



CAPTURE

Canadian platform to increase usage of real-world evidence

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

ADAPTATION FRAMEWORK: A GUIDE FOR ADAPTING EXISTING SURVEY TOOLS FOR USE IN NORTHERN, RURAL AND ABORIGINAL COMMUNITIES

**DEVELOPED BY:
RECIPROCAL CONSULTING**

**KIM VAN DER WOERD
SAMANTHA TSURUDA
BILLIE JOE ROGERS
KYLEE SWIFT**

OCTOBER 25, 2011

INTRODUCTION

Program A was a year into their program and was curious to see how they were doing, so they decided to complete a program evaluation. Program A gathered all the tools for evaluating their program; they found program evaluation and program logic model templates.

After describing their program and goals in the program logic model, they wondered how they could accurately evaluate their program. Program A researched ways to collect data and found a survey that had been used by similar programs.

Program A decided to use the survey but needed to adapt it for their community. They first formed an advisory committee to help make the survey relevant. Program A held a community event to hear opinions and suggestions about the survey questions. At the event, program A was told that mailing out a survey to all program participants was not the best option, and that an in-person interview was preferred. Program A and the community worked to adapt the survey into an interview that could be conducted face-to-face; that way community members could tell their stories. The interview also considered the local context.

Once the survey was changed, program A and some additional community members worked to collect the information and then analyze it. After the information was analyzed, program A held another community event and presented their results.

The program was a success and many lessons were learned! Program A and the community worked together to find a way to share the results in a meaningful way.

This scenario shows that evaluation can be positive experience for a community. This document is intended to help people working in program evaluation achieve these types of positive outcomes for communities and the programs that serve them.

In the past, evaluation was community placed (e.g. directed by government within communities) rather than community based (e.g. led by the community). This tool can help make the process more collaborative. The *Adaptation Framework* is meant to be a broad resource to provide principles that can guide you in modifying surveys, or thinking about other ways to collect information. It may also help guide the development of an evaluation protocol or agreement between an evaluation team and a community.

WHY CREATE A FRAMEWORK FOR ADAPTING DATA COLLECTION TOOLS?

Throughout Canada, a variety of organizations – including government, not-for-profit organizations and community-based groups – work to develop and offer programs designed to improve people’s health and wellbeing. An important element of this process is program evaluation: determining whether programs are achieving their goals and meeting the needs of the community and the funder.

While it can be a challenge to build an evaluation culture in any community, this can be particularly true in northern, remote and Aboriginal communities. Historical and cultural context, along with the community’s past experience with research and evaluation, can mean that evaluation approaches and tools that work well in some communities are not appropriate in others.

Program planners and evaluators need to understand the issues around evaluation, and they need practical approaches and tools that can help make evaluation more acceptable and helpful to these communities. The *Adaptation Framework* is intended to help them achieve these goals.

ABORIGINAL PEOPLES IN CANADA

In Canada, there are three unique groups of Indigenous people:

- Defined by the National Aboriginal Health Organization (2009), **First Nations** is a term used to describe Indigenous people of Canada who are not Métis or Inuit;
- **Inuit** refers to Indigenous people living in the arctic regions of Canada;
- **Métis** refers to people of mixed European and Aboriginal ancestry.

In this framework, “Aboriginal peoples” will refer to these three diverse Indigenous groups in Canada.

Across Canada, there are more than 600 recognized First Nations, Inuit and Métis groups, each with distinctive cultures, languages, art, and music. Since it is impossible to know everything about a culture, it is important to be open-minded and considerate when doing research or evaluation with any community (The Colorado Trust, 2007).

PLANNING FOR EVALUATION

Smith (1999) identified a list of questions a researcher or evaluator must ask when working with communities:

- Whose research/evaluation is it?
- Who owns it?
- Whose interests does it serve?
- Who will benefit from it?
- Who has designed its questions and framed its scope?
- Who will carry it out?

- Who will write it up? How will its results be [shared]?

GUIDING PRINCIPLES FOR DATA COLLECTION

The guiding principles for this *Adaptation Framework* come from the four “Rs” for research with Aboriginal peoples (Kirkness & Barnhardt, 1991). The four Rs are: **Respect**, **Relevance**, **Reciprocity** and **Responsibility**. These are valuable concepts to consider when working with any community. First, each R will be explained in depth, and then brought into context under Steps for Adapting Surveys.

RESPECT

Valuing and building on the diverse knowledge of the individual, culture and community.

Community engagement

- Respect includes the willingness to learn about a community’s cultural practices and including them in the research process. Being treated with respect can also facilitate the willingness of community members to engage in the research or evaluation process.
- Participatory research is a way to be respectful by involving the community. It is an approach that has different groups working together to develop a shared purpose, plan, and conducting the project (Israel, Schulz, Parker, & Becker, 1998). This type of research can bring diverse views and cultures together (Israel et al., 1998). Participatory research can build resilience by developing relationships and connections within the community and culture (Riecken, Scott, & Tanaka, 2006).
- A way to engage the community is through working with a bridge builder or cultural translator (The Colorado Trust, 2007). This could be the person who hired you, or someone who is known by the funder, a colleague, or community residents who are contacted with the help of the funder. It is important to respect the time spent by staff, leaders and other people involved in the process.

Cultural safety

- Cultural safety goes beyond cultural sensitivity, awareness or competence. It reminds us to consider how research, education, practices, and health policies may bring up the traumas Aboriginal peoples have dealt with. Cultural safety aims to improve experiences that Aboriginal people have in the health care system through addressing systemic inequities by allowing those who receive the service to contribute in its design and policy.

Respect for different ways of knowing

- It must be recognized that some cultural groups have different ways of knowing. For example, many Aboriginal people value traditional, oral, and Indigenous knowledge (Kirkness & Barnhardt, 1991). These types of knowledge come through lived experience and are used in everyday life. Since Aboriginal and Western ways of knowing do not always fit, it is important for mutual respect of different forms of knowledge (Kirkness & Barnhardt).
- According to the Colorado Trust (2007), it is important to make time to respectfully ask the right questions when beginning to work with a cultural group:
 - How do people from this culture usually greet each other?
 - Does the community have any past experiences with evaluators or researchers?
 - When considering the survey that is to be adapted, what types of changes would you make around Respect?

- How do you think the approach of participatory research applies to survey adaptation?

RELEVANCE

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.

Community driven

- Relevance involves the idea that communities identify their research or evaluation needs and dreams in order to help them grow. The researcher or evaluator works with the community to make sure the project is relevant and meets the community's goals. The community can also be involved in building or adapting a survey to make it relevant for their people. If they decide surveys are not an appropriate way to collect data, they can decide which methods are preferable, such as focus groups or one-on-one interviews. It involves listening to the needs of the community members, free of judgment, and supporting and encouraging their values.

Adaptation

- Communities differ from one another in a variety of ways: certain practices and policies may be relevant to some but may not apply to others. When working with different cultural groups, it is important to develop a project plan that is culturally relevant and accepts unique perspectives (Kirkness & Barnhardt, 1991). Evaluators should make sure that they build relationships, have good communication, and gather information that is relevant to the community needs.
- When adapting surveys, it is important to be mindful that surveys are not always the most effective method of gathering information. Start by considering the audience: sometimes there is more value in collecting information through focus groups, workshops, in-person interviews, or in community settings. For example, in Aboriginal communities, some Elders have a wealth of knowledge and experiences, yet would prefer to share them through story telling rather than through surveys.
- Questions to ask may be (The Colorado Trust, 2007):
 - Does this translate to the community's language?
 - Do the questions asked make sense to the community?
 - How can the evaluation or research help address challenges in the community?
 - Will the questions produce meaningful results?
 - Is a survey the most appropriate way to gather your information?

RECIPROCITY

When the researcher and community both benefit from the project/evaluation, and learning and research is a two-way process.

Sharing the information

- There is often a gap between knowledge that is produced and knowledge that is used in the community. It is important to create reciprocal relationships between the researcher and community, where both the community and researcher benefit from the project.
- It is good practice to set aside time and resources to build relationships and trust. Trust and respect may develop in the relationship through consulting with community members before starting the project, as well as during the process.
- Part of reciprocity is also having a feedback system between the community and researcher or evaluator. This may include meetings where all evaluation users can share their opinions on survey questions. In terms of recommendations, it is important for the community and the evaluator or researcher to consider each other's feedback.
- Questions to ask may be (The Colorado Trust, 2007):
 - Who is going to benefit from this process (i.e., funder, evaluator, community)?
 - How will community members use the findings?
 - Were everyone's opinions valued during the process?

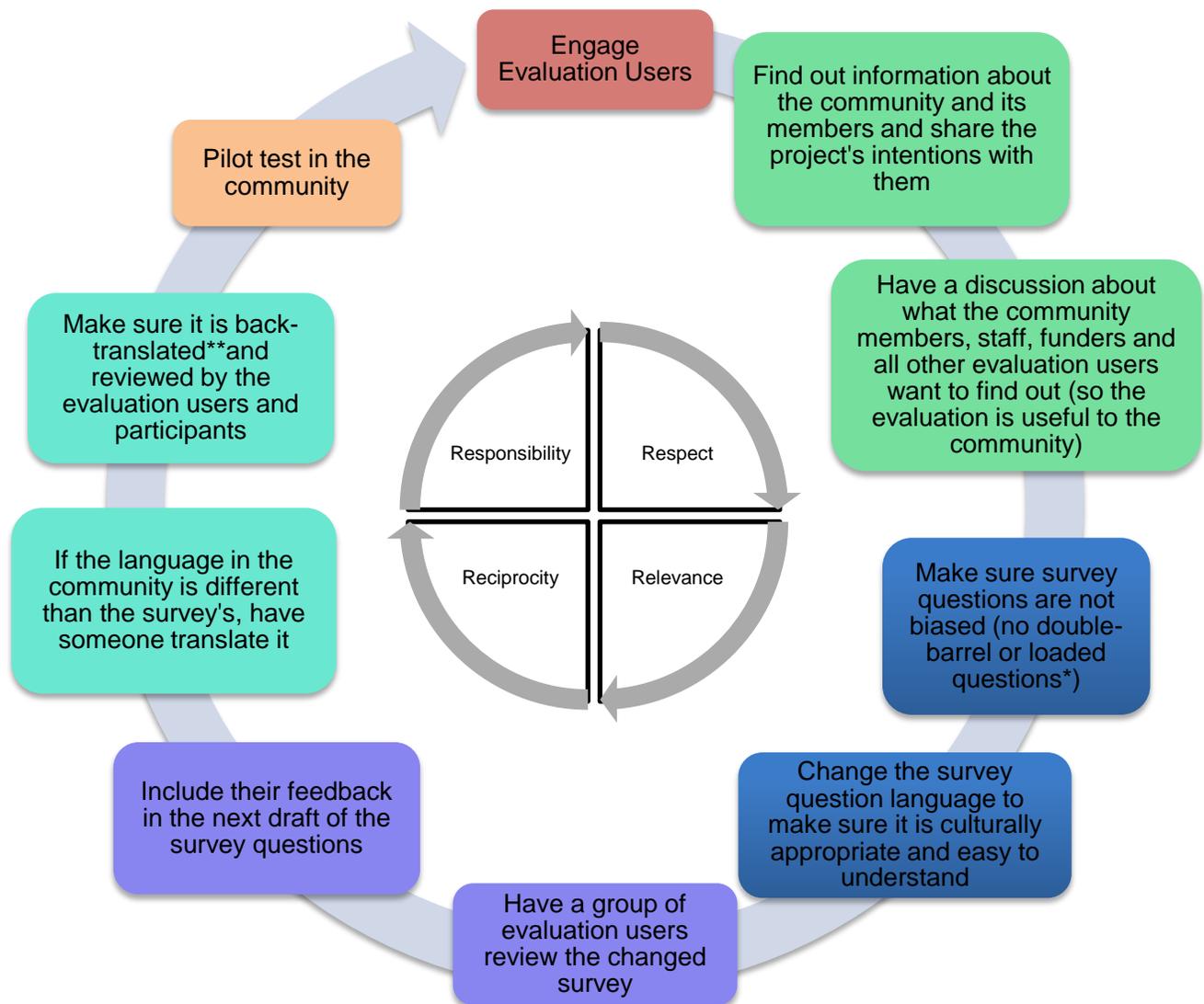
RESPONSIBILITY

An overarching concept of the previous three Rs, and the researcher/evaluator is mindful of all perspectives during the process.

- Responsibility includes the researcher or evaluator being mindful of respect, relevance, and reciprocity, and following ethical guidelines during all stages. Responsibility means that the community has access to the project data, and is able to review it and influence the sharing of the results, with a clear picture of how the results will be used to tell the story about their program or shape future programs.
- Confidentiality is a key part of responsibility, making sure that responses in surveys are anonymous, especially in smaller communities. Results should be shared with the program and community members. Responsibility also means making sure the original purpose of the project meets the needs of the community. Examples of responsible guidelines for working with indigenous communities:
 - Ethical Principles For The Conduct of Research in the North: <http://acuns.ca/website/wp-content/uploads/2010/09/EthicsEnglishmarch2003.pdf>
 - Royal Commission on Aboriginal Peoples. (1993). Ethical Guidelines for Research: <http://www.pre.ethics.gc.ca/francais/pdf/RCAP.1993.eng.pdf>
 - International Development Research Centre: Working with Indigenous Knowledge: A Guide for Researchers: www.idrc.ca/openebooks/847-3/
 - CIHR Guidelines for Health Research Involving Aboriginal People: http://www.cihr-irsc.gc.ca/e/documents/ethics_aboriginal_guidelines_e.pdf
 - Interviewing Elders – Guidelines from the National Aboriginal Health Organization: <http://www.naho.ca/media-centre/interviewing-elders-guidelines/>
 - OCAP Principles: www.naho.ca/documents/fnc/english/FNC_OCAPInformationResource.pdf
 - Maori Health Directorate- Treaty of Waitangi Principles: <http://www.maorihealth.govt.nz/moh.nsf/pagesma/325>

STEPS FOR ADAPTING SURVEYS

Below are steps to consider when adapting surveys using the Four Rs. The principles of *respect*, *relevance*, *reciprocity* and *responsibility* should be understood and embraced before adapting surveys or undergoing an evaluation. Within each step below, many principles can apply. For example, “finding out information about the community” is both respectful and relevant. This explains why the Four Rs are presented holistically in the centre of the steps.



* **Double-barrel question:** when more than one question is being asked in the same question;
Loaded question: when the language of a question is assuming or leading the participant to respond a certain way

**** Back-translation:** when the translated piece is translated back into its original language, and the versions are compared for accuracy

ACKNOWLEDGMENTS

An enormous thank you to Advisory Committee members for their support and contributions.

Jody Butler Walker
Angeline Latendre
Lori Meckelborg
Jeff Reading
Shelley Thomas Prokop
Lloy Wylie

The development of this Adaptation Framework was made possible by the Canadian Platform to Increase the Usage of Real World Evidence (CAPTURE) and funded by the Public Health Agency of Canada, in partnership with the Canadian Partnership Against Cancer.

REFERENCES

- 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.
- Browne, A. J., McDonald, H., & Elliott, D. (2009). *First Nations Urban Aboriginal Health Research Discussion Paper. A Report for the First Nations Centre, National Aboriginal Health Organization*. Ottawa, ON: National Aboriginal Health Organization.
- 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>
- The Colorado Trust (2007). The Importance of Culture in Evaluation: A Practical Guide for Evaluators. Cultural Safety: Module 3. Peoples' experiences of colonization in relation to health care. Retrieved March 18, 2011, from <http://web2.uvcs.uvic.ca/courses/csafety/mod3/glossary.htm>
- Harkness, J. (2010). Cross-Cultural Survey Guidelines: Adaptation.
- 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.
- 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.
- Kirkness, V., & Barnhardt, R. (1991). First Nations and Higher Education: The Four Rs— Respect, Relevance, Reciprocity, Responsibility. *Journal of American Indian Education*, 30(3), 1-15.
- Lee, K. (2007). The Importance of Culture in Evaluation: A Practical Guide for Evaluators. Retrieved May 11, 2011, from <http://www.communityscience.com/pdfs/CrossCulturalGuide.r3.pdf>
- 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.
- 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.
- 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.

CONTACT THE CAPTURE PROJECT

Simon Fraser University

8888 University Drive

WMC Room 2805

Burnaby, BC V5A 1S6

Telephone: 778.782.6707

Fax: 778.782.3055

Website: www.thecaptureproject.ca

Email: info@thecaptureproject.ca