern policy (81)
- Have the research rooted in the community rather than implanted there (86)
- Research should be driven by community needs not the researchers needs (86)
- Alaska Native communities prefer research that builds long term relationships between researchers and community members – this empowers them (86)
- Work with, and through councils for approvals and guidance (87)
- Return meaningful research results to the participants and community (87)
- Spend an adequate amount of time in the community to develop an understanding of the communities needs, sensitivities, and customs (87)
- Be involved in the community while conducting research there (88)
- Follow guidelines established by Indigenous people: WHO CINE, Alaska Federation of Natives Guidelines, NSF Guidelines (88-89)
- Be culturally sensitive and respectful (89)
- Promote hiring and training of Native staff as a part of the research – build capacity (89)

Good Knowledge Translation with Aboriginal People

- No information

Objective 3: Information Re: Expansion of indicators/Tools for Nutrition/Physical Activity Interventions to be Implemented in Remote, Northern, and Aboriginal Communities

- Different diets between Indigenous traditional food and general population (ex., consumption of fish is 6 times higher in Alaska Natives than the general U.S. population; 83)
- In some areas, diets are mixed with traditional foods and market foods (83)
- Different Indigenous groups/areas (Yukon versus Inuit) have different traditional diets – Yukon FN eat moose and caribou whereas Inuit eat caribou and sea mammals (83)

USING FOCUS GROUPS

Willgerodt, M.A. (2003). Using Focus Groups to Develop Culturally Relevant Instruments. Western Journal of Nursing Research, 25(7), 798-814.

Respect

- The culture of participants may influence their recruitment into focus groups- for example, the focus group concept of gathering people together to discuss a topic is not a Chinese cultural norm (806)
- In conducting focus groups, it is crucial to be mindful of the service participants are doing, and be respectful and genuine (807)
- Showing respect, particularly to elders, is a virtue of many cultures i.e. the Chinese (807)
- Respect is also important especially when certain groups are used to being treated like second-class citizens by outsiders i.e. immigrants (808)

Relevance

- In setting up a foundation for successful focus groups, five elements of planning are identified (804):
 - Build relationships with key community members, demonstrating the research team's commitment to the community (804)
 - Collaborate with the community and plan focus groups in advance, showing respect for participants (804)

- Develop multiple advocates for the project, enhancing the recruitment of participants and project completion (804)
- Provide an interpreter to sustain the research team's independent perspective of community occurrences (804)
- Identify a location that increases participation and minimizes burden on participants (804)
- A connection with a known organization/institution and careful relationship building helped gain access to the community (804)
- If applicable to the community situation, bilingual research assistants may be needed in order to assure accurate interpretations in focus groups (805)
- Having this interpreter lessens the burden on the community agency staff members who may unknowingly incorporate bias into their translations (805)
- In regards to focus group participation, it is essential that community members know the recruiter- they are able to discuss the study as a peer (806)
- Recruitment can be difficult, especially when the research is on a personal topic i.e. family relationships (806)
- Since research teams are community outsiders, they can build project credibility when securing "buy-in" from informal and formal leaders (807)

Reciprocity

- Meetings with relevant community organizations/institutions demonstrate the research team's commitment to improve the wellbeing of the community (consequently facilitating the researchers' acceptance) (804)
- Small gestures like scheduling focus groups/meetings around the community members' schedules set the tone for mutually respectful and collaborative partnerships (804)

Responsibility

- The behaviour of focus group leaders sets the tone and can affect participants comfort in disclosing their true opinions (807)
- In discussing sensitive issues, a strategy for the researcher is frame the issue as if it is the experience of someone else- helps make it less personal (808)
- When conducting focus groups, it is crucial to have a skillful and sensitive moderator (808)
- Having a note-taker present during the focus group can help trigger memories upon analysis of the transcripts (809)
- During data analysis of focus groups, it is essential to remain open and flexible to unforeseen discoveries (810)

SURVEY ADAPTATION

Beaton, D.E., Guillemin, F., Bombardier, C., & Ferraz, M.B. (2000). Guidelines for the Process of Cross-Cultural Adaptation of Self-Report Measures. SPINE, 25(24), 3186-3191.

Respect

- Possible scenarios in which a questionnaire needs to be adapted (3187):
 - "Use in established immigrants in source country- needs cultural adaptation" (3187)
 - "Use in other country, same language- needs cultural adaptation" (3187)
 - "Use in new immigrants, not English-speaking, but in same source country- requires language translation and cultural adaptation" (3187)

- “Use in another country and another language- requires language translation and cultural adaptation” (3187)

Relevance

- Stage 1: Initial translation is made
 - Recommended to have at least two translators, who can then compare and contrast version and help eliminate ambiguous wording. (3188)
- Stage 2: Synthesize the translations (3188)
 - The two translators and an observing recorder review the two translations (T1 and T2) and a common translation (T-12) is made, while documenting the process (3188)
 - Important that consensus resolves issues of disagreement (3188)
- Stage 3: Back translation is needed (3188)
 - A translator then translated the T-12 version back into its original language (3188)
 - Two back translations are considered a minimum (BT1 and BT2), as they are only one type of validity (3188)
- Stage 4: Expert committee is formed (3188)
 - Comprised of all relevant professionals and translators (3188)
 - Review all translations and discuss discrepancies (3188)
 - Needs to be equivalence in four areas:
 - Is there semantic equivalence? (Do all words mean the same thing?) (3188)
 - Is there idiomatic equivalence? (Are colloquialisms or idioms expressed accurately?) (3188)
 - Is there experiential equivalence? (Are the experiences drawn up cross-cultural?) (3189)
 - Is there conceptual equivalence? (Are word meanings cross-cultural?) (3189)
- Stage 5: Test the prefinal version (3189)
 - The ideal test number is between 30 and 40 participants (3189)
 - After completion of the questionnaire, each participant is interviewed to probe their reactions/interpretations to the questions (3189)
- Stage 6: Submission of documentation to developers for appraisal of the adaptation process (3189)
 - Verify that the recommended stages were followed and if so, assumed that the translation is acceptable (3189)

Harkness, J. (2010). Cross-Cultural Survey Guidelines: Adaptation.

Respect

- Important to adapt surveys in cross-cultural and multilingual projects (1)
- Linguistic phrases (such as different types of measurements) may need to be changed to improve comprehension, since not all cultures share the same systems (3)
- Adapt survey based on cultural sensitivities (4)

Relevance

- Researchers want to modify surveys based on the different projects (1)
- Wording can be changed to appropriately reflect social realities (1)
- Wording can be changed to suit a different age group/population (1)

- Socio-demographic questions often need altering (2)
- May adapt (maintain or reduce) the level of difficulty (5)
- Adapting survey design components/characteristics (4)
- Adapt the grammar may be necessary (4)
- The goal is to make a survey more fitting to a new population, location, language or mode (6):
 - Step 1: Decide on the policy, people and procedures for adaptation (6)
 - Step 2: Recruit a team to carry out the adaptation (7)
 - Step 3: Review the source questionnaire as needed during adaptation (8)
 - Step 4: Review the translated questionnaire as needed (9)
 - Step 5: Record the adaptations and their reasoning (10)
 - Step 6: Test the new questionnaire on the target population (11)

McColl, E., Jacoby, A., Thomas, L., Soutter, J., Bamford, C., Steen, N., Thomas, R., Harvey, E., Garratt, A., & Bond, J. (2001). Design and use of questionnaires: a review of best practice applicable to surveys of health service staff and patients. *Health Technology Assessment, 5*(31), 1-6.

Respect

- Pre-notification is respectful to prepare the respondent for timing (3)

Relevance

- There was no superior mode of administration between self-completion and interviewer administration (3)
- Question wording and sequencing (including the choice/order of response options) can have a significant impact on response quality (3)
- The design and layout can reduce the risk of error and in recording/coding responses (3)
- Individual survey researchers must take the particular goals of the study, the population it is intended for, and the available resources into account (3)
- The main goal is always to obtain reliable, valid and unbiased data (3)

Reciprocity

- When enhancing response rates, the respondent's perceived costs must not exceed the benefits (3)

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