

International Collaborative Indigenous Health Research Partnership  
Roots of Resilience:  
Transformations of Identity and Community in Indigenous Mental Health

## **Stories of Resilience Project**

### **Manual for Researchers, Interviewers & Focus Group Facilitators**

#### **Part 1 Project Overview**

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# **Stories of Resilience Project**

## **Manual for Researchers, Interviewers & Focus Group Facilitators**

### **Part 1 Project Overview**

Prepared for

the Culture & Mental Health Research Unit

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# TABLE OF CONTENTS

<b>ACKNOWLEDGEMENTS</b> .....	<b>4</b>
<b>TABLE OF CONTENTS</b> .....	<b>5</b>
<b>INTRODUCTION</b> .....	<b>7</b>
<b>OVERVIEW OF THIS MANUAL</b> .....	<b>7</b>
PURPOSE OF THIS MANUAL .....	8
CONTENTS OF THE MANUAL .....	8
<b>PART 1</b> .....	<b>9</b>
<b>PARTICIPATORY RESEARCH</b> .....	<b>9</b>
WHAT IS PARTICIPATORY RESEARCH? .....	10
COMMUNITY ENGAGEMENT AND PARTICIPATION.....	11
CIHR GUIDELINES FOR HEALTH RESEARCH INVOLVING ABORIGINAL PEOPLE .....	12
ADDITIONAL RESOURCES ON PARTICIPATORY RESEARCH .....	13
<b>PART 2</b> .....	<b>14</b>
<b>OVERVIEW OF THE PROJECT</b> .....	<b>14</b>
A. PROJECT OVERVIEW .....	15
<i>Objectives of the study</i> .....	15
<i>Methodology</i> .....	15
B. THE PEOPLE INVOLVED .....	15
<i>Researchers</i> .....	16
<i>Research coordinators</i> .....	16
<i>Community researchers</i> .....	17
<i>Community advisory group</i> .....	17
<i>Research assistants</i> .....	17
<i>Participants</i> .....	17
<i>Research teams</i> .....	18
C. PROJECT PHASES .....	18
<i>Phase 1: Community consultation and ethics approval</i> .....	18
<i>Phase 2: Focus groups on local concepts of resilience</i> .....	19
<i>Phase 3: Data analysis 1 – preliminary analyses</i> .....	20
<i>Phase 4: Validation of focus group results</i> .....	20
<i>Phase 5: Individual narrative interviews</i> .....	20
<i>Phase 6: Validation of individual narrative interviews</i> .....	20
<i>Phase 7: Data analysis 2 – individual interviews</i> .....	21
<i>Phase 8: Draft final reports</i> .....	21
<i>Phase 9: Knowledge exchange</i> .....	21
<b>PART 3</b> .....	<b>23</b>
<b>CONDUCTING THE STUDY</b> .....	<b>23</b>
A. FOCUS GROUPS.....	24
<i>Recruiting participants</i> .....	24
<i>Coordinating the focus group</i> .....	24
<i>Moderators</i> .....	25
<i>Using the focus group protocol</i> .....	26
<i>Focus group procedure</i> .....	26
B. INDIVIDUAL NARRATIVE INTERVIEWS .....	27
<i>Recruiting participants</i> .....	27
<i>Coordinating the interview</i> .....	28

<i>Using the interview protocol</i> .....	28
<i>Interview procedure</i> .....	28
<b>PART 4</b> .....	<b>30</b>
<b>QUESTIONS ABOUT THE STUDY</b> .....	<b>30</b>
GENERAL QUESTIONS ABOUT THE STUDY .....	31
QUESTIONS ABOUT THE PEOPLE INVOLVED IN THIS STUDY .....	32
QUESTIONS ABOUT THE RESEARCH METHODS .....	33
<b>PART 5</b> .....	<b>34</b>
<b>KEY CONTACT INFORMATION</b> .....	<b>34</b>
<b>ADDITIONAL READING</b> .....	<b>35</b>

# **INTRODUCTION**

## **OVERVIEW OF THIS MANUAL**

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### **PURPOSE**

This section introduces the manual and includes information about:

- Purpose of the manual
- The contents of this manual

## PURPOSE OF THIS MANUAL

This manual has been created to guide researchers, interviewers and focus group facilitators of the Stories of Resilience research study.

The manual aims to:

- Provide researchers with an overview of the research project.
- Inform researchers of the people involved in this research project.
- Outline the phases involved in this project.
- Provide guidelines for how to coordinate and conduct the focus groups and interviews.

This manual will assist researchers in establishing:

- Clear roles and responsibilities of the interviewers and focus group facilitators
- Project planning processes
- Consistency throughout the research
- Community representation and a participatory framework for the research
- Knowledge translation and dissemination

## CONTENTS OF THE MANUAL

This manual is made up of six parts. Part 1 includes information about participatory research and the principles used in participatory research. Part 2 provides an overview of the study, objectives and methodology. Part 3 provides necessary information about the steps involved in conducting the study. Part 4 provides questions that participants may have about the research, and how to answer these questions. Part 5 includes contact information for the key researchers involved in the study.

**Research tip:** The information found in these boxes highlights useful tips to help researchers coordinate and conduct certain aspects of the project. These are “tips from the field” from others that have already gone through the process.



# **PART 1**

# **PARTICIPATORY RESEARCH**

---

## **PURPOSE**

This section provides an overview of participatory research, and principles important to research involving Aboriginal peoples. This section will provide you with an understanding of the process of participatory research and lays the foundation for the research process in this study. This section includes:

- Information about participatory research
- Information about community participation and engagement
- CIHR guidelines for health research involving Aboriginal people
- Additional resources on participatory research

## **WHAT IS PARTICIPATORY RESEARCH?**

Participatory research has been defined by the Royal Society of Canada as the “systematic investigation, with the collaboration of those affected by the issue being studied, for purposes of education and taking action or effecting social change.” In other words, participatory research means involving people from the community in all components of the research, i.e. they participate as researchers, as advisors, as analysts, as participants, etc.

The following questions can be used as a guide for participatory research with community partners (adapted from Green et al., 1995):

1. Participants and the nature of their involvement:
  - a. Do members of the community participating in the research have concern or experience with the issue?
  - b. Are interested members of the community provided opportunities to participate in the research process?
  - c. Is attention given to barriers to participation, with consideration of those who have been under-represented in the past?
  - d. Has attention been given to establishing within the community an understanding of the researchers' commitment to the issue?
  - e. Are community participants enabled to contribute their physical and/or intellectual resources to the research process?
2. Origin of the research question:
  - a. Did the impetus for the research come from the community?
3. Purpose of the research:
  - a. Can the research facilitate capacity building among community participants?
  - b. Can the research facilitate collaboration between community participants and resources external to the community?
  - c. Will the research benefit the community, and how?
4. Process and methodological implications:
  - a. Does the research process apply the knowledge of community participants in the phases of planning, implementation and evaluation?
  - b. For community participants, does the process allow for learning about research methods?
  - c. For researchers, does the process allow for learning about the community and the process of conducting research in the community?
  - d. Does the process allow for flexibility or change in research methods and focus, as necessary?
  - e. Are community participants involved in data analysis and interpretation?
5. Opportunities to address the issue of interest:

- a. Is the potential of the community for individual and collective learning reflected by the research process?
  - b. Is the potential of the community for action reflected by the research process?
  - c. Does the process reflect a commitment by researchers and community participants to social, individual or cultural actions consequent to the learning acquired through research?
6. Nature of the research outcomes:
- a. Will community participants benefit from the research outcomes?
  - b. Is there attention to or an explicit agreement for acknowledging and resolving in a fair and open way any differences between researchers and community participants in the interpretation of the results?
  - c. Is there attention to or an explicit agreement between researchers and community participants with respect to ownership of the research data?
  - d. Is there attention to or an explicit agreement between researchers and community participants with respect to the dissemination of the research results?

## **COMMUNITY ENGAGEMENT AND PARTICIPATION**

Research must be based on principles of mutual respect and the commitment to nourish respectful relationships. Linda Tuhiwai Smith (2005) describes the importance of relationships in conducting research with indigenous peoples as follows:

For indigenous and other marginalized communities, research ethics is at a very basic level about establishing, maintaining, and nurturing reciprocal and respectful relationships, not just among people as individuals but also with people as individuals, as collectives, and as members of communities, and with humans who live in and with other entities in the environment. The abilities to enter preexisting relationships; to build, maintain, and nurture relationships; and to strengthen connectivity are important research skills in the indigenous arena. They require critical sensitivity and reciprocity of spirit by a researcher (p. 97).

With this in mind, the following principles provide a guide for community engagement and participation in this research:

- Build relationships based on trust, respect and the sharing of knowledge and power.
- Take time to listen and understand the experiences of others.
- Ask how we can ensure communities benefit from the research.
- Ask what communities need in order to participate.
- Be inclusive, and involve the community in every step of the research process.
- Go to where people are in order to provide them with an opportunity to be heard and participate.
- Communicate openly and effectively.

- Be reliable in carrying out tasks and following up as agreed.
- Accept that the views of others are worthy of consideration.

## **CIHR GUIDELINES FOR HEALTH RESEARCH INVOLVING ABORIGINAL PEOPLE**

In all phases of this project we are following the CIHR Guidelines for Health Research Involving Aboriginal People. The guidelines are meant to assist researchers and institutions in carrying out ethical and culturally competent research involving Aboriginal people. The main points addressed in the guidelines and that apply to the Stories of Resilience research project include:

1. A researcher should understand and respect Aboriginal worldviews, including responsibilities to the people and culture that flow from being granted access to traditional or sacred knowledge.
2. A community's jurisdiction over the conduct of research should be understood and respected.
3. Communities should be given the option of a participatory-research approach.
4. A researcher who proposes to carry out research that touches on traditional or sacred knowledge of an Aboriginal community, or on community members as Aboriginal people, should consult the community leaders to obtain their consent before approaching community members individually. Once community consent has been obtained, the researcher will still need the free, prior and informed consent of the individual participants.
5. Concerns of individual participants and their community regarding anonymity, privacy and confidentiality should be respected, and should be addressed in a research agreement.
6. The research agreement should, with the guidance of community knowledge holders, address the use of the community's cultural knowledge and sacred knowledge.
7. Aboriginal people and their communities retain their inherent rights to any cultural knowledge, sacred knowledge, and cultural practices and traditions, which are shared with the researcher. The researcher should also support mechanisms for the protection of such knowledge, practices and traditions.
8. Community and individual concerns over, and claims to, intellectual property should be explicitly acknowledged and addressed in the negotiation with the community prior to starting the research project. Expectations regarding intellectual property rights of all parties involved in the research should be stated in the research agreement.
9. Research should be of benefit to the community as well as to the researcher.
10. A researcher should support education and training of Aboriginal people in the community, including training in research methods and ethics.
11. A researcher has an obligation to learn about, and apply, Aboriginal cultural protocols relevant to the Aboriginal community involved in the research.
12. A researcher should, to the extent reasonably possible, translate all publications, reports and other relevant documents into the language of the community.

13. A researcher should ensure that there is ongoing, accessible and understandable communication with the community.
14. A researcher should recognize and respect the rights and proprietary interests of individuals and the community in data and biological samples generated or taken in the course of the research.
15. Transfer of data from one of the original parties to a research agreement, to a third party, requires consent of the other original party(ies).
16. Secondary use of data requires specific consent from the individual participant and, where appropriate, the community.
17. Secondary use requires REB review.
18. An Aboriginal community should have an opportunity to participate in the interpretation of data and the review of conclusions drawn from the research to ensure accuracy and cultural sensitivity of interpretation.
19. An Aboriginal community should, at its discretion, be able to decide how its contributions to the research project should be acknowledged. Community members are entitled to due credit and to participate in the dissemination of results. Publications should recognize the contribution of the community and its members as appropriate, and in conformity with confidentiality agreements.

The full guidelines can be found at [www.cihr-irsc.gc.ca/e/29134.html](http://www.cihr-irsc.gc.ca/e/29134.html). Alternatively, please contact the research coordinator for a copy of these guidelines.

## **ADDITIONAL RESOURCES ON PARTICIPATORY RESEARCH**

### **Participatory Research at McGill**

[www.pram.mcgill.ca](http://www.pram.mcgill.ca)

### **Kahnawake Schools Diabetes Prevention Project (KSDPP)**

KSDPP has developed an extensive code of ethics with participatory research guidelines.

[www.ksdpp.org](http://www.ksdpp.org)

### **Community-Campus Partnerships for Health (CCPH)**

<http://depts.washington.edu/ccph>

### **Agency for Healthcare Research and Quality (AHRQ)**

[www.ahrq.gov/RESEARCH/cbprrole.htm](http://www.ahrq.gov/RESEARCH/cbprrole.htm)

[www.ahrq.gov/downloads/pub/evidence/pdf/cbpr/cbpr.pdf](http://www.ahrq.gov/downloads/pub/evidence/pdf/cbpr/cbpr.pdf)

### **CBR Networking Website**

[www.cbrnet.org](http://www.cbrnet.org)

### **University of Victoria Community Based Research Initiative**

[www.research.uvic.ca/CBRF/index.htm](http://www.research.uvic.ca/CBRF/index.htm)

### **Community-University Institute for Social Research - University of Saskatchewan**

[www.usaskstudies.coop/socialeconomy/CUIISR\\_main](http://www.usaskstudies.coop/socialeconomy/CUIISR_main)

# **PART 2**

## **OVERVIEW OF THE PROJECT**

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### **PURPOSE**

The purpose of this section is to provide you with information about the research project. This section includes the following information:

- Project overview
- Objectives of the study
- Methodology
- The people involved
- Project phases

## **A. PROJECT OVERVIEW**

The Stories of Resilience research project is part of a larger study called *Roots of Resilience: Transformations of Identity and Community in Indigenous Mental Health*, which began in 2005. The research is funded by the Canadian Institutes of Health Research (CIHR), and Dr. Laurence J. Kirmayer is the program lead investigator for the study.

The aim of the Stories of Resilience project is to collect stories to help define resilience from Aboriginal perspectives and to identify factors that to promote resilience among individuals and communities. We are collaborating with multiple communities across Canada in order to get many different stories and viewpoints. When we use the word “resilience” we mean the ability of a person or group of people who have faced significant life challenges, to adapt to or get through these challenges, and be well in their life. We are therefore interested in how factors at individual, family, and community levels interact with larger social and cultural factors to enable some individuals and communities to do well while others do not do well.

## **OBJECTIVES OF THE STUDY**

The main objectives of this study are:

- 1) to understand resilience, healing, recovery, and transformation from Aboriginal perspectives
- 2) to identify ways to promote resilience and healing in each community

## **METHODOLOGY**

The study uses a participatory research approach, and will take place in communities across Canada including Aboriginal communities in British Columbia, Saskatchewan, Ontario, Quebec, Nova Scotia and Nunavut. In each location, the study will use qualitative methodology through focus groups and interviews to explore perspectives on resilience. Focus groups will look specifically at people’s perspectives of their *community’s* resilience and ability to get through challenges. Individual narrative interviews will look at people’s *own personal* stories of resilience and what has helped them get through challenges. The protocols have been designed this way so that we can see how people’s views on community resilience and personal resilience interact.

There are a number of phases in this project: 1) community consultation and ethics approval; 2) focus groups on local concepts of resilience; 3) preliminary data analyses 4) validation of focus group results; 5) individual narrative interviews; 6) data analysis; 7) validation of individual interviews; 8) drafting final reports, and 9) knowledge exchange (see page 17 for overview of all phases).

## **B. THE PEOPLE INVOLVED**

The lead researchers involved in this project are based at the Jewish General Hospital’s Culture and Mental Health Research Unit in Montreal, the University of British Columbia in Vancouver, and the University of Auckland in New Zealand.

## **RESEARCHERS**

There are three lead investigators for this research study:

**Program lead investigator:** Dr. Laurence J. Kirmayer, MD, FRCPC, James McGill Professor and Director of the Culture and Mental Health Research Unit and Division of Social and Transcultural Psychiatry, Department of Psychiatry, McGill University.

**Canada lead investigator:** Dr. Roderick McCormick, a Mohawk Psychologist and Associate Professor in the Counselling Psychology Program at the University of British Columbia.

**New Zealand lead investigator:** Dr. Pamela Bennett, MD, Senior Lecturer in the Division Maori and Pacific Island Health, Faculty of Medicine, University of Auckland.

### **Co-investigators include:**

Dr. Jacob Burack, McGill University

Dr. Michael Chandler, University of British Columbia

Dr. Christopher Lalonde, University of Victoria

Dr. Caroline Tait, University of Saskatchewan

Dr. Cornelia Wieman, University of Toronto

Dr. Phyllis Zelkowitz, Institute of Community & Family Psychiatry, Jewish General Hospital

## **RESEARCH COORDINATORS**

There is one main research coordinator for this study, and several other research coordinators who are responsible for coordinating fieldwork in each participating community. The research coordinators are responsible for coordinating and overseeing the research in each community. They are responsible for the overall direction of the research, including:

- Carrying out research activities in each community in coordination with the community researcher
- Organizing research team meetings
- Communicating with community partners regarding community ethics approval
- Working with community researchers to adapt interview and focus group protocols to the community context
- Working with community researchers to plan and facilitate focus groups and interviews, data analysis, knowledge exchange and report writing



Below is contact information for each research coordinator:

Name	Role/Community	Phone	E-mail
Stéphane Dandeneau	Scientific Coordinator	514-340-8222 ext. 2386	<a href="mailto:stephane.dandeneau@mcgill.ca">stephane.dandeneau@mcgill.ca</a>
Katya Petrov	Logistical Coordinator	514-340-8222 ext. 2192	katya.petrov.namhr@gmail.com

### **COMMUNITY RESEARCHERS**

A community researcher is a person who comes from the community where the research is being conducted. Each research site must have a community researcher and a research coordinator in order to ensure that there is sufficient expertise to guide the research and ensure its ethical application. The community researcher is responsible for working with the research coordinator to carry out the research activities in their community.

It is helpful if the community researcher speaks the languages spoken in the community however this is not essential. It is also important that this person is very comfortable speaking, reading and writing in English. Ideally, the community researcher would also have some training in a related discipline (e.g., psychology, anthropology, sociology), in addition to being able to interact well with people and have basic computer skills.

### **COMMUNITY ADVISORY GROUP**

A community advisory group must be established in each community. This group should be made up of three or four local people who have something important to say about resilience in their community. These people will make suggestions to the project and help guide the work every step of the way. Community advisory group members can be youth, parents, professionals, elders, etc. who themselves have faced or are still facing challenges in their lives. This committee will help to refine the interview and focus group protocols, identify appropriate ways of recruiting participants, and guide the process of respectful research. Each member of this committee should be compensated with \$80 for their participation in each meeting. The amount will depend on what is acceptable in each community (i.e., based on location, cost of living, etc.).

### **RESEARCH ASSISTANTS**

These are people who, if necessary, can travel to the different sites where the research is being carried out and offer training and support. They will have skills to share with the research coordinators and community researchers, and will help with various aspects of the research including transcriptions, data analysis, conducting interviews, literature review, etc.

### **PARTICIPANTS**

The research aims to achieve a broad understanding of resilience among indigenous people, therefore our goal is to include participants of all ages, including youth, adults and elders. Each community should be involved in defining who are youth, adults and

elders. In all cases, the research should try to include an equal number of men and women.

*Youth:* These are young people who are seen by their communities as being at the point of moving from childhood to adulthood. In each community, the age at which this happens will be different. It is important that the community help the research team decide when children make this important transition. We are including two categories of youth in this study, 1) ages 16 – 17, and 2) ages 18 - 30. A separate focus group must be conducted for each youth category.

*Adults:* Adults are any individuals seen by their community as having something important to say about resilience and the challenges they and their community face or have faced. These might be professionals, parents, caregivers, spiritual leaders, etc. In general, we are including as adults people from the ages of 31 - 55.

*Elders:* Elders are highly respected individuals in the community. The community should help the community researcher and research coordinator decide who the elders are in the community. Generally, we are including as Elders people from age 55 and older.

**Research tip:** Some institutional ethics review boards will require parental consent forms are signed in order for youth younger than 18 to participate. Please see part 2 of this manual for these forms.

## **RESEARCH TEAMS**

Each community has their own community-specific “Research Team” which consists of the following people: a research coordinator, at least one community researcher, research assistants, and researchers/co-investigators from the academic team. These small research teams are therefore made up of members from inside and outside the community and from Aboriginal and non-Aboriginal heritage.

## **C. PROJECT PHASES**

This study consists of nine phases described below. In all phases the main goal is to conduct participatory research, whereby there is a constant discussion with the community about how to go about the research.

### **PHASE 1: COMMUNITY CONSULTATION AND ETHICS APPROVAL**

The first step in starting the research is to identify partners in the community interested in the project. Once a relationship has been established with community partners, a research agreement must be agreed upon with the appropriate governing/decision making body (e.g., either with the local community research council, Elders, band council, etc). During this startup phase, the goal is to become familiar with the community and the process of conducting research in the community. A community researcher must also be identified, and a Community Advisory Group established.

#### **1.1 COMMUNITY ETHICS APPROVAL**

This project has been approved by the research ethics review board of the Sir Mortimer B. Davis – Jewish General Hospital, Montreal. The research must also be approved in each participating community and the investigator’s affiliated university. The procedure for ethics review will vary depending on the community involved. Some communities will require the research be approved through a formal research council or ethics board, while others may require the approval of Elders or the band council. In each community, the research coordinator and community researcher must determine the relevant procedure for ethics approval. It is important to begin the process of ethics approval early to leave lots of time for meetings and discussions about the research.

**Research Tip:** Community ethics approval may take some time, up to a few months, so you should start discussions with the community early to make sure you have lots of time to thoroughly discuss the research with them.

## **1.2 KEY INFORMANT INTERVIEWS**

The purpose of the key informant interviews is to get an idea of how resilience is talked about in each community from the perspectives of key people in the community. Key informant interviews can be conducted during the community consultation phase of the research, once the research has received approval in the community. Key informants can be selected to participate by using snowball sampling. For example, key informants can include teachers, Elders, community leaders, etc. About 2 - 4 key informant interviews should be conducted in each community. The key informant interview protocol follows the same themes as the focus group protocol (below). Key informant interviews are recorded with the consent of the participants, and transcribed for thematic analysis. The analysis of key informant interviews helps to make any modifications needed for the focus group protocol. Results of the key informant interviews should also be included in the community final report (phase 7).

## **PHASE 2: FOCUS GROUPS ON LOCAL CONCEPTS OF RESILIENCE**

The purpose of the focus groups is to talk about people’s views of resilience and the challenges that their community has been through. Four separate focus groups will take place in each community: 1) Elders; 2) adults ages 31 - 55; 3) youth ages 16 – 17, and 4) youth ages 18 - 30.

The same questions will be asked in each of the focus groups. The questions are divided into five sections: 1) views of resilience; 2) views of wellness or doing well; 3) language, words and expressions related to resilience; 4) examples of resilience, and 5) traditional stories of resilience. Focus groups will take approximately two hours, and a meal is provided as well as a \$25 honorarium to all participants in the focus group. The focus group discussions are recorded, with the consent of participants, in order to facilitate their transcription. Once the focus groups are transcribed, a thematic analysis will be conducted to determine the main themes arising from each focus group. The thematic results of the focus group sessions will be used to adapt the individual narrative interview protocol to reflect their own community’s context.

### **PHASE 3: DATA ANALYSIS 1 – PRELIMINARY ANALYSES**

The first phase of data analysis involves reviewing the focus group transcripts. First, these transcripts will be reviewed by the community research team (i.e. research coordinator, community researcher, research assistants, and researchers/co-investigators) to identify the main themes that arise. These themes will then be used to adapt the individual narrative interview protocol to the specific context of each community. Second, focus group data will also be analysed in greater depth to investigate the narratives of resilience (i.e., how people talk about and construe the concept of resilience) in order to prepare a community report that will give an overview of the ways people talk about the community's resilience.

A central database of all transcriptions will be held at the Culture and Mental Health Research Unit (CMHR).

### **PHASE 4: VALIDATION OF FOCUS GROUP RESULTS**

The initial results of focus groups are to be presented to the Community Advisory Group for their input and guidance on the appropriate interpretation of themes or whether certain themes were missed. This important validation step will help the research team and Community Advisory Group identify themes on which to focus or gaps that need to be addressed.

### **PHASE 5: INDIVIDUAL NARRATIVE INTERVIEWS**

The purpose of the individual narrative interview is to talk about people's own personal stories of resilience and the life challenges that they have been through. The interview protocol is divided into five sections: 1) your stories of resilience; 2) language, words, and expressions related to resilience; 3) traditional stories of resilience; 4) future outlook, and 5) sharing knowledge. Approximately 20 - 24 individuals will be identified with the help of the Community Advisory Group and interviewed in each community. As with the focus groups, individual narrative interviews should be conducted with the following age categories: 1) Elders; 2) adults ages 31 - 55; 4) youth ages 18 - 30, and 3) youth ages 16 - 17. Four or five interviews should be conducted for each age category (a total of 20 - 24 interviews), and as best as possible an equal number of interviews should be conducted with men and women in each age category.

Based on the focus group thematic findings, some questions in the interview protocol must be adapted to reflect the community's context (e.g., language, words and expressions related to resilience, traditional stories of resilience, community challenges). Individual narratives are recorded, with the participant's and/or parent's permission, and later transcribed (see interview protocol).

### **PHASE 6: VALIDATION OF INDIVIDUAL NARRATIVE INTERVIEWS**

Those who participated in individual narrative interviews will be provided with the transcripts of their interviews and will have the opportunity to validate their quotations and the transcript of their stories. The transcript must be printed out and delivered to each individual participant in person or by post. Research coordinators and community researchers should be aware that in some cases there may be factors that prevent people

from being able to read their interview transcript (e.g., illiteracy, vision problems). In these cases arrangements must be made with the participant to ensure they are able to participate in this process (e.g., they can listen to the digital recording with the researcher who will record the changes requested).

### **PHASE 7: DATA ANALYSIS 2 – INDIVIDUAL INTERVIEWS**

Members of the research team will analyse the data from the individual narrative interviews using Atlas.ti software. Individual's responses will be analysed to (i) document stories of resilience from the perspectives of individual interview participants; (ii) explore individuals' healing experiences, and (iii) use the insights and experiences of participants to identify potential interventions and initiatives that can facilitate resilience and healing in their community and / or other communities.

It is recommended that team members involved in the analysis are familiar with Atlas.ti software. The CMHRU regularly organises Atlas.ti workshops to help team members learn or perfect their Atlas.ti skills.

### **PHASE 8: DRAFT FINAL REPORTS**

A final report will be written that compiles the research results for each community, including the results of the focus group discussions and the individual narrative interviews. A comprehensive report that includes the results from all communities across Canada will also be compiled. Each community's final report will be distributed back to those who participated in the research (i.e., individual interview and focus group participants) as well as to community research boards, Community Advisory Groups, and all other appropriate community organizations.

### **PHASE 9: KNOWLEDGE EXCHANGE**

A community forum will be held in each community with the purpose to present the results of the research to the community, and to get the feedback of community members regarding these results. Some examples of the questions we will pose at the community forums are:

1. We want to be sure the research results make sense to you. What do you think?
2. Is there anything you think we have misunderstood?
  - a. If yes, please explain to us what we have misunderstood?
  - b. How should we fix what we have misunderstood?
3. What do you think are the best ways to tell others about the results of this research?

Ideas on knowledge exchange will come out of discussions with the Community Advisory Group and through the community forum. These include ideas for how to disseminate the knowledge gained from the research results in the communities as well as to others. Knowledge exchange activities could include:

- Presentations of the research to the community
- Summary of the research published in the local newspaper

- Interviews on the local community radio stations
- Interviews on local television news channels
- Final report of the results from the community compiled and distributed in the community
- Publications in academic journals
- Presentations at conferences
- Creation of a film about the research findings
- Creation of a learning module about the research findings

The final reports will be adjusted according to feedback from the community forum.

# **PART 3**

## **CONDUCTING THE STUDY**

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### **PURPOSE**

This section provides procedures and tips for coordinating and conducting interviews and focus groups. The section includes information on:

- Recruiting participants
- Coordinating the focus groups and interviews
- Using the focus group and interview protocols
- Procedures for focus groups and interviews

## **A. FOCUS GROUPS**

The purpose of the focus groups is to gain a broad understanding of how resilience is talked about in each community, and to collect enough data to be able to adapt the individual narrative interview protocol to each community context (if needed). This section includes information about the procedure for conducting the focus groups on local concepts of resilience, including information about: recruiting participants, coordinating the focus group, use of the focus group protocol, and focus group procedure.

### **RECRUITING PARTICIPANTS**

Encouraging people to participate in focus groups will happen differently in each community, and ideas on how to recruit participants should be discussed with the Community Advisory Group. The general recruitment guidelines to follow in each community include:

1. Find out from the Community Advisory Group what is the best way to recruit the three different categories of participants: youth, adults and elders.
2. Recruit a wide range of people for each focus group (e.g., students, professionals, etc.).
3. Recruit 6 – 8 people to participate in each focus group.
4. Aim to recruit an equal number of male and female participants in each focus group.

Some general recruitment strategies to follow are:

1. Place an ad in the local community newspaper or on the radio or TV station
2. Send an email out to listservs that may exist in the community
3. Word of mouth
4. Through already organized community groups (e.g., youth group, elder's lodge)

If these strategies do not work, then you may have to contact specific individuals directly by telephone, by email or by post. Once individuals have confirmed they would like to participate in the focus group, they should receive written confirmation or a telephone call. At this time it is important to confirm the date, time and location of the focus group session.

**Research tip:** Organizing focus groups in the communities might be challenging for many reasons. People might not feel comfortable talking in front of other community members or people they are related to. Depending on the time of year, people might be busy with work, travel outside the community, ceremonies, etc. The Community Advisory Group and community researcher will be able to give guidance on the best way to organize the focus groups.

### **COORDINATING THE FOCUS GROUP**

The focus groups should be conducted in the language that the focus group participants choose. If the language chosen is other than that spoken by the researchers, then simultaneous translation should be arranged so that everyone can follow along with the



focus group discussion. The research coordinator and community researcher can follow these steps to guide the process of coordinating each focus group session:

1. Select dates that are likely to be convenient for potential participants (e.g., evening is often better for adults and youth)
2. Translate the focus group protocol, information letter and consent form into the languages spoken in the community
3. Arrange for simultaneous translation services if necessary
4. Arrange a neutral, convenient place in the community to conduct the focus group (e.g., community centre)
5. Pre-order catering for the focus group session (e.g., lunch, coffee, tea, water)
6. Make sure to have enough \$25 honorariums for each participant.

### **MODERATORS**

The community researcher and research coordinator should share the role of facilitating the focus group discussions. The purpose of having both individuals as facilitators is to ensure that the focus group is moderated with a balanced “insider-outsider” perspective. The moderators have an important role in the process of each focus group discussion. Their primary role is to *facilitate* the discussion by asking questions and helping participants explore their ideas of resilience. They should be well prepared prior to the focus groups with an understanding of the research study, the potential nature of the group dynamics that may arise, the topic to be discussed, the focus group protocol, and the physical setting of the group. In their preparation for the focus groups, facilitators should also reflect upon their own biases, including: 1) develop an understanding of the sources and nature of biases that can affect the validity of the focus group data, and 2) consider the steps that could be taken to cope with these biases (Stewart et al., 2007, p. 84).

While there are no strict rules for how to moderate a focus group discussion, the following traits of a good moderator can be used as a guide:

1. Lets others talk freely
2. Genuinely interested in hearing other people’s thoughts and feelings
3. Expressive of their own feelings
4. Animated and spontaneous
5. Have a sense of humor
6. Are empathetic
7. Admit their own biases
8. Are insightful about people
9. Express thoughts clearly
10. Are flexible

Most importantly, moderators must at all times be respectful of the participants and the views that are expressed. They must also be sensitive to the issue being discussed.

## **USING THE FOCUS GROUP PROTOCOL**

The focus group protocols have been developed to guide the discussion and to make sure there is consistency across focus groups, so please follow the focus group protocol as closely as possible. It is also important to allow the participants to openly discuss their opinions on the questions asked, which may lead the facilitator to ask other questions not included in the focus group protocol. The facilitators will have to gauge what are the appropriate questions to ask in these instances.

Here are some tips to guide the use of the focus group protocol:

- Please follow the focus group protocol as closely as possible (that is, do not modify the order of the questions).
- Allow discussions to happen naturally, and to continue if you think the topics discussed are relevant to the research.
- If you feel the discussion is going off topic, refer back to the focus group protocol to move on to the next question.

## **FOCUS GROUP PROCEDURE**

Before each focus group begins, the research coordinator and community researcher will need to:

1. Distribute the information letter and consent forms as people arrive to the focus group.
2. Introduce themselves.
3. Ask participants to introduce themselves.
4. Introduce the research according to the preface noted on the focus group protocol.
5. Have each participant read the consent form. It is sometimes helpful to offer to read the consent form out loud in the case any participants are unable to read it.
6. Answer any questions that participants may have concerning the research, the information letter, or the consent form.
7. Make sure that all participants sign a consent form, and collect all consent forms. In the case that some people do not feel comfortable signing a consent form, verbal consent is acceptable.
8. Have the focus group protocol ready to refer to.
9. Set up the digital recorder and microphone to make sure that all voices will be recorded.
10. Have a paper and pen ready to take notes.

As you start the focus group, the facilitators will need to:

1. Turn the digital recorder on and test it.
2. Inform the focus group participants that the recorder has been turned on.
3. Mark the time the focus group starts.
4. Remind participants that they may choose to leave the focus group session if at any point they do not feel comfortable.
5. Encourage the participants to ask any questions they have about the research.

6. Read the questions as they are written on the focus group protocol. There are a number of prompts to help guide the facilitators through the focus group protocol in case participants ask for clarifications.

During the focus group be sure to:

1. Take notes, even though the focus group will be recorded. This will help when analysing data.
2. Use neutral probes/additional questions as needed. Before accepting an answer of “I don’t know,” be sure to probe. Participants frequently use that phrase in a way that says, “I am thinking.” Some examples of probes you might use are:
  - Yes, I see.
  - Could you be a little more specific?
  - I’m not sure I am entirely clear about what you mean. Could you explain it a little more?
3. Suggest taking a 5-minute break part way through the focus group if you feel participants are getting tired, and then come back to the next question on the protocol.
4. Keep a close watch on the time; participants are expecting to participate for no longer than 2 hours.

When the focus group is over be sure to:

1. Make sure that the participants are comfortable with the information given. Ask if they feel we should have covered any other aspect of resilience.
2. Express genuine and grateful appreciation for their participation.
3. Turn the digital recorder off.
4. Immediately record the time and calculate the length of the focus group.
5. Record the facilitator’s name(s) on the focus group protocol.

## **B. INDIVIDUAL NARRATIVE INTERVIEWS**

The interviews you will be conducting are based in narrative inquiry, which means they will have the nature of a guided conversation where you will be asking questions and listening to responses to hear the meaning that people are trying to convey. The purpose of the interviews is to find out what it is that has helped or continues to help people get through life challenges.

### **RECRUITING PARTICIPANTS**

As with the focus groups, encouraging people to participate in interviews will happen differently in each community, and ideas on how to recruit participants should be discussed with the Community Advisory Group. Ultimately we would like to interview people who have experienced life challenges and who would like to tell their stories of how they got through these challenges. The goal is to interview between 20 - 24 people in each community. Please refer to Part 2 of this report for specific procedures for identifying interview participants.

## **COORDINATING THE INTERVIEW**

As with focus groups, interviews should be conducted in the language that the participant chooses. The research coordinator and community researcher can follow these steps to guide the process of coordinating the interviews:

1. Select a date that is convenient for the participant.
2. Translate the interview protocol if necessary.
3. Arrange for simultaneous translation of the interview if necessary.
4. Arrange a place that is convenient for the participant to conduct the interview (e.g., community centre, the participant's home).

## **INTERVIEWERS**

Participants will be given the choice of being interviewed by either the community researcher or the “outside” researcher coordinator. In this study, the role of the interviewer is that of a listener, and a good interviewer is one that develops the traits described above for focus group facilitators (page 24).

## **USING THE INTERVIEW PROTOCOL**

The interview protocol has been developed to guide the discussion and to make sure there is consistency across interviews. It is therefore important that interviewers follow the interview protocol as closely as possible. However, as with the focus groups, a balance must be struck between following the protocol and respecting the free-flowing nature of discussions. Since we are asking people to tell us their stories, it is important to allow the participant to follow their thinking and openly discuss their opinions on the questions asked. This may sometimes lead to other questions or topics not necessarily included in the interview protocol that can help better explain people's thoughts and opinions.

It is important to allow these discussions to happen naturally, and to continue if you think the topics discussed are relevant to the research. If new questions are asked that are not included in the interview protocol, be sure to write them down. This will assist in the transcription and understanding of the data. If anything is unclear or unusual, whether in the terms used, the nature of the experience or event, or the chronology, it is important to ask for clarification.

Sometimes the interview might stir up emotions, and it is important to make the participant feel comfortable and not pressured to continue the interview if they feel upset. Also be sure to have information about counseling and resources available should any participants ask for this kind of information (see consent form).

## **INTERVIEW PROCEDURE**

Before each interview begins, the interviewer will need to:

1. Introduce him / herself.
2. Introduce the research according to the preface noted on the interview protocol.

3. Have the participant read and sign a consent form. It is sometimes helpful to offer to read the consent form out loud for the participant.
4. Answer any questions that participants may have concerning the research, the information letter, or the consent form.
5. Have the interview protocol ready to refer to.
6. Set up the digital recorder and microphone.
7. Have a paper and pen ready to take notes.

As you start the interview, the interviewer will need to:

1. Turn the digital recorder on.
2. Mark the time the interview starts.
3. Read the questions as they are written on the interview protocol. There are a number of prompts to help guide the interviewer in the case participants ask for clarification of a question, etc.

During the interview be sure to:

1. Take notes, even though the interview will be recorded.
2. Use neutral probes/questions as needed. Before accepting an answer of “I don’t know,” be sure to probe. Participants frequently use that phrase in a way that says, “I am thinking.” Some examples of probes you might use are:
  - Yes, I see.
  - Uh-huh, stated in an expectant manner and followed by a pause.
  - Could you be a little more specific?
  - I’m not sure I am entirely clear about what you mean. Could you explain it a little more?
3. Suggest taking a 5 minute break if you feel the participant is getting tired, and then come back to the next question on the protocol.

When the interview is over be sure to:

1. Make sure that the participants are comfortable with the information given. Ask if they feel we should have covered any other aspect of resilience.
2. Express genuine and grateful appreciation for their participation.
3. Turn the digital recorder off.
4. Immediately record the time and calculate the length of the interview.
5. Record the interviewer’s name on the interview protocol.

**Research tip:** Throughout the process of conducting the study it is important to keep in mind that we have an ethical and legal obligation to the research participants to keep the information they discussed confidential. Therefore, please do not tell anyone of the substance or any specific part of the focus groups or individual narrative interviews.

# **PART 4**

## **QUESTIONS ABOUT THE STUDY**

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### **PURPOSE**

A number of questions might come up prior to or during the focus groups and individual narrative interviews. It is important that the facilitators and interviewers know how to address these questions. The purpose of this section is therefore to provide examples of questions that might be asked, and suggestions for how to respond to these questions. This section is divided into four parts:

- General questions about the study
- Questions about the people involved in this study
- Questions about the research methods

## **GENERAL QUESTIONS ABOUT THE STUDY**

### **What is the Culture and Mental Health Research Unit (CMHRU)?**

It is a research team based at the Jewish General Hospital that integrates researchers from several McGill University departments and other hospitals. Our studies concern the most common mental disorders in the community and in primary care. We use epidemiology, psychology and anthropology in our research. The CMHRU is involved in research projects like this one in which we are attempting to find out people's views on resilience.

### **Who is sponsoring (paying for) this research?**

This research is sponsored by the Institute of Aboriginal Peoples' Health of the Canadian Institutes of Health Research (CIHR). CIHR is a health research funding agency that supports health research in many areas. The Institute for Aboriginal People's Health (IAPH) is the part of CIHR that supports research collaborations with Aboriginal communities and populations. This project is one of several funded by IAPH under a program called the International Collaborative Indigenous Health Research Partnership. We are working with partners across Canada and in New Zealand.

### **Who designed this project? / Was it community generated?**

The grant proposal for this project was developed by a group of indigenous and non-indigenous researchers. The project was further generated through a collaboration with researchers at the Culture and Mental Health Research Unit and communities participating in the project. The methodology for the project is discussed with each participating community research council or ethics board, as well as each Community Advisory Group and community researcher, and it is adapted according to feedback. This is to make sure the research is appropriate for each community context. In addition, Community Advisory Groups will be asked for their ideas about future research needed in their community.

### **What is the purpose of this research?**

The purpose of this study is to:

- 1) Understand resilience, healing, recovery, and transformation from Indigenous perspectives
- 2) Identify ways to promote resilience and healing in each community

### **What do you mean by "resilience"?**

When we use the word "resilience" we mean the ability of a person or group of people who have faced life challenges to adapt to or get through these challenges. But we would like to know *your* views of resilience, and how you would define the ability to overcome life challenges.

### **How will this research benefit our community?**

Some of the benefits include:

- 1) Training of community researchers.
- 2) Encouraging community researchers in the pursuit of higher education.

- 3) Increased awareness in the community, through the final report and community presentations, of stories of resilience in the community.
- 4) Communities may benefit from archiving the stories of resilience for their own future use.
- 5) The research may be used to identify the types of relationships, structures, resources and interventions that can provide people with opportunities needed to meet challenges, move past adversity and maximize their well-being.
- 6) The research may contribute to the professional development and cultural competence of mainstream health and social service providers by providing culturally valid information for working with Aboriginal peoples.
- 7) The identification of patterns of resilience may also provide important information for the design of programs and services that reinforce individual and community well-being and resilience.

**Does this research have anything to do with the government?**

No, there is no government involvement except that it is sponsored by the CIHR, the Government of Canada's health research funding agency. The government allocates the overall CIHR budget but does not influence what projects get funded; that depends on evaluation of proposals by scientific committees with community representation.

**What will happen with the results of this research?**

The results of the research will be compiled into a final report and given back to you (each participant) and the community including the research council, community advisory group and other community organizations. We will also present the results to the community. The results of this research will also be published in academic journals, and presented at academic conferences.

**How can I be sure this research is authentic?**

I can give you the research coordinator's number, Dr. Stéphane Dandeneau, and you can call her. That number is (514) 340-8222, Ext. 2386. You can also call Dr. Laurence Kirmayer at (514) 340-7549, or the community researcher. You can also find information about this research on the Internet if you visit [www.mcgill.ca/resilience](http://www.mcgill.ca/resilience).

## **QUESTIONS ABOUT THE PEOPLE INVOLVED IN THIS STUDY**

**Who is the person responsible for this research?**

The person responsible for this research is Dr. Laurence Kirmayer, a Professor of Psychiatry at McGill University and the Director of the Culture and Mental Health Research Unit at the Jewish General Hospital in Montreal. Dr. Kirmayer can be contacted at (514) 340-7549. You can also contact the Scientific coordinator, Dr. Stéphane Dandeneau, at (514) 340-8222, Ext. 2386.

In answering this question you should also have community contacts information. For example, provide contact information for the community research council or ethics



review board (or whoever approved the research at the community level). You should also provide the contact information for the community researcher.

## **QUESTIONS ABOUT THE RESEARCH METHODS**

### **Is this information confidential?**

Yes. After the interview / focus group is completed the responses are transcribed without identifying names. The matter of confidentiality is very important for us in order to develop a trusting relationship with our participants. We are therefore very careful of protecting people's anonymity.

### **Why have you chosen to do this research in this community?**

We are working with a number of communities across Canada on this research. Your community is one of the communities we are working in, in this province / part of Canada (if applicable). We have been working with the community researcher as well as the research council, who have agreed that this research would be valuable to the community. We hope that the results of this research will be of use to the community.

### **Why have you chosen to do this research with Aboriginal people?**

There has been little research conducted on resilience from the perspectives of Aboriginal people, and so we feel it is important to do this research so that communities can benefit from exploring their ways of getting through challenges. In addition, this research is funded by the Canadian Institutes of Health Research, the Government of Canada's health research funding agency, by a research grant that is specifically for research into resilience among indigenous people.

# PART 5

## KEY CONTACT INFORMATION

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### PURPOSE

Below is a list of contact information for the people leading this study, including the lead investigators, and research coordinators. You may find this information useful if you have any questions about the study not covered in this manual.

Name	Role	Phone	E-mail
Laurence J. Kirmayer	Lead investigator	514-340-7549	<a href="mailto:laurence.kirmayer@mcgill.ca">laurence.kirmayer@mcgill.ca</a>
Rod McCormick	Canada lead investigator	604-822-6444	<a href="mailto:rod.mccormick@ubc.ca">rod.mccormick@ubc.ca</a>
Pamela Bennett	New Zealand lead investigator		<a href="mailto:pam.bennett@auckland.ac.nz">pam.bennett@auckland.ac.nz</a>
Stéphane Dandeneau	Roots of Resilience Scientific Coordinator	514-340-8222 ext. 2386	<a href="mailto:stephane.dandeneau@mcgill.ca">stephane.dandeneau@mcgill.ca</a>

# ADDITIONAL READING

Here are some additional readings that you might find useful in preparing to conduct participatory research:

- Green, L. W., George, A., Daniel, M., Frankish, C. J., Herbert, C. P., Bowie, W. R., et al. (1995). *Study of Participatory Research in Health Promotion: Review and Recommendations for the Development of Participatory Research in Health Promotion in Canada*. Ottawa: Royal Society of Canada.
- Smith, L. T. (2005). On Tricky Ground: Researching the Native in the Age of Uncertainty. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage Handbook of Qualitative Research* (3 ed., pp. 85-107). Thousand Oaks, London, New Delhi: Sage Publications, Inc.
- Stewart, D. W., Shamdasani, P. N., & Rook, D. W. (2007). Focus Groups Theory and Practice. *Applied Social Research Methods Series, 20*.