COMMUNITY-BASED HEALTH RESEARCH: A Summer Institute

Weaving the Tapestry

Final Report

November 2011

June 19 - 24, 2011
University of Regina, Regina, SK

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COMMUNITY-BASED HEALTH RESEARCH: A Summer Institute

Weaving the Tapestry

The success of the Community-Based Health Research Summer Institute was the result of a dedicated and visionary planning committee, skillful and knowledgeable instructors and facilitators, inspiring keynote speakers and a group of participants from a variety of backgrounds who were keen to both learn and share.

With thanks to the planning committee members:

Bonnie Jeffery, Co-Chair
Jo-Ann Episkenew, Co-Chair
Sylvia Abonyi
Juanita Bacsu
Carrie Bourassa
Marissa Desjardins
Diana Fedosoff
Paula Migliardi
Pammla Petrucka

With thanks to the instructors & facilitators:

Sylvia Abonyi
JoLee Blackbear
Carrie Bourassa
Gloria DeSantis
Jo-Ann Episkenew
Linda Goulet
Jan Haffner
Mary Hampton
Bonnie Jeffery
Shanthi Johnson
Diane Martz
Tom McIntosh
Albert McLeod
Paula Migliardi
Nazeem Muhajarine
Cassandra Opikokew
Pammla Petrucka
Margaret Poitras
Leanne Yuzicappi

TABLE OF CONTENTS

Section 1 – Overview

Section 2 – Program Content

Section 3 – Outcomes

Section 4 – Reading List & Resources

Appendix A

"Thank you many times over! I came to the Summer Institute with specific academic, professional and personal goals. I have been able to move forward on all fronts."

COMMUNITY-BASED HEALTH RESEARCH: A Summer Institute

Weaving the Tapestry

SECTION 1 – OVERVIEW

1. Introduction

The Saskatchewan Population Health and Evaluation Research Unit (SPHERU), Indigenous Peoples' Health Research Centre (IPHRC), and the Prairie Community-Based HIV Research Program joined together in June 2011 to host the *Community-Based Health Research Summer Institute: Weaving the Tapestry*. The Institute was created with the intent to share successful strategies, approaches, and innovations in community-based health research. The themes for the Institute included: building partnerships; research methods; information management; and knowledge translation and communications.

Funding and support for the Institute was provided by the Saskatchewan Health Research Foundation (SHRF), SPHERU, IPHRC, Prairie Community-Based HIV Research Program, University of Saskatchewan, University of Regina, and Canadian Institutes of Health Research (CIHR). Donations and prizes were provided by the University of Regina Bookstore, the University of Saskatchewan Bookstore and SaskEnergy.

The purpose of this report is to provide a summary of activities and key documents from the Institute, so that participants and others can benefit from the knowledge shared.

2. Purpose of the Institute

The overall goal of the Community-Based Health Research Summer Institute (CBHRSI) was to provide knowledge and build capacity through applied training in community-based research using a population health approach. The Institute incorporated a range of learning opportunities including: expert presentations; hands-on workshops; case studies; keynote speakers; and group discussions with leading practitioners. The full program outline can be found in Appendix A.

Another key goal of the planning committee was to offer the opportunity for formal accreditation for graduate student participation in the Institute in order to build capacity for community-based health research. Student work from the course is presented in Section 3 Outcomes.

The Institute addressed the following specific learning objectives and outcomes.

Learning Objectives:

- To facilitate knowledge translation and educate participants on the fundamental concepts in community-based health research;
- To share successful strategies, approaches, and innovations for addressing health inequity through community-based health research;
- To educate participants on innovative knowledge translation and communication strategies and techniques;
- To provide formal and informal knowledge exchange and networking opportunities for future multidisciplinary collaborations in community-based research using a population health approach.

Learning Outcomes:

- Identify effective strategies, approaches, and methods for addressing health inequity through community-based health research; utilize effective information management techniques and data management tools; and identify strategies to address potential opportunities and challenges that may arise in community-based health research;
- Understand the foundations of academic integrity and research ethics such as the concepts of respect, beneficence, justice and risk in community-based health research;
- Utilize a variety of strategies and approaches for knowledge translation and effective communication;
- Develop networks and the opportunity to exchange knowledge and perspectives on community-based health research with a diverse group of stakeholders.

3. Program Outline

The Institute was held from June 19-June 24, 2011 at the University of Regina. The agenda was created with the intent to share successful strategies, approaches, and innovations in community-based health research across four themes – building partnerships, research methods, information management, and knowledge translation and communications.

The week included lectures by guest speakers, presentations and case studies. The case studies were a primary component of the Institute. Each of the partnering organizations (SPHERU, IPHRC, Prairie Community-Based HIV Research Program) contributed two case studies that focused on working with local community-based organizations (CBO) on an issue identified by the CBO. An overview of the week's events and activities follows, with the full program provided in Appendix A.

Community-Based Health Research: A Summer Institute

Program Outline

Sunday, June 19	Registration & welcome reception
Monday, June 20	Opening Address – Charlotte Reading, University of Victoria *Community-Based Research: Walking the Path Together* Session I – Developing Relationships & Partnerships Part 1 – Collaboration Case Study Introduction Sessions
Tuesday, June 21	Session I – Developing Relationships & Partnerships Part 2 – Research Ethics Session II – Research Methods for Community-Based Health Research Part 1 – Qualitative Methods Case Study Work
Wednesday, June 22	Session II – Research Methods for Community-Based Health Research Part 2 – Quantitative Methods Session III – Information Management Case Study Work Community Conversations Night: Andrée Cazabon *3rd World Canada - Engaging Communities in Reconciliation*
Thursday, June 23	Session IV: Knowledge Translation & Communications Part 1 – Policy Makers Part 2 – Communities Case Study Work
Friday, June 24	Case Study Presentations Closing Remarks & Prayer

“Very applicable info for working in Community Health Services. This week’s learning expanded my already solid base for engaging and partnering with communities.”

COMMUNITY-BASED HEALTH RESEARCH: A Summer Institute

Weaving the Tapestry

SECTION 2 – PROGRAM CONTENT

Content for the Institute included the following components: presentations, case studies, keynote address and an evening community event.

1. Presentations

Presentations by expert instructors were delivered across four days and covered the following topics: developing relationships & partnerships; research methods; information management; and knowledge transfer and communications. The following pages provide an overview of each of the four sessions, with the accompanying powerpoint presentations included in Section 4 – Reading List and Resources.

Session I – Developing Relationships & Partnerships

Part 1 - Collaboration

Instructors: *Linda Goulet, First Nations University of Canada*
Gloria DeSantis, SPHERU, University of Regina

The objective of this session was to explore the challenges and benefits of engaging academic and non-academic research partners in the research process. This session provided an introduction to professional research skills such as project management, leadership, collaboration, and teamwork. Case examples were used to examine potential situations, and to discuss challenges that may arise in community-based health research.

Community based research:

Relationships are foundational

Community Based Health Research Conference
June 20, 2011
Regina, Saskatchewan

Dr. Linda Goulet
Department of Indigenous Education
First Nations University of Canada

Developing relationships and partnerships: Collaboration

Gloria DeSantis, PhD
Saskatchewan Population Health & Evaluation Research Unit
University of Regina
June 2011

Part 2 – Research Ethics

Instructors: *Diane Martz, SPHERU, University of Saskatchewan*
Carrie Bourassa, IPHRC, First Nations University of Canada

The objective of this session was to provide an opportunity for participants to learn about the foundations of academic integrity and research ethics. In addition, this session explored the concepts of respect, beneficence, justice, and risk in community-based health research. Case examples were used to apply and examine ethical considerations in community-based health research.

COMMUNITY-BASED HEALTH RESEARCH:

Developing Relationships & Partnerships: Part 2 - Research Ethics

Dr. Diane Martz, SPHERU, Director, REO, U of S
and
Dr. Carrie Bourassa
IPHRC, First Nations University of Canada
June 21, 2011

Session II – Research Methods for Community-Based Health Research

Part 1 – Qualitative Methods

Instructors: *Sylvia Abonyi, SPHERU, University of Saskatchewan*
Pammla Petrucka, SPHERU, University of Saskatchewan

The objective of this session was to increase participants' understanding and knowledge of a variety of qualitative research methodologies useful in population health and community-based research. Interactive learning and group work was used to identify a "tool kit" of various qualitative methods. The advantages and limitations of different methods were identified and practical techniques to carry out effective community-based health research discussed. Case examples were used to provide participants with hands-on experience in determining appropriate qualitative research methods.

COMMUNITY-BASED HEALTH RESEARCH:

Qualitative Research: A Brief Overview

June 2011

Part 2 – Quantitative Methods

Instructors: *Nazeem Muhajarine, SPHERU, University of Saskatchewan*
Shanthi Johnson, SPHERU, University of Regina

The objective of this session was to develop an appreciation and knowledge of a variety of quantitative research methodologies useful in community-based health research. This session discussed a “tool kit” of relevant quantitative research methods for investigating community-based health research questions using a population health lens. The session identified the limitations and advantages of various approaches and discussed practical techniques to carry out effective community-based health research. Case examples were used to provide participants with hands-on experience in determining appropriate quantitative research methods.

Quantitative Research:
An overview

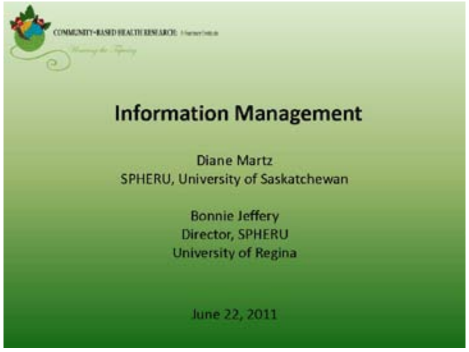
Shanthi Johnson, Faculty of Kinesiology and Health Studies, U of Regina
Nazeem Muhajarine, Community Health and Epidemiology, U of Saskatchewan

June 22, 2011

Session III – Information Management

Instructors: *Bonnie Jeffery, SPHERU, University of Regina*
Diane Martz, SPHERU, University of Saskatchewan

The objective of this session was to develop an understanding of issues related to effective information management in community-based health research. This session discussed data and information management, anonymity and confidentiality, security, and tracking of data. The session provided an introduction to effective strategies used for information and data management.



COMMUNITY-BASED HEALTH RESEARCH:

Information Management

Diane Martz
SPHERU, University of Saskatchewan

Bonnie Jeffery
Director, SPHERU
University of Regina

June 22, 2011

Session IV – Knowledge Translation & Communications

Part 1 – Policy Makers

Instructor: *Tom McIntosh, SPHERU, University of Regina*

The objective of this session was to develop an understanding of the key methods of engaging non-partner organizations, and in particular policy-makers, in the up-take of research findings as part of broadening the dissemination of the research.

COMMUNITY-BASED HEALTH RESEARCH:

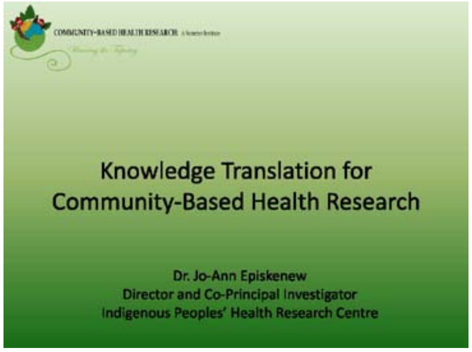
Engaging Policy Makers:
Making Opportunities for Change

Tom McIntosh
Political Science & SPHERU
University of Regina

Part 2 - Communities

Instructors: *Jo-Ann Episkenew, IPHRC, University of Regina*
Cassandra Opikokew IPHRC, University of Regina

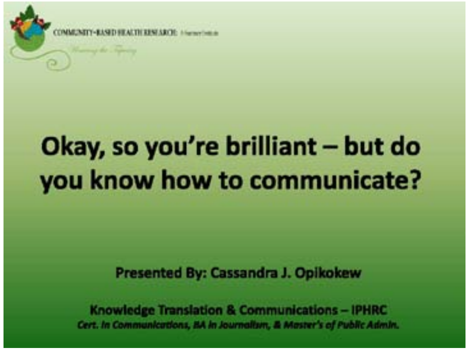
This session focused on the engagement of community partners in research using different knowledge translation methods. This session provided an overview of various media and communication approaches to use as KT tools to enhance the dissemination of community-based research to the public.



COMMUNITY-BASED HEALTH RESEARCH:

Knowledge Translation for
Community-Based Health Research

Dr. Jo-Ann Episkenew
Director and Co-Principal Investigator
Indigenous Peoples' Health Research Centre



COMMUNITY-BASED HEALTH RESEARCH:

Okay, so you're brilliant – but do
you know how to communicate?

Presented By: Cassandra J. Opikokew

Knowledge Translation & Communications – IPHRC
Cert. in Communications, BA in Journalism, & Master's of Public Admin.

2. Case Studies

Case studies were a key learning component of the Institute. Each of the partnering organizations (SPHERU, IPHRC, Prairie Community-Based HIV Research Program) contributed two case studies that focused on working with local community-based organizations (CBO) on an issue identified by the CBO. The case studies were drawn from Aboriginal and non-Aboriginal agencies in Saskatchewan and Manitoba, and were designed to give participants experience in working with community-based organizations to address an actual existing issue. The case studies covered issues across all of the topic themes, ranging from developing partnerships to knowledge translation.

Prior to the Institute, the planning committee organized participants into the six case study groups depending on the participants' selected area of interest. On the last day of the Institute, the groups presented their final recommendations to the entire Institute group.

Organization of the Case Study Model

On Day 1, the participants were divided into their six case study groups. Each case study had an academic and a representative from the community-based organization who provided the case study content and facilitated the discussion throughout the week. In the initial case study meeting, the community-based organization representative provided a ten to fifteen minute overview of the organization's issue that the case study group would address throughout the week.

On Days 2-4, the case study groups met for two work sessions each day (morning and afternoon). The content of the discussion for each of the work sessions were designed to reflect the content of the Institute modules from building partnerships to knowledge translation (please refer to table). This structure encouraged engagement and facilitated effective learning of the various content covered during each session.

On Day 5, the case study groups presented their key points and recommendations from their cases to the whole group. Prior to the presentations, the case study groups were given an hour and forty-five minutes to prepare for their presentation. These presentations provided ample opportunities for people to share lessons learned and gain insight into the potential challenges and complexity of conducting community-based health research.

Following are abbreviated case study descriptions. Full descriptions of each case study along with the graduate student papers are provided in Section 3 – Outcomes.

1) All Nations Hope AIDS Network: Community-Based Research and Capacity Development

Dr. Carrie Bourassa and Margaret Poitras

All Nations Hope AIDS Network (ANHAN), a small community-based organization (CBO) wants to apply for more tri-council funding so that they can advance their research agenda. ANHAN supports and assists First Nations, Métis and Inuit families living with HIV/AIDS and Hepatitis C to live meaningful lives, and to provide professional quality services, education, training, and awareness of HIV/AIDS and Hepatitis C. The last time the CBO applied for funding was extremely time consuming and became a burden to the small CBO. ANHAN would like to become a community-based research leader that could provide guidance, training, and support to other CBOs in Saskatchewan. ANHAN is seeking recommendations to demonstrate that CBOs like their organization should be eligible to hold tri-council funding.

2) *Lung Association of Saskatchewan: Effective and Culturally-Safe Knowledge Translation for First Nations and Métis Peoples' Respiratory Health*

Dr. Jo-Ann Episkenew and Jan Haffner

The Lung Association of Saskatchewan (LAS) conducts research into the causes and treatment of lung disease, and education of medical practitioners, the public, and those who suffer from respiratory diseases. The LAS has developed training programs (RESPTrec) to train health care professionals on how to educate people with lung disease to better manage and control lung disease. These guidelines and training programs, however, are designed with mainstream Canadians in mind and do not consider the specific history and health status of First Nations and Métis people. The existing training programs use case studies and scenarios that are not always applicable to the challenges faced by First Nations and Métis people. The LAS is seeking recommendations and a plan of action outlining how they should move forward to develop effective and culturally-safe knowledge translation on respiratory health for First Nations and Métis people.

3) *Play It Safer Network: What's hot and what's not…? Ensuring the community input and investment of a community-based organization*

Dr. JoLee Blackbear and Carrie Pockett

The Play It Safer Network (PISN) is a community-based organization with networks in northern Manitoba and southeastern Saskatchewan that uses a community-based approach to provide healthier lifestyle choices through education, prevention, treatment, and medical and social supports for Human Immunodeficiency Virus (HIV) /Acquired Immune Deficiency Syndrome (AIDS), Sexually Transmitted Infections, (STIs) Hepatitis C.

Although PISN has qualitative data and evaluates projects to determine success, they have never considered the "impact" of the PISN. They would like to determine the effectiveness and impact of their projects, awareness campaigns, access to resources, delivery strategies, and if they are reaching their target populations. They hope to identify a useful tool that would provide concrete evidence to demonstrate the impact of their community-based organization. Assessing the impact of PISN would enable them to improve their programs and services in the future.

4) *Paths to Living Well for Standing Buffalo Youth: Sharing the Learnings*

Dr. Pammla Petrucka and Leanne Yuzicappi

The community of Standing Buffalo First Nation (SBFN), a small rural reserve in southern Saskatchewan, hosts community-based research partnerships, which includes the community and academic researchers from the University of Saskatchewan, First Nations University of Canada (FNUC), and University of Regina. These partners developed the community-based research project entitled, Ocanku Duta Amani: Paths to Living Well – Youth which focuses on exploring "paths to being or becoming well" from the perspective of Aboriginal on reserve youth. This study was developed in response to the issues faced by Aboriginal youth ranging from mental health challenges (i.e., suicide) to substance abuse issue. The prevalence of these issues established the need to engage Aboriginal youth in research to collectively address how historical, social, cultural, and environmental factors impact on their health. As this project is nearing completion, the team is seeking recommendations outlining a 'Knowledge to Action' plan to disseminate and implement the findings of this research into action.

5) *The 595 Prevention Team: What Goes Around: How Peers Use their Social Networks to Share Safer Drug Use Resources*

Paula Migliardi and Albert McLeod

The 595 Prevention Team is a coalition of over 100 member organizations interested in addressing the determinants of health and preventing the transmission of sexually transmitted infections (STI) and blood borne infections (HIV/AIDS, HCV) in Manitoba. One of the most effective methods of ensuring vulnerable populations have access to information and resources regarding HIV and HCV prevention and safer drug use is through peer-to-peer knowledge exchange. However, further research is required to have a greater understanding of how peers use their social networks to share information, particularly when this information is shared "informally" and without initiation from service providers. As well, what does "safer drug use" mean to peers? Is HIV and HCV prevention information of highest priority to peers or is other "safer drug use" information more important? The 595 Prevention Team is seeking recommendations outlining a research plan to explore the processes in which peers share safer drug use information within their social networks.

6) *Saskatoon Poverty Reduction Partnership: Community-Based Research Case Study*

Dr. Sylvia Abonyi and Dr. Mary Hampton

For more than a decade, poverty has been an issue of concern in Saskatoon. As a response to the growing issue of poverty, the Saskatoon Regional Intersectoral Committee (SRIC) and several community-based organizations came together to form the Saskatoon Poverty Reduction Partnership (SPRP). The main goal of the SPRP was to develop and implement a poverty reduction action plan, scheduled to be released in September 2011. A governance model for the

SPRP was created which includes a Leadership Group, a Coordinating Group, and Action Groups. However, the Action Group's progress in maintaining momentum and community engagement has been problematic. The SPRP is seeking recommendations and a plan of action on how to encourage community engagement and mobilization.

3. Keynote Speaker

Dr. Charlotte Reading

Dr. Charlotte Reading is a Professor with the University of Victoria in the new School of Public Health and Social Policy in the Faculty of Human and Social Development. Dr. Reading provided an opening keynote presentation on community-based health research. Dr. Reading's presentation is available as a DVD included in this report and online at www.spheru.ca.

Along with describing the challenges and benefits of conducting community-based research, Dr. Reading discussed the importance of recognizing the 'positionality' and the multiple role demands of the researcher and the community partners. She also highlighted key principles in conducting community-based research such as:

- Ensuring that partnerships reflect shared responsibilities as well as benefits;
- Negotiating time lines that address academic and community needs;
- Respecting different knowledge and language;
- Negotiating a consensus on research goals, objectives and activities;
- Accommodating multiple role demands on research partners;
- Negotiating a balance between academic and community relevance;
- Incorporating capacity building;
- Pursuing culturally appropriate ethical review;
- Implementing OCAP principles within academic protocols.

Dr. Reading concluded her keynote presentation by noting that community-based research is complex but also rewarding: "CBR is complicated, time consuming, challenging work – that is entirely worth it!"

4. Community Conversations Night

Andrée Cazabon

Andrée Cazabon is a Gemini nominee and inspirational speaker whose films and youth advocacy have been recognized by Canada AM, the Vicky Gabreau show, CTV, and the Vancouver Film Festival. Andrée Cazabon's keynote presentation began with the viewing of her most recent and fifth documentary *Third World Canada*. The documentary explores a First Nation community's struggle to deal with third world conditions and the aftermath of suicides in the community.

Following the documentary, Cazabon discussed the difficult content of the film and opened the discussion to the audience. Her presentation touched on the challenges but also highlighted the strengths within the community. Over 100 people attended the event at the Albert Scott Community Centre in north central Regina with food and refreshments provided by Chili for Children, a local community organization that began in 1979.

“Such an amazing experience for grad students to work collaboratively with CBO’s. I cannot envision a better learning experience!”

COMMUNITY-BASED HEALTH RESEARCH: A Summer Institute

Weaving the Tapestry

SECTION 3 – OUTCOMES

Measuring the success of the CBHRSI and documenting the achievement of its goals were important components incorporated into the design of the Institute. To guide the course content and delivery, a set of well defined objectives and outcomes were articulated that would meet the goals of the Institute. Expert presenters and leading practitioners provided the knowledge base from which participants could expand their skills. Through the case studies, participants were exposed to different research methods and issues experienced by community-based organizations (CBOs) in Saskatchewan and Manitoba. The case studies enabled participants to share a range of successful strategies, approaches, and innovations for addressing health inequity through community-based health research. The number of participants and their array of backgrounds allowed for networking opportunities which will help facilitate future multidisciplinary collaborations.

Success of the Institute was assessed in a number of ways including: participation rate and breadth; accreditation of KHS 872; case studies and papers; and formal evaluations.

1. Participants

A total of 51 participants, made up of students, representatives of community organizations, and academics attended the Institute from Saskatchewan, other provinces and the United States. Twenty (20) participants representing a range of large and small community-based organizations from various areas of Saskatchewan and Manitoba attended. Of the 25 graduate students, over one-half (13) took advantage of the formal accreditation option and registered as credit students. Six university faculty members, three of whom were from outside Saskatchewan also attended. Fourteen (14) universities were represented at the Institute including:

Arizona State University
Brock University
First Nations University of Canada
McMaster University
Memorial University
Simon Fraser University
University of Alberta
University of Manitoba
University of Pennsylvania
University of Regina
University of Saskatchewan
University of Southern California
University of Toronto
University of Victoria

2. Course for Credit – KHS 872 (University of Regina)

The credit course was situated in the Faculty of Kinesiology and Health Studies at the University of Regina (KHS 872: Population Health) and co-taught by Dr. Shanthi Johnson (Faculty of Kinesiology and Health Studies/SPHERU), Dr. Bonnie Jeffery (Faculty of Social Work/SPHERU), and Dr. Jo-Ann Episkenew (IPHRC). All of the 13 registered students successfully completed the accredited course. Attendance at all the Institute sessions and the case study group work sessions was a requirement for successful completion of the course. In addition, students completed three written assignments which were submitted to the instructors over the two months following the end of the Institute. A description of the three assignments follows:

a) Reflective Journal

The reflective journal will focus on your responses to each learning module covered at the Institute as well as your experience working on the case study. The journal should be 8-10 double spaced pages and include discussion of the key points, approaches and or challenges explored in each session. The journal is intended to be a critical self-reflective exercise to help you increase your awareness of your personal responses to the material on community-based health research, which can assist you in developing your ability to integrate the material into your research. You may write in first person. Entries should include reference to the following:

1. Your response to the material in each module and the case study experience. Try to be specific about what you found helpful/unhelpful, powerful, unsettling, interesting, boring, etc.

2. Your self-critique should focus on some or all of these questions: Why do I think/respond this way? What assumptions did I bring to my understanding of the material? What challenges me most about the ideas or experiences? What makes me resist some of these ideas or experiences? Am I discovering gaps in my knowledge that I wasn't aware of? Why are those gaps there and what can I do about it?

b) Annotated Bibliography

The annotated bibliography should include a minimum of 8 citations and each should address two components:

1. Summarize: What are the main arguments? What is the point of this book or article? What topics are covered? If someone asked what this article/book is about, what would you say? The length of your annotations will determine how detailed your summary is.

2. Assess: After summarizing a source, you should also evaluate it. Is it a useful source? How does it compare with other sources in your bibliography? Is the information reliable/useful? What is the goal of this source? Would you integrate this into your community-based health research initiatives?

c) Major Paper

During the course of the Institute, you have had the opportunity to work with a community organization on a case study that outlines a challenge the organization faces. By the last day of the Institute, each group will have developed a basic plan to address that challenge. In your major paper, you will use the information that the community has provided, the basic plan that the group has developed, and the tools that you have acquired during the Institute to articulate a detailed community-based research strategy to address the challenge set out in the case study. Your paper should **include all of the elements of community-based research** presented at the Institute: **community engagement, research ethics, research methodology, information management, and knowledge translation**. Your plan should provide the community with choices, and you must set out the pros and cons of each choice. You will, however, be expected to recommend a course of action and justify your recommendation. Please remember that you are a university researcher writing for your community partner, so adapt your writing style accordingly to ensure that it is clear, accessible, and free of jargon. When you find it necessary to include technical terms, you will need to explain those terms. This means that you must understand the communication style of the community organization that you are serving. In addition to being a report for the community, this is still a major paper for credit in a graduate course. The community organization has already provided the basis of your research question. Your paper, then, must include a clear thesis, which would likely encapsulate the basic point of your recommendation. Also, each paragraph must make a point that supports your thesis. Any secondary sources that you use must be cited using APA formatting, which you can find in many other on-line resources, including http://owl.english.purdue.edu/owl/resource/560/01/. And, you must list your references on a separate page. In the spirit of reciprocity that is a basic principle of community-based research, we will be seeking your permission to share your papers will the community organization. However, you will have an opportunity to revise your graded paper before we do so.

3. Evaluation Summary

Participants completed a questionnaire to provide feedback on the learning opportunities, relevancy of topics and program content, opportunities for knowledge translation, impact of keynote speakers, recommendations and areas for improvement. A summary report of the evaluation questionnaire responses follows.

EVALUATION SUMMARY

Total Number of Evaluations: 27

1. *How would you describe yourself? (check one)*

19%	Community Researcher
11%	Graduate Student (non-credit)
30%	Graduate Student (course for credit)
7%	University Researcher
33%	Other (please specify – see comments below)
	• Health professional population health • Community Worker • Academic/Faculty • Undergraduate student • Manager of SCO – 7.5 years • Independent • Community Rep from Health Care • Diabetes Education/smoking addiction cessation counselling • Front-End Worker – work with marginalized population and who are homeless and are infected with HIV/HCV and are addicted to different drugs

2. *How did you hear about the Summer Institute? (check all that apply)*

15%	A particular website
0%	An internet search
21%	Mass email directly from the Institute
7%	Friend / Co-worker / Family
15%	Interdepartmental memo / Newsletter
21%	From an education source (i.e., professor); *e-mail to grad students from a faculty member; NAMHR newsletter, e-mail (McGill University)*
21%	Other (please specify – see comments below)
	• *From the E.D. of the 595 Peer Working Group. I am a peer of the 595.* • *Senior leadership team* • *From MB NEAHR coordinator* • *Jo-Ann Episkenew* • *Ministry of Health consultant (employer)* • *Job browsing in Saskatchewan*

3. ***Why did you choose to attend the Summer Institute? (check all that apply)***

89%	To increase my general knowledge on Community Based Research (CBR)
67%	To use it in my work
74%	To network with others involved or interested in CBR
19%	To potentially find partners for specific CBR projects
	• *Not immediately but for networking for the future*
70%	To contribute to my academic knowledge
11%	Other (please specify – see comment below)
	• *For academic credit* • *Check out job possibilities and going to university*

4. ***What is your overall rating of the Summer Institute? (check one)***

65% Excellent	**23%** Good	**12%** Average	**0%** Fair	**0%** Poor

5. ***How well did the Summer Institute meet your expectations?***

65% Excellent	**23%** Good	**12%** Average	**0%** Fair	**0%** Poor

6. ***Please rate your knowledge / skill level on Community Based Research before the Summer Institute? (check one)***

0% None	**33%** Limited	**52%** Some	**15%** Significant

7. ***Please evaluate the Case Study Component of the Summer Institute. Please indicate what case study group you participated in.***

Case Study #1 – All Nations Hope AIDS Network – 4 participants

Rate the following	**Excellent**	**Good**	**Average**	**Fair**	**Poor**
Effective as a learning tool	100%				
Ability to share ideas	100%				
Co-learning	100%				
Overall approach	100%				
Facilitation skills	100%				

Case Study #2 – Lung Association of Saskatchewan - 2 participants

Rate the following	Excellent	Good	Average	Fair	Poor
Effective as a learning tool	50%		50%		
Ability to share ideas	50%		50%		
Co-learning	50%		50%		
Overall approach	50%		50%		
Facilitation skills		50%	50%		

Case Study #3 – Play it Safer Network - 3 participants

Rate the following	Excellent	Good	Average	Fair	Poor
Effective as a learning tool	100%				
Ability to share ideas	75%	25%			
Co-learning	75%	25%			
Overall approach	100%				
Facilitation skills	75%		25%		

- *I am not sure I learned much more from others than vice versa*

Case Study #4 – Paths to Living Well for Standing Buffalo Youth - 2 participants

Rate the following	Excellent	Good	Average	Fair	Poor
Effective as a learning tool	50%	50%			
Ability to share ideas	50%	50%			
Co-learning	100%				
Overall approach	50%	50%			
Facilitation skills	50%	50%			

- *Case Study – initially served some reticence with group. Facilitation was very loose but generally worked. Ended with feeling privileged to have the information shared with us. Very helpful to have Elders presence and guidance and presence of Aboriginal person knowledgeable about culture and ways of doing. Thank you.*

Case Study #5 – The 595 Prevention Team- 5 participants

Rate the following	Excellent	Good	Average	Fair	Poor
Effective as a learning tool	20%	80%			
Ability to share ideas	20%	40%	40%		
Co-learning	40%	40%	20%		
Overall approach		60%	40%		
Facilitation skills		80%	20%		

- *The discussions on the first day of the case study felt like we were going in circles, however subsequent discussions were more focused. Although discussion were good, at times I felt we were a bit restricted because the real people involved with the real world case seemed to stick to what they thought would work or not work and kept reminding us of the fact of the case. This may have been OK due to time constraints but put a slight damper on brainstorming and free range discussion.*

Case Study #6 – Saskatoon Poverty Reduction Partnership - 4 participants

Rate the following	Excellent	Good	Average	Fair	Poor
Effective as a learning tool	25%	25%	50%		
Ability to share ideas	50%	50%			
Co-learning	75%	25%			
Overall approach		100%			
Facilitation skills	50%	50%			

- *It would really have helped if we had had more involvement from our community partners on this case study*
- *Missing the follow-up piece such as a debrief or what was the actual end result. This is not feasible here in this case study but is a natural progression or follow through to know the impact of the recommendations made.*

Case Study not indicated on the evaluation form - 4 participants

Rate the following	Excellent	Good	Average	Fair	Poor
Effective as a learning tool	100%				
Ability to share ideas	100%				
Co-learning	100%				
Overall approach	100%				
Facilitation skills	100%				

8. ***Please evaluate the various topics presented at the Summer Institute. (please mark the appropriate boxes for each one)***

Rate the following	Knowledge gained			This topic could have been expanded	Could have done without the topic
	None	Some	Significant		
Opening Address – CBR: Walking the Path Together	0%	48%	52%	11%	
Developing Relationships and Partnerships – Collaboration	4%	48%	48%	7%	
Developing Relationships and Partnerships – Research Ethics	11%	35%	54%	7%	
Qualitative Methods	11%	53%	36%	7%	
Quantitative Methods	7%	60%	33%	15%	4%
Information Management	7%	37%	56%	7%	
Knowledge Transfer & Communications – Policy Makers	11%	26%	63%		
Knowledge Transfer & Communications - Communities	7%	28%	65%		

- *Topics were well covered in the time allowed and a lot of information covered in 4 days*
- *Could have done without the topic – or at least shortened course*
- *This topic could have been expanded – Opening Address – charismatic, funny good opening*

- *This topic could have been expanded – Developing Relationships – Research Ethics – process itself*
- *This topic could have been expanded – Qualitative Methods – methodologies (is my weak area)*
- *This topic could have been expanded – Information Management – lots of good examples given*
- *This topic could have been expanded – Knowledge Transfer – Policy Makers – Excellent!*
- *This topic could have been expanded – Knowledge Transfer – Communities – Excellent communications piece especially*
- *This topic could have been expanded – Qualitative Methods – Methods of analysis*

9. Summer Institute Overall Outcomes

Rate the following	**Strongly Agree**	**Agree**	**Neutral**	**Disagree**	**Strongly Disagree**
The institute increased my knowledge	40%	52%	4%	4%	
The institute increased my ability to meet my organization's/professional goals	37%	41%	18%		4%
The Institute increased my ability to meet research goals	37%	44%	15%		4%
The Institute provided an essential educational opportunity	66%	33%	7%		4%
The Institute provided an essential networking opportunity	55%	30%	4%	11%	
The Institute has been a worthwhile experience	81%	15%			4%

- *The Friday case study presentations were most valuable. I hope someone has taken notes to share with everyone*
- *Would like a certificate or letter of completion for lab tech. Continuing Education*

10. Summer Institute Organization

Rate the following	**Excellent**	**Good**	**Average**	**Fair**	**Poor**
Registration procedure	59%	33%	4%	4%	
Visibility on the internet	33%	52%	11%	4%	
Ease of registration at venue	77%	19%		4%	
Institute package provided at registration	67%	33%			
General organization of the event	81%	15%	4%		

11. Comments or suggestions about the Summer Institute

Program Content/Format

- Thank you many times over! I came to the S.I. with specific academic, professional and personal goals. I have been able to move forward on all fronts. I might suggest you have a section on mixed methods research and transdisciplinary and/or interdisciplinary research. The TUTOR-PHC program might be a good resource. This was excellent and I hope you continue to create the kinds of opportunities where academics and a host of other people from a variety of agencies can meet and mingle. TUTOR-PHC: Transdisciplinary Understanding and Training on Research-Primary Health Care.

- Use of non words (not in the dictionaries).
- Events relating to National Aboriginal Day should have been promoted as part of the week.
- The week exceeded all expectations I had. I would definitely recommend others to attend and hope this will be an annual event.
- I loved how the schedule was adhered to.
- I was expecting more advance coverage of lecture topics. Future conferences may consider offering multiple tracks of courses whereby participants with more knowledge in given area can obtain more appropriate information. The lectures seemed appropriate for the undergraduate level or for those without advance academic training.
- Excellent to have 3 bound notebooks: 1) working list, schedule and power points; 2) notebook in which to record notes; 3) KT Casebook
- Day 1 – First Thing – Introduction to the week/overview.
- This was good information for introductory class. I was hoping to get some more information and best practice that could be applied to specific situations. This was a unique opportunity to get so much information from experts in the field and I felt I was not able to absorb all the wonderful experiences people had to share and learn from it. I also hoped there would be a range of topics that could be examined as case studies.

Case Studies

- Unfair for Poverty Group not to be able to access their agency/board member.
- Case studies need re-evaluation.
- I loved the format with the case studies.
- Loved the casework! Great learning experience.
- Participant expectations in the case groups were unclear. At times it was quite difficult to contribute to the case project. The organization members seemed closed off to academic partnership which led to group difficulties in terms of project process.
- Safety of Researchers – Clearer direction of purpose of case studies.
- Organizations that submit case studies should designate a representative to be available for questions and clarification. This would be best as a mandatory component of submission; at least for specified time eg. 4:00 on the Monday or 10:45 Tuesday for 30 minutes. I would not want a rep for all cast study sessions as I think this would stifle a group and be uncomfortable. It would be preferable to have a designate quite familiar with case who would not have to take too many questions back to yet another person. Case studies are an excellent learning tool and teaching tool. Facilitators are hugely beneficial to guiding and keep groups on track.

Organization/Facilities

- Great food and facility!
- Have “energizers” (physical) to introduce breaks.
- Excellent food.
- Parking an issue for people with disabilities.

- No microphone use by some – hard to hear at times.
- Excellent food provided.
- Yellow on slides does not show up to class.
- Unable to hear – muffled words.
- The link in the e-mail couldn't open and I had difficulty finding information in advance of attending. My registration also wasn't confirmed until June 9th rather than sooner after registration in April.
- 1.5 hours is too long for lunch break.
- The food was amazing!!
- Great food! But hate to throw out plates 3X per day!
- Many of the presentations were visually hard to read – use of yellow type illegible; too much type or detailed tables. Would be helpful to get larger power points (eg. 2 per page) so they are readable.
- Very friendly, knowledgeable staff (Diana's a gem!) and faculty. Beautiful campus. Incredible food. Very well organized.
- Suggestions: Ask people to minimize wearing perfume (hard for those with asthma/sensitivities).
- Kudos to the caterers for the great food.
- Thank you for all the work done to organize this event!
- Thank you for providing breakfast, lunch and break snacks – it allowed more networking time and no time wasted looking for meals.
- Some of the logistics may need refining. While arriving on a Sunday might have been a wrinkle, the U of R knew some of us were coming and/or the "application" process/forms for residence and parking adapted so that dishes, TV's, etc could be ordered ahead or an automatic notice they would be there on arrival if organizing group did this piece. Was not familiar with enough to know if or what to ask about/for.
- Separate room for lunch/meals from activity type sessions so it is more conducive for that may people to socialize at meals and participate effectively/appropriately in activity.
- Housekeeping on Day 1 – while we are adults and can come and go as we choose – it would be nice to remind people that being on time for lecture session (in particular) would be appreciated. It is distracting and disrespectful to saunter in and out.

General Comments/Suggestions for Future Institutes

- This has been an amazing learning experience for me and will assist the CBO that I work for.
- Excellent organization of training – great job!
- Do it again – suggest every two years.
- It was a great opportunity to learn and network.
- It has been a very inspiring week. Thank you for this opportunity!
- Such an amazing experience for grad students to work collaboratively with CBO's. Cannot envision a better learning experience!

- Thank you so much for all the effort in organizing such a rich learning and relationship building experience! Have a great summer!
- I hope this becomes a recurring event – much needed in the field. The diversity of researches/practitioners involved was excellent and CBO's.
- Well done, I would recommend the institute to my colleagues and senior leadership.
- Very pleased to be part of this and did learn some new things.
- Met some very nice people from different places.
- I have thoroughly enjoyed the experience.
- Very worthwhile, I will attend again.
- An extraordinary networking/learning week.
- Very applicable info for working in Community Health Services. This week's learning expanded my already solid base for engaging and partnering with communities. Thanks for the opportunity!
- Look forward to next year!

4. Case Studies and Papers

The detailed case study description along with a student paper from each case study group follows, with the exception of *The 595 Prevention Team: What Goes Around*, for which no student paper was available. The papers can be found directly following each case study description.

Case Study #1

All Nations Hope AIDS Network:

Community-Based Research and Capacity Development

Facilitators:

Dr. Carrie Bourassa and Margaret Poitras

All Nations Hope AIDS Network: Community-Based Research and Capacity Development

Case Study

Facilitators: Dr. Carrie Bourassa and Margaret Poitras

Introduction:

All Nations Hope AIDS Network (ANHAN) has been in Saskatchewan since 1995 and they are the only Aboriginal AIDS Service Organization in Saskatchewan. Our service mandate includes all regions in the province of Saskatchewan. The Network is in partnership with various groups at regional, provincial and national levels. All Nations Hope AIDS Network consists of Aboriginal staff, Board of Directors, volunteers and Advisors Circles.

The Directors of the Corporation (which are elected by the members) are responsible for overseeing the business and affairs of the corporation. Ordinarily, the directors' function is to ensure that they act honestly, in good faith and in the best interest of the corporation. The director must act in accordance with the limitations set out in the bylaws of the corporation. Traditionally, the role of the directors is to oversee the ongoing business activities of the corporation and ensure the corporation affairs are being carried out in a prudent and reasonable manner. Please see Appendix A for Board of Directors Portfolios and Staff Profiles.

Since 1996, All Nations Hope AIDS Network Inc. supports and assists First Nations, Métis and Inuit families living with HIV/AIDS and Hepatitis C to live meaningful lives, and to provide professional quality services, education, training and awareness of HIV/AIDS and Hepatitis C in the community and envisions a center which responds to the spiritual, emotional, physical and mental needs of Aboriginal people living with HIV/AIDS and Hepatitis C.

We are an Aboriginal AIDS organization in Saskatchewan that offers services and programs to all nations. The target population has been identified as all nations, priority being given to those who are vulnerable and affected/infected by HIV/AIDS and Hepatitis C. The target populations are marginalized, stigmatized and unfairly deprived of essential services and programming that are ineffective to their unique needs.

The primary target population includes the following: populations at risk, people living with HIV/AIDS and/or HCV. This would be inclusive of the youth, women, two spirit people, inmates and people struggling with addictions.

The secondary target population consists of Aboriginal key stakeholders, organizations and networks in Saskatchewan. These are the Aboriginal front line workers in both rural and urban settings in Saskatchewan. These Aboriginal groups are the treatment centers, provincial corrections centers, community service providers, existing networks, and harm reduction based services.

ANHAN's experience in working among these target populations has been consistent throughout the past 12 years. Through completed projects and grants, ANHAN was able to provide information and services to specific groups in Saskatchewan. We were also able to make contacts within these groups through presentations, workshops, conferences and fund-raising events. Also through our extensive work on committees, boards, meetings and task forces, we were able to initiate new partnerships among the Aboriginal groups. Through our commitment in the fight against HIV/AIDS among the Aboriginal people, we continually become involved in different avenues to address the epidemic. Appendix B details several funded initiatives the Network is currently involved in.

The Network actively engages in community partnerships in Regina and Saskatchewan for service delivery, research and evaluation. There is a regional, provincial and national perspective in the maintaining and development of partnerships across Canada. Most recently the Network has engaged in international work in terms of sharing the knowledge and building relationships with Indigenous Peoples.

ANHAN is seen as a strong, caring and compassionate agency providing knowledgeable services in a safe environment. They are committed professionals who are persistent in their efforts to provide confidential service with many of them having personal experiences with HIV/AIDS and Hepatitis C. Within a friendly atmosphere, they listen, support, guide, assist, advocate and encourage All Nations living with HIV/AIDS and hepatitis C. As a learning organization, they provide educational workshops and training opportunities for clients and staff so that the best service can be available. They are seen as leaders in their field of health care utilizing a family and client focused approach to service delivery because of their commitment to focus at the grass roots and community level. A solid sense of their spirituality underscores all their efforts.

ANHAN is very community oriented and has a solid community presence. By utilizing Aboriginal cultures it stays connected and has a sense of belonging in the community it serves.

ANHAN’s mandate, vision and mission are as follows:

Mandate

Being a network of Aboriginal people, organizations and agencies, we respectfully strive to provide support and services to our First Nations, Métis and Inuit families and communities who are experiencing HIV/AIDS and Hepatitis C.

Mission

ANHAN mission is to support and assist First Nations, Métis and Inuit and all other people and their families living with HIV/AIDS and Hepatitis C to live meaningful lives, and to provide professional training, and awareness of HIV/AIDS and Hepatitis C to the community.

Vision

All Nations Hope AIDS Network envisions a center which responds, holistically, traditionally, and spiritually, to the needs of Aboriginal people living with HIV/AIDS and Hepatitis C. ANHAN is an agency that has credible partnerships and is well respected for the work it does. ANHAN engages in partnerships for service delivery, research, and evaluation.

Overview/Analysis:

Research has always been on the agenda of the Network, they have taken part in national, provincial and regional research projects in different capacities. In 2007 they were successful in obtaining a $25,000 seed grant from the Canadian Institutes of Health Research (CIHR). The Chief Executive Officer, Margaret Akan was the Nominated Principal Applicant and Dr. Carrie Bourassa was the Co-Principal Applicant. The goal of the research was to consult with key Aboriginal (First Nations, Métis and Inuit) including people living with HIV/AIDS (APHA's) to develop a research agenda. While the project was successful (see Appendix A for a summary of the project), it took over two years for ANHAN to become eligible to hold the funds for the project. This caused great hardship for ANHAN as they had to find a way to pay for the research until the funds were released.

ANHAN believes that community-based research is essential to their organization in order to meet their vision, mission and mandate. They feel that research should inform their programs and services and, moreover, it should inform local, provincial and federal policy as well as assist in their ongoing effort to lobby funders for increased funding. Please see Appendix C for ANHAN Chief Executive Officer Contributions.

Case Problem:

The Chief Executive Officer wants to apply for more tri-council funding so that they can advance their research agenda; however, she is worried that she will once again have to struggle to demonstrate that ANHAN, as a Community-Based Organization (CBO) has the ability to carry out tri-council funding. The last process was extremely time consuming and became a burden to the small CBO. The Chief Executive Officer wants to be a leader for other CBO's in Saskatchewan. She would like to see ANHAN become a CBO that could provide guidance, training and support to other Aboriginal CBO's in Saskatchewan working in this area. She is seeking recommendations from you to help her to demonstrate that CBO's like ANHAN should be eligible to hold tri-council funding that would lead to ANHAN becoming a leader in community-based research in Saskatchewan. The deliverable is a two to three page report outlining recommendations that ANHAN could consider in order to become recognized as having the ability to hold tri-council funds.

The Chief Executive Officer has some ideas about what might assist in this process. Should she try to lobby for a provincial or local Aboriginal ethics board? Would an MOU with an existing ethics board such as the University of Regina or the Regina Qu'Appelle Health Region be helpful? Should she establish a community/academic research advisory board at ANHAN?

Examine the situation and prepare a plan of how you would approach the problem.

Appendix A

Board of Directors Portfolios:

Art Kaiswatum

- Former Chief of Piapot First Nation.
- Six term Board Member.
- Spiritual Advisor for Regina Correctional Services for 7 years.
- Ipsco Employee for 10 years.
- Union Representative, shop steward for Steelworkers Union.
- Carrier of Ceremonies and teachings, singer and drummer.
- Traditional pipe carrier.
- Cross Cultural workshops.
- Organized and implemented Taekwon-Do Club in Piapot First Nation.
- Individual Spiritual Service Award, Regina Multifaith Forum.
- Award by Canadian Centre for Police – Race Relations.
- Saskatchewan Volunteer Medal 2000.
- Cross Cultural work with Indigenous people in Costa Rica, Spain.

Diane Kaiswatum

- 4 term Board Member, currently Board Treasurer.
- Currently employed with Government of Saskatchewan.
- Raising 5 grandchildren.
- Active community member of the Piapot First Nation Women's Group.
- Ceremonies and teachings, Traditional Pipe Carrier, Cross Cultural workshops.
- Member of Piapot First Nation Health Committee – 5 years.
- Member of committee for RCMP Relations with Piapot First Nation.
- Regina Correctional Centre Elder's helper for 5 years.
- Cross Cultural work with Indigenous people in Costa Rica, Spain.

Vern Bellegarde

- Member of the Little Black Bear First Nation.
- Second Term Board Member, Chairperson of the Board.
- RCMP Special Constable Keeseekoose First Nation.
- District Representative Touchwood File Hills Qu'Appelle Tribal Council.
- First Vice-Chief Federation of Sask Indian Nations.
- Chief of Treaty Nation Alliance of Western Canada.
- Executive Director Qu'Appelle Indian Residential School.
- General Manager Digital Print Centre.
- Marketing Director File Hills Telecom.
- Management Accounting Certificate.
- Life Skills Coaching Certificate.

- Supervisory Training Modules U of R.
- Human Resource Development Training.

Angie Brabant

- Member of the Peepeekisis First Nation.
- Second term Board Member.
- Retired Registered Nurse.
- Board of Directors with the Parkland Community College for 3 years.
- Board Member with Saskatchewan Legal Aid for 5 years.
- Catholic Minister since 1985.

Jacqueline Anaquod

- First Term Board Member.
- Member of the Muscowpetung First Nation.
- Education and Prevention Coordinator for the AIDS Program South Saskatchewan.
- Second year student with Saskatchewan Indian Institute of Technology, Community Services Addiction Diploma.
- Honors Roll with Saskatchewan Indian Institute of Technology for past two years.
- Recipient of the National Aboriginal Achievement Award.
- Interest in Traditional, Cultural Events and Ceremonies.
- Commitment as volunteer and community support for awareness of the addictions and social problems which our Youth are faced with today.
- Single-parent of a 15 year old daughter.

Krista Shore

- Board Member for four terms.
- HIV Positive member of the Board.
- Dedicated volunteer and inspirational speaker for Youth on awareness and issues pertaining to HIV/AIDS.
- Educated and trained through conferences and skills building sessions from the Canadian Aboriginal HIV/AIDS Network, Canadian HIV/AIDS Legal Network, Canadian Advocacy Treatment Information and Exchange and ANHAN annual conferences.

Amy Gordon

- First term Board Member, Board Secretary.
- Member of the Gordon's First Nation.
- Light House Tabernacle Church, Assistant Manager.
- Life Skills Counselor for Youth.
- Facilitator of Residential School Survivor Meetings.
- Apostolic Ministry Certificate – Mary Patrick.
- Interest in assisting recovering addicts of all age groups.
- Representative of the Gordon's Urban Committee.

Iris Acoose

- Member of Sakimay First Nation.
- Mother of 3 children, Grandmother of 11 children, Great Grandmother of 3 children.
- Board Member for three terms, Board Vice Chairperson.
- Resolution Health Support Worker Yorkton Tribal Council.
- Travelled extensively through First Nation Communities in Canada, completing alcohol and drug awareness.
- Worked in the Criminal Justice System, in federal institutions for men and women.
- Dedicated career to socially advance those who have been disadvantaged.

ANHAN Staff Profiles

Margaret Poitras is currently the ANHAN CEO; she has been in the position of leadership for 12 years. She is of Cree ancestry and is from Muskowekwan First Nation. She has dedicated her career to working in the community for over 20 years; she has been involved in the field of HIV/AIDS since 1988. Past achievements include: Keynote speaker at the 19th Annual Canadian Conference on HIV/AIDS Research May 2010, Past Founder of the Dream Catchers Girls Softball teams, Past Board Member of the Canadian Aboriginal AIDS Network representing Saskatchewan Region 2001 -2006, Co- Principal Applicant on ANHAN Gathering of Support Research Grant 2006-08, Recipient of Certificate of Honor from Art of Living Foundation in 2006, Speaker at the Harm Reduction 2008: International Harm Reduction Association’s 19th International Conference in Barcelona Spain. She is currently the First Nation Co-Chair of the National Aboriginal Council on HIV/AIDS, a council to advise Health Canada on HIV/AIDS issues that affect all Canada's Aboriginal peoples. NACHA, developed and launched in May 2001 with the strong participation of Aboriginal people, reflects the needs of First Nations, Inuit and Métis. Margaret is currently involved with numerous committees, gatherings, conferences, and meetings to address HIV/AIDS and HCV among the Aboriginal peoples of Canada.

Leona Quewezance is from the Saulteaux First Nation. She began working for All Nations Hope AIDS Network 12 years ago. She started as the Health Promotion Coordinator which took her across Saskatchewan facilitating HIV/AIDS workshops. She has held several different positions throughout the years and is currently the Program Director. Her accomplishments include resources such as the Saskatchewan Harm Reduction Guide, Hepatitis C and HIV Kit and the Sharing the Knowledge (Train the Trainers) manual. She has coordinated many of the annual events such as the AIDS Walk and the ANHAN annual conference. Her position as Program Director is challenging and rewarding. She started from the frontlines and continues to work with people one on one.

Lana Holinaty is currently the Director of Operations at ANHAN. She has been working in the field of HIV/AIDS and with the Network since 2005 and is dedicated to her work in the community. She is of Métis ancestry and was born and raised in Regina, SK. Past achievements include: Diploma in Network Administration, Certificate of Excellence - recognition for attendance, academic achievement, leadership and communications-CDI College of Business and Technology, Certificate Level 1 Occupational Health and Safety, and Applied Suicide Intervention Skills Training. She was the coordinator of the 3rd National Hepatitis C Conference. She was a collaborator on the ANHAN Research Team “A Gathering of Support: Developing an Aboriginal Grassroots Research Network on HIV/AIDS”. She currently sits on the National AIDS Committee for the Scotiabank AIDS Walk for Life.

She has assisted with the creation of new resources on HIV/AIDS and HCV. Lana is involved with many aspects throughout the Network, assisting with addressing the issues surrounding HIV/AIDS and Aboriginal people.

Ken Ward is from the Enoch Cree Nation community in Alberta and currently residing in Regina and working at ANHAN as a Resolution Health Support Worker. His background revolves around the Support/care and education in specifics with HIV/AIDS in the Aboriginal community in Canada. He has also worked as an educator in the correctional institutes of Saskatchewan and Alberta for the last 20 years doing similar work. He has experienced the residential school life at the Blue Quills School based near Saddle Lake reserve in Alberta. He has done contract work in Vancouver, British Columbia for a short term as a support worker for residential school survivors.

Ashley Norton is a young woman descending from the Métis Nation of Saskatchewan. Her involvement with the Aboriginal Community throughout the past 9 years has been outstanding. Ashley is an Aboriginal Youth Advocate. She has worked as a Coordinator and Adult Mentor with Youth Voice, an organization which targets inner-city Regina youth. She is currently the Youth Director for All Nations Hope AIDS Network and her time is dedicated to helping improve the social status and well being of our Aboriginal Youth. She served in provincial and national capacities within the Friendship Centre Movement. Ashley has been a youth advisory member with Youth Action Now, a member of the Regina Homelessness Committee, the Saskatchewan Provincial Youth Advisory Committee, and the Regina Urban Aboriginal Strategy. Currently Ashley is an interim-board member of the Regina Riel Métis Council Inc. She won the SaskTel Aboriginal Youth Award for Leadership in 2002 and in 2004 was awarded the YWCA Young Woman of Distinction Award.

Gordon Keewatin has worked in various fields throughout his life and has experienced many challenges in his positions. He has held such jobs as a farm labourer, store clerk, warehouse man, maintenance man, office clerk, child care worker, community worker, court worker in justice, artist in residence and aboriginal liaison cultural worker. He is an artist through the attainment of a Fine Arts degree (B.F.A.) majoring in Indian Art at the First Nations University of Canada. He is currently one of the Elders at ANHAN with the Residential School Program. As a residential school survivor, He understands the impact that this dilemma has had on First Nations people and their culture. He continues to move forward in working with other survivors and providing mutual support for members of the community.

Audra-Jo Isaac was a fourth year, double major in Indigenous Studies and Health, university student but felt that she would benefit from time away from school to work in the community. Her passion in life is to work directly with First Nations people regarding health issues and barriers. She was hired at All Nations Hope AIDS Network in June 2010 as the Zero Stage Housing Manager which is a program that is in the very early stages of planning. The project would serve as a homeless shelter, in which is community based. She strives every day to insure that this project is successful in the future.

Wesley Keewatin has been doing volunteer work in the community for many years and is currently a Community Outreach Worker at ANHAN. He has held various position in his years with the Network and some of his accomplishments include; certification as a Life Skills Coach with Red Echo Associates and he has also developed a Two Spirit manual. He has facilitated HIV/AIDS and HCV workshops throughout the community. As an Outreach Worker, Wesley has an understanding and compassion for the people that walk through the doors of ANHAN.

Marjorie Obleman is of Métis ancestry and she brings many skills and abilities to the Network. She has been employed as a social worker, an educator, a family worker and a corrections officer. She brings the knowledge of a like skills coach, a job finding coach and an Aboriginal Parenting Facilitator. She believes in holistic healing and is also a Reiki practitioner. She is a mother of five and a kokum of eight.

Selina Brittain is from the Sakimay First Nation, with a Saulteaux cultural background. She attended Marieval Residential School. She is a mother, grandmother and great-grandmother and has lived the majority of her life in Regina, where she successfully completed upgrading classes through Manpower and SIAST. Her main concern has always been for the safety and well being of children, people and families. Her role with The Early Learning Center and Scott Collegiate Daycare involved working closely with young mothers and their children. Through the SIIT training program, Selina has achieved a certificate in Family Development. Selina is currently at ANHAN as a Resolution Health Support Worker. Her role is to provide emotional health and wellness support to former (IRS) students and their families.

Brett Friday started at All Nations Hope AIDS Network as a participant, straight out of high school, of the youth group I Almost Know Every Thing But not Yet. By the time the youth group was over and he got several certificates and an offer to be trained and employed by All Nations Hope AIDS Network. Once the life skills coach contract was over he got another offer to be the youth mentor. Within three years Brett Friday graduated from high school, obtained several certificates, went to SIAST for his life skills facilitator training, been employed as a Life Skills coach and is now a youth mentor for ANHAN. Not bad for a young native man born in 1990.

Viola Gordon is currently in the position of Elder for the Resolution Health Support Program at the Network. She was married and worked with her late husband Pastor Winston Gordon for a number of years providing emotional and spiritual support to families. She received her Associate Ministries Diploma from Christian Bible School where she attended for 4 ½ years. She worked for Peyakowak, a family centered support program in the city of Regina for 18 ½ years as a family support worker. Viola is currently retired and volunteers as a board member on a number of organizations in the community.

Appendix B

AIDS Community Action Program
-Strengthening the Network, operational funding in amount of $125,000 for fiscal year 2010-2011. Contact person is Neena Saxena.

To assist in strengthening the network in Saskatchewan to address HIV/AIDS among the Aboriginal population. Provide education, support and prevention to those infected or affected by HIV/AIDS. Develop resources and tools to deal effectively with the epidemic. Be a voice for concerns surrounding the impact of HIV/AIDS among Aboriginal communities. Support Aboriginal people living with HIV/AIDS.

Saskatchewan Health
-Support of Aboriginal People living with AIDS and HIV, operational funding in the amount of $31,943 for fiscal year 2010-2011. Contact person is Susannah Fairburn. To meet the needs of Aboriginal people living with AIDS and HIV positive persons. To educate Aboriginal communities about HIV/AIDS and other blood-borne pathogens. To address issues in society, that may arise as a result of HIV/AIDS and other blood-borne pathogens.

Hepatitis C Program
-Incorporating Hepatitis C project funding in amount of $20,000 for fiscal year 2010-2011. Contact person Neena Saxena.

To build a strong foundation of the network to incorporate Hepatitis C in governing documents. To strengthen the network in work pertaining to Hepatitis C.

UMAYC – Heritage Canada
-“I almost know everything, but not yet!” Youth talking to Youth about HIV/AIDS, sex, drugs and ways of knowing better. Aboriginal Youth Joining the Circle. Project funding in the amount of $100,000 for fiscal year 2009- 2010. Contact person Doug Moran. Currently waiting this fiscal year approval.

Educate and train Aboriginal youth to be peer leaders in the community. Provide youth leaders with tools and resources that are acceptable with their peers. To train Aboriginal Youth in addressing current health and social issues that is impacting the generations of past and present.

Non-Reserve First Nations, Inuit, and Inuit Métis Communities HIV/AIDS Project Fund
-A Journey of Healing, Aboriginal people living with HIV/AIDS Joining the Circle project. Project funding in the amount of $100,000 for fiscal year 2009 – 2010. Contact person is Susan Parker. Currently waiting this fiscal year approval.

To increase organizational capacity-building for Aboriginal HIV/AIDS positive people to develop skills and knowledge to provide accurate culturally appropriate Aboriginal HIV/AIDS information among health and social service providers to Aboriginal community. To train life skill coaches to deal effectively with people at risk.

First Nations and Inuit Health, Saskatchewan Region
-Operational funding in the amount of $42,000 for fiscal year 2010-2011. Contact person is Brent Dow. Annual Aboriginal HIV/AIDS and HCV Conference and support for resources.

To increase knowledge of the epidemic within First Nations on-reserve communities by improving community-based knowledge development, improving analysis of surveillance data and improving translation of knowledge into practice.

Urban Aboriginal Strategy
- Amount: $85,000 for fiscal year 2010-2011. Urban Aboriginal Strategy. Contact person is Neil Hintz.

Zero Stage Housing Project, building support and capacity for Aboriginal people living with HIV/AIDS & HCV and the Aboriginal community.

Building that serves as a safe place for all people to go that need somewhere to sleep, eat, shower, get clean set of clothes, hang out and get help if needed. A come and go housing that is open 24 hours per day, no strings attached, people can come high or intoxicated, no involvement from systems or institutions. A place where people belong regardless of their status and many labels placed on them. We will not ask any identifying information, open to all people; men, women, youth, transgender and families.

A-Track Research Project
- Amount: $9,600 for fiscal year 2010-2011. Title: Pilot Site Assessment movement towards development of a second generation HIV surveillance system among Aboriginal people in Regina, SK

Research Team: All Nations Hope AIDS Network Inc., Regina Qu'Appelle Health Region and Public Health Agency of Canada, First Nations University of Canada.

Background: The project's goal is to assess the environment for a site-specific survey protocol and logistical requirements for developing a second generation HIV surveillance system among Aboriginal peoples in Regina. In 2006-09, the Public Health Agency of Canada worked with Aboriginal representative on development of a generic protocol and questionnaire for piloting and establishing a second generation HIV surveillance system among Aboriginal peoples in Canada. With the collective input of the A-Track Working Group members, a draft generic protocol and questionnaire have now been developed and Regina is the pilot site.

Community Initiatives Fund – City of Regina
- Amount: $25,000 for fiscal year 2010-2011. Title: Awakening the Spirit is a project that assists youth, children and families in the community to improve education, health and well being in a holistic manner. Aboriginal culture, tradition and teachings will be implemented by the grandmothers and grandfathers in the community.

2010 Urban Aboriginal Community Grant Program – City of Regina
- Amount: $9,600 for fiscal year 2010-2011. Title: Life Safe Play Safe is a project offering organized play in two gyms 3 times per week. Activities will help children and youth develop the ability to: manage stress, resist peer pressure, cope with stress and loss, communicate assertively, identify and challenge stigma, negotiate, cooperate with others and work in teams, make decisions and set goals, motivate and lead others.

Farm Credit Canada – RCC Regina Spirit Fund
- Amount: $10,000 in fiscal year 2009-2010. To provide funding for providing clients with a nutritious meal at two to three sessions per week.

CURRENT SERVICES AVAILABLE	
Workshops	HIV/AIDS Workshop Harm Reduction Workshop Hepatitis C Workshop Two Spirit Workshop
Training	Sharing the Knowledge - two day training on HIV/AIDS & HCV. Sisters in Spirit Training - three day training on a harm reduction approach dealing with Aboriginal women struggling with addictions. Circle of Knowledge Keepers - training for correctional inmates. Youth Leadership - five day training for youth. Two Spirit Training - two day training
Aboriginal Life Skill Sessions	Offered on a quarterly basis for groups: spring, summer, fall and winter. Offered throughout the year for individuals upon request.
Resolution Health Support Program	Provide eligible former residential students involved in claims with access to emotional health and wellness support services through the Indian Residential Schools Resolution Health Support Program in Regina and area.
Youth Program	Youth Camps, Live Safe Play Safe Gym Nights, Youth Joining the Circle, Youth Advisory Circle
Displays & Resources	Provides resources and displays for community groups upon request
Bi-Monthly Newsletter	Positive Journeys is available as an e-version and upon request will be mailed to members of ANHAN.
Website	Informative web site with the latest information and resources. Individuals can join the Face book group or blog on issues related to HIV/AIDS and HCV.
Life Chat Line	Available through ANHAN website from 9-5, Monday to Friday, excellent resource for connecting with people and having your questions answered.
Drop In/Outreach	Available from 10 am-4 pm, Monday to Friday, referrals accepted for Aboriginal people living with HIV/AIDS or at-risk population. RQHR Addiction nurse available Tuesdays, MASCI addiction counselor available Mondays, Eagle Moon Healers last Wednesday of each month.
Sharing Circles	Available on a weekly basis for drop in from community members.
AA Meetings	Healing Spirits AA meeting held every Tuesday at 3:oo pm.
Elders	Access to Elders on a weekly basis and upon request. Access to Traditional Ceremonies upon request.
Arts/Crafts	Sessions on Tuesdays at 1:00 pm. All are welcome and bring your art/craft to share with the community
Movie Time	Available on Fridays at 1:00 pm. All are welcome, bring a friend.

Appendix C

ANHAN Chief Executive Officer Contributions:

1) A major contribution to the HIV/AIDS movement in Canada has been the position of the Chief Executive Officer held by Margaret Akan of All Nations Hope AIDS Network since 1999. The network consists of Aboriginal people, organizations and Aboriginal people living with HIV/AIDS in Saskatchewan. She has been actively seeking funding to sustain the network to deliver services and programs to the Aboriginal population. She has also been involved in bringing current issues to the forefront of aboriginal groups involved with policy and decision making among the networks, both rural and urban areas. Finally, she has also been involved as an active partner in the Aboriginal Community based research opportunities that arise through Aboriginal academic institutions and researchers.

2) Epidemics in Our Communities are an annual provincial conference that she has been part of in the planning, implementation and evaluation. The conferences took place in 2003, and 2004, 2005, 2006, and a second one in 2006. The events has been an interest to those working with addictions (injection drug use, addicted babies, blood borne pathogens, methadone treatment, FASD, gambling) social issues, community research, youth, HIV and HCV infection. Target populations include anyone from a physician to a person living with a blood borne pathogen. It is certainly part of the network mandate.

3) The Regina and Area Drug Strategy Report was published in June 2003. Being involved with the community consultations, she was asked to be co-chair of several working groups that arose to deal with the implementation of the strategy. She has been co-chair of the Healing continuum working group and of the Harm Reduction working group. ANHAN continues to address these issues in our communities.

4) The Saskatchewan Advisory Committee on AIDS has been established in 1985 to address the need for HIV/AIDS education and provincial initiatives as well as to answer questions relating to HIV/AIDS. The committee reports directly to the Minister of Health through the Department of Health. The Minister of Health had appointed me to the committee from 2003 - 2007. She has been an Aboriginal voice for issues pertaining to HIV/AIDS and the Aboriginal community.

5) Completed a research project as a co-applicant of a Canadian Aboriginal AIDS Network research project entitled, “Promoting Cultural Awareness and Sensitivity in Addressing HIV/AIDS in Aboriginal Communities.” (2004)

6) Completed a research project as a co-investigator with the Canadian Aboriginal AIDS Network research project entitled, “Canadian Aboriginal Cultural Competence for HIV/AIDS Health Care Providers” (2009).

7) Completed a research project as a nominated principal applicant with All Nations Hope AIDS Network, A Gathering of Support (2009).

8) Appointed to the National Aboriginal Council on HIV/AIDS, First Nation Co-Chair since 2004 - current, and provide policy advice to the Minister of Health.

Activities and Contributions

1) Currently a Co-Investigator for Aboriginal-Track, Public Health Agency of Canada Surveillance study in Regina, SK.
2) Committee member and presenter at the 1st Canadian HIV/HBC/HCV Research Summit in Toronto Ontario Oct 30th –Nov 1, 2010.
3) Committee member and Keynote speaker at CAHR in Saskatoon, SK. May 2010.
4) Committee member and Speaker at the CATIE Regional Conference May 2010 in Saskatoon, SK.
5) Presentations as a guest speaker in Barcelona, Spain in 2008 19th International Harm Reduction Conference.
6) In 2006, a member of the project advisory team, the Canadian Aboriginal AIDS Network, Enhancing Dissemination – Journal.
7) In 2006, presented at the Indigenous Satellite for the 17th International Conference on the Reduction of Drug Related Harm.
8) Chairperson of the 3rd National Aboriginal Hepatitis C Conference hosted by All Nations Hope AIDS Network in Regina Saskatchewan 2005.
9) In 2004, I was requested to be on a peer review committee for the AIDS Community Action Program for the Manitoba/Saskatchewan region. The committee review proposals submitted for operational and project funding.
10) Presentations as a guest speaker in Vancouver, B.C. in 2004 at the BC Aboriginal HIV/AIDS Conference.
11) Presentations as a guest speaker in Richmond, B.C. in 2003 at the 2nd National Aboriginal Hepatitis C conference.
12) Presentations as a guest speaker in Banff, Alberta in 2003 at the 4th Annual Harm Reduction Conference.

Publications

1) Harm Reduction in Saskatchewan, A Resource Guide. (2001-2002), All Nations Hope AIDS Network
2) HIV/AIDS Aboriginal Women, Children and Families – a position statement (March 2004), Canadian Aboriginal AIDS Network
3) Strengthening Ties – Strengthening Communities, An Aboriginal Strategy on HIV/AIDS in Canada. (July 2003), Canadian Aboriginal AIDS Network.
4) Epidemics in Our Communities Final Report. (2003) (2004) (2005) (2006) All Nations Hope AIDS Network.
5) Best Practices Approach, the Integration of STI Prevention, and Education with HIV/AIDS and Addictions programs. (2004) Canadian Aboriginal AIDS Network.
6) Annual Aboriginal HIV/AIDS and HCV Conference final report. (2008) (2009)

All Nations Hope AIDS Network:

Research and Capacity Development

Margarita Sysing

KHS 872 – Population Health

Shanthi Johnson

August 12, 2011

Aboriginal people in Canada have experienced systematic colonization and domination (Levin & Herbert, 2004). Aboriginal people are consistently overrepresented in the HIV epidemic in Canada (Public Health Agency of Canada, 2004, as cited in Tang & Browne, 2008). In an effort to rebuild their communities, Aboriginal communities are empowering themselves as organized and educated peoples. There is a definite need for more research to be conducted on HIV and AIDS among Aboriginals (Majumdar, Chambers & Roberts, 2004). In response, Aboriginal organizations and leaders are faced with the challenge of trying to conduct their own research and to secure funding to gather reliable data in support of community-based research (CBR) initiatives. As Aboriginal communities are becoming more self-sufficient in directing the delivery of health services to their people, agencies are also requiring reliable research data on the health status in Aboriginal communities and evaluations of their health programs and methods of service delivery (Noojmowin Teg Health Centre, 2003). All Nations Hope AIDS Network (ANHAN) has proven that their agency is capable of holding funds from the Canadian Institute of Health Research (CIHR) funds, which makes it appropriate for ANHAN to also engage and deliver a research agenda. As a result, ANHAN has asked participants of CBR: A Summer Institute at the University of Regina to develop an action plan that will help them to advance their research agenda (Summer Institute, 2011). This paper will include a brief background on this Case Study, including a conceptual model that was devised by the participants assigned to this group. In addition, this paper will address research goals and objectives, partnerships, capacity building and knowledge translation, and major recommendations. Of these major recommendations, there will be a discussion on the construction of a local/regional Aboriginal ethics research board, ethics, and how the medicine wheel is involved in the process of carrying out CBR at ANHAN. It is evident that ANHAN can be a successful leader in CBR for other Aboriginal organizations aiming to develop and maintain research as a major component of their operations.

Background on Case Study

Aboriginal people in Canada have been disproportionately affected by HIV/AIDS. Health Canada (2001, as cited in Miller, Spittal, Wood, Chan, Schechter, Montaner & Hogg, 2006) states that Aboriginal people on average made up nearly a quarter of the newly diagnosed HIV infections in Canada. The number of Aboriginal HIV/AIDS cases in Canada is also rising (Majumdar et al., 2004). In addition, ‘race’ matters in addressing health care for Aboriginals, as it “intersects with other social categories including class, substance use, and history to organize inequitable access to health and health care for marginalized populations” (Tang & Browne, 2008, p. 109). In other words, the issue of ‘race’ comes into play when discussing health care and subsequent health research for Aboriginals, including the area of HIV/AIDS, as other social factors come into play, which also affect this population. As a result, Aboriginal organizations such as ANHAN have surfaced to help serve Aboriginal communities affected by HIV/AIDS. ANHAN is a network of Aboriginal organizations providing support and holistic services to individuals and families of First Nations, Métis and Inuit living with and affected by HIV/AIDS and Hepatitis C Virus (HCV). ANHAN is community-focused and implements Aboriginal approaches to stay connected with the community it serves. In addition, ANHAN provides professional training and awareness to service providers and the community. As an additional priority, CBR has also become a focus for ANHAN as it aims to become a leader in the area of Aboriginal health research (ANHAN, 2011).

The Chief Executive Officer (CEO) of ANHAN has the goal of applying for additional tri-council funding to improve the organization's efforts in the area of research. However, the CEO is concerned that as a Community-Based Organization (CBO), ANHAN will be challenged with proving again that they have the capacity to carry out tri-council funding. Last recent efforts to secure research funding was very time consuming and burdensome for ANHAN. The CEO of ANHAN aims to be a leader for other CBOs in Saskatchewan that would be able to provide guidance, training and support to similar Aboriginal CBOs in the province working in the area of Aboriginal HIV/AIDS health and research. This case study seeks recommendations to demonstrate that ANHAN should be eligible to hold tri-council funding that would allow ANHAN to become a leader in community-based research in Saskatchewan (Summer Institute, 2011).

Conceptual Model

A conceptual model or framework has been developed for the purposes of ANHAN and their research agenda. This conceptual model describes a circular framework involving key topics that were discussed in the Summer Institute, which include qualitative and quantitative research methods, information management, knowledge translation (policy makers and communities), and developing relationships and partnerships (collaboration and research ethics). For ANHAN to be effective in their research agenda, all of these concepts must work together and are interdependent, in order for CBR to be implemented and successful.

In the centre of this model, are the concepts of qualitative and quantitative research methods and information management. ANHAN's CBR would entail both qualitative and quantitative research methods that would incorporate information management. Qualitative research methods explore a deeper understanding and meaning of human experience, with the purpose of formulating theoretically rich observations (Rubin & Babbie, 2005). Quantitative research methods "emphasize precise, objective, and generalizable findings" (Rubin & Babbie, 2005, p. 754) which can be numerically measured and expressed. Qualitative and quantitative research methods are combined with information management, which stresses that information gathered during research should be protected both during the research project and after the project is completed. Information management ensures that research data is electronically and physically ensure, so that privacy, anonymity, and confidentiality are maintained (Martz & Jeffery, 2011).

Linked to qualitative and quantitative research methods and information management is knowledge translation at both levels of policy makers and communities. Knowledge translation (KT) allows researchers at ANHAN to communicate their findings to the larger community. By using communication tools such as social media, media, and publications, KT is an effective method of communicating the research results to academia, communities, and the general public (Opikokew, 2011).

Lastly, this circular conceptual model involves the concept of developing relationships and partnerships, which includes collaboration and research ethics. When working with partnerships in CBR, it is essential to recognize that all parties must work in collaboration as equal partners involved in all steps of the research process (DeSantis, 2011). ANHAN through their partnerships with academia and community members must therefore acknowledge all research participants as they go through the processes of CBR to research their research goals. The challenge of CBR is to create a balance, where all parties (academia and community) are ethically working together, and imbalances of power are diminished so that everyone has a voice in carrying through the research (DeSantis, 2011). To incorporate capacity building in CBR, a culturally appropriate ethical review must also take place (Reading, 2011).

Research Goals and Objectives

By following an example set out by Manitoulin Island, Ontario on culturally appropriate Aboriginal health research (Noojwomin Teg Health Centre, 2003) ANHAN can also set its own research goals and objectives that would be appropriate for their research agenda. The general guidelines set out by Noojwomin Teg Health Centre (2003) on Manitoulin Island, Ontario, on Aboriginal health research can also be applicable for ANHAN and their research agenda. The main idea is that the gathering of information on research guidelines and ethics should be based on local First Nations perspectives and culture, through the guidance of a traditional advisory group. This would ensure that research guidelines are developed that respect Aboriginal culture and values in consultation with Aboriginal people.

ANHAN's research would involve CBR for social action, meaning that the research carried through would advance and meet the social needs of the community and its people. ANHAN would involve the recognition of traditional, spiritual, and cultural Aboriginal values in CBR. The target audiences of ANHAN through CBR would reach Aboriginal communities in Saskatchewan, but also the larger academic and research world at the local, provincial, national, and international levels. The themes that ANHAN would cover in CBR would include individuals, family (e.g. inter-generations), community, support, barriers, and education. These general themes would consider the culture of people and their backgrounds; socioeconomic and behavioural factors (e.g. housing, transportation, access to services); factors affecting vulnerability; healthy lifestyle; and support from Elders, therapists, alternative therapists, healers, and counsellors. ANHAN in their CBR would also address HIV/AIDS and HCV care and treatment and support (both medical care or alternative treatments). Lastly, ANHAN would need to consider the role that infrastructure plays in CBR, which would refer to those things that support research (technology-computers, recordings, documentation and includes financial resources and human support such as elders) (ANHAN, 2011).

Partnerships

ANHAN has local, provincial, national, and international partners that would support them in their research agenda. Partnerships include all forms of partners such as operational, funding, political, formalized, and informal (ANHAN, 2011). Although a partnership at all of these levels is ideal, it is important to note that conflicts may arise due to differing ideologies and values. Therefore, it becomes a challenge in CBR to be able to establish healthy partnerships that would encourage common goals and objectives that everyone agrees upon (DeSantis, 2011).

Some of the partnerships that ANHAN has established include the following: local (Regina Qu'Appelle Health Authority, First Nations University of Canada); provincial (Meadow Lake Tribal Council, AIDS Saskatoon); and national (Canadian Aboriginal Aids Network, National Aboriginal Health Organization) (ANHAN, 2011).

Capacity Building and Knowledge Translation

Through capacity building and knowledge translation, ANHAN will be able to further advance their research agenda. Capacity building refers to increased knowledge, skills, abilities, and resources (financial, human, and material) leading to better results. In-house capacity means learning to do for yourself, especially in the areas of research and education. Knowledge translation is a key way to communicate and publicize research results, thus making funders and institutions satisfied (Opikokew, 2011). By setting organizational priorities and considering impacts (e.g. balance research activities with services, community level funding), ANHAN will improve clients' health through service enhancement. In addition, ANHAN should continue to engage Traditional Healers in capacity building and knowledge translation utilizing traditional teachings. ANHAN will receive its support for research from several venues, such as political leadership (e.g. advocacy, band/tribal councils), public engagement (e.g. community feast), and research infrastructure (e.g. databases).

Recommendations

ANHAN is responsible to assess the impact of adding research to their circle. As such, the following recommendations have been made to help ANHAN advance their research agenda: to conduct a needs assessment and organizational review; to determine research priorities regarding health and social determinants; to address intellectual property rights; to secure political support and educate leadership; to ensure the continued engagement of Elders; to maintain standards of research (e.g. integrity and address misconduct); and to create an ANHAN-led Aboriginal Research Ethics Board. A needs assessment will help to ask the community of its wants/needs. Furthermore, intellectual property rights can relate to protecting traditional/sacred knowledge from leaving the hands of the culture. Finally, enhanced engagement of elders means continued involvement in AHHAN activities, including research.

Local/Regional Aboriginal Ethics Research Board

Due to the high volume of research request that ANHAN receives and the fact that they have no formalized process in place to approve their research, the creation of an ANHAN ethical research board (AERB) is necessary. Through the model established through the AERB at Manitoulin Lake, Ontario (Noojwomin Teg Health Centre, 2011), ANHAN can also develop its own local/regional AERB. It is recommended that ANHAN first develop a local Aboriginal Ethics Board, and once this is established and running can expand to a regional AERB based on their research objectives.

There are several benefits to first developing a local AERB. This would ensure that local committee members would have a good understanding of the community's politics, culture, language, beliefs, and values. By having local community participants on the local AEB, this would allow for local input and would build capacity in the communities. As local community participants have a voice in conducting the research, communities can decide for themselves what type of research is needed and how it would benefit its people. This more collaborative approach to research makes it more helpful for academics to connect with the community people (Noojwomin Teg Health Centre, 2011).

Ethics

Ethics means to do research in a good way and to do no harm. ANHAN supports research that is beneficial to people, communities, and organizations. To achieve research standards and integrity, ANHAN will do good research that leads to good practice. ANHAN Principles in ethics collaboration takes into account Aboriginal perspectives, values, and beliefs. Research much be conducted within a historical context of Aboriginal experience, with respect for human dignity and well-being. In order for ANHAN's research efforts to be effective, relevant research (e.g. applied/interventions) must take precedence over curiosity research. ANHAN must use both Aboriginal ways of knowing and mainstream methodologies. Moreover, the OCAP ethical principles of Ownership, Control, Access, and Possession must be considered when ANHAN conducts its research (ANHAN, 2011).

The principles of Ownership, Control, Access, and Possession (OCAP) must be considered when ANHAN conducts its research agenda. OCAP is “self-determination applied to research” (NAHO, 2004, as cited in Martz & Bourassa, 2011, p. 24). OCAP principles ensure that Aboriginal people are consulted, especially when dealing with CBR. Because of the poor history of research conducted with First Nations and Métis communities, OCAP was formed to emphasize the priorities and concerns of Aboriginal peoples in research (NAHO, 2004, as cited in Martz & Bourassa., 2011). Ownership refers to the protection of knowledge and information. Control refers to the engagement of community partners’ lives and institutions in all aspects of the research process. Access suggests the right to manage and access collective community information. Possession involves stewardship of research findings (Reading, 2011).

Medicine Wheel

Inherent in Aboriginal traditions and practices is the use of the Medicine Wheel. The medicine wheel is a First Nations cultural symbol; however ANHAN would also respect Métis and Inuit ways of being. This example is adapted from the Manitoulin Guidelines for Ethical Aboriginal Research in Northern Ontario. This model is an example of how an AERB can operate within ANHAN and can be adapted by ANHAN for their research agenda. The project begins its journey from the Eastern to the Western Doorway, signifying the project or life from beginning to end. The East represents the birth of a research project which is shared with the community/organization. This research project is then referred to ANHAN Research Review Committee for Ethics Review. The research applicant either receives approval or receives recommendations for changes to enhance the project (Noojwomin Teg Health Centre, 2011). The West shows the completion of the Research Review process whether the proposal has been accepted or rejected. This process demonstrates that a research proposal has come full circle and that all parties involved are given the opportunity to evaluate the proposed project (Noojwomin Teg Health Centre, 2003).

Process

A more detailed review process of research proposals at the community level has been developed for Manitoulin Lake, Ontario (Noojwomin Teg Health Centre, 2003), which can also be adapted for the purposes of ANHAN and their research efforts. Proposals should be reviewed with a focus on two main areas: 1) Aboriginal ethics review; and 2) Research review.

Aboriginal Ethics Review

This process will determine if the proposed research is ethical. This would involve the ethics committee's review of the research proposal. The ethics review committee would act as a subcommittee of the health research review committee. The ethics committee would be composed of people who are specialized and trained in the area of research ethics. This subcommittee would be made up of a minimum of a chairperson and two to three additional members, each signing a confidentiality form. The ethics committee will conclude whether proposals are ethical from a First Nations perspective, by developing a standard score sheet to evaluate proposals (Noojwomin Teg Health Centre, 2003).

Research Review

This process will determine if the proposed research fits within the ANHAN local research agenda, and will also make suggestions for ensuring that the community is also benefiting from the proposed research. If a proposal has passed the Aboriginal ethics review process, it is further reviewed by the larger Research Review Committee. This committee will evaluate the proposal based on the topic and the relevance of research methods to the larger community (Noojwomin Teg Health Centre, 2003). ANHAN will develop a standard assessment form which will address "how well the proposal matches local research priorities and makes practical recommendations for improving the project to maximize community benefit" (Noojwomin Teg Health Centre, 2003, p. 12). The Research Review Committee then brings forth its recommendations back to ANHAN.

Creation of a Aboriginal Ethics Research Board

It is recommended that ANHAN create a policy/procedures manual for an AERB. These points are also suggested by the Manitoulin Lake, Ontario project (Noojwomin Teg Health Centre, 2003). The manual would outline tools and strategies aimed to help ANHAN make educated choices about developing and managing CBR. It is the hope that this manual would be a useful document for ANHAN, agencies, community-based researchers, and external health researchers in their goals to partake in meaningful research with First Nations, Métis, and Inuit organizations and communities.

This manual would include: 1) background information and history on why and how the document was developed; 2) a vision for Aboriginal CBR based on First Nations, Métis, and Inuit values and promoted by the established Research Review Committee; 3) ethical research guidelines for community-based health and social research in Aboriginal communities in Saskatchewan to confirm that research projects reflect local First Nations, Métis, and Inuit people and traditions, in addition to following high scientific standards; 4) guidelines for the review process of research proposals by partnering community agencies and bodies; and 5) use of a steering committee to lead the implementation of research projects (Noojwomin Teg Health Centre, 2003).

Conclusion

Aboriginal people experience a significantly great burden of HIV infection among adults in Canada (Marshall, Kerr, Livingstone, Li, Montaner & Wood, 2008). More than one in every one hundred Aboriginal persons fifteen years of age and older was living with HIV in 2001 (Hogg, Strathdee, Kerr, Wood & Remis, 2005). Often times, federal and state public health agencies use evidence-based interventions without taking into account efforts that will better fit the cultural and historical context of local communities (Duran, Harrison, Shurley, Foley, Morris, Davidson-Stroh, Iralu, Jiang & Andrasik, 2010). Strategies for engaging communities affected with HIV/AIDS must take into account the specific issues, barriers, and facilitating factors that communities face while simultaneously creating a safe space for diversity and capacity within these communities (Travers, Wilson, Flicker, Guta, Bereket, McKay, van der Meulen, Cleverly, Dickie, Globerman & Rourke, 2008). As a result, culturally appropriate and urgent action is needed to address the inequalities Aboriginals affected by HIV face, as this is a marginalized and vulnerable population in Canadian society (Marshall et al., 2008). A critical method towards improved health outcomes is a commitment to Aboriginal traditions of health and wellness (Duran et al., 2010). One way in which this can be achieved is through the efforts of action-oriented CBR, which values community engagement and needs of communities (Reading, 2011). ANHAN through their efforts in CBR has the potential of being a leader for other organizations in Saskatchewan seeking to do research in Aboriginal health. Their vision of securing additional tri-council funding to improve the organization's efforts in the area of research will enable them to carry through their research agenda in the area of Aboriginal HIV/AIDS research (Summer Institute, 2011). By establishing an Aboriginal Ethics Research Board and following the recommendations as outlined in this paper, ANHAN can achieve its goal of becoming a leader in Aboriginal HIV/AIDS research.

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Case Study #2

Lung Association of Saskatchewan: Effective and Culturally-Safe Knowledge Translation for First Nations and Metis Peoples' Respiratory Health

Facilitators:

Dr. Jo-Ann Episkenew and Jan Haffner

Lung Association of Saskatchewan:
Effective and Culturally-Safe Knowledge Translation
For First Nations and Métis Peoples' Respiratory Health
Case Study
Facilitators: Dr. Jo-Ann Episkenew and Jan Haffner

INTRODUCTION

The Saskatchewan Anti-Tuberculosis League was formed in 1911 to fight tuberculosis, a highly-contagious and deadly disease. Under its auspices Fort Qu'Appelle Sanatorium was opened in 1917 to provide rest and fresh air, but the rest cure was long and tedious, and few could afford to remain until they were healed. So in 1929, through the League's urging, Saskatchewan was the first province to make the care and treatment of tuberculosis free of charge.

Even as tuberculosis has been brought under control since 1911, it is still a significant health concern in the North, particularly in the First Nations and Métis population. There were 87 new cases of TB reported in Saskatchewan in 2008: 50 were in First Nations people and 16 were in Métis. In some northern Saskatchewan communities, TB rates are 60 to 100 times higher than the rest of the province.

Since 1911, other respiratory ailments have become increasingly troublesome: asthma, emphysema, COPD. The League added new projects and began to take new paths to deal with this broader area of respiratory disease. In 1987 the name of the organization was changed to the Saskatchewan Lung Association to reflect this broader concern for the respiratory health of the people of Saskatchewan. The caring atmosphere however, remained unchanged. Today, the Lung Association of Saskatchewan (LAS) is a member of the Canadian Lung Association partnership.

Education and research had always been important elements of the Anti-Tuberculosis League's activities. Today the dominant activities of the LAS are research into the causes and treatment of lung disease, and education of medical practitioners, the public, and those who suffer from respiratory diseases.

The LAS estimates that there are 193,000 smokers in Saskatchewan. Smoking is the number one preventable cause of lung disease. The groups at highest risk are First Nations and Métis people and people with mental health disorders. The LAS is currently working with the Saskatchewan Ministry of Health Tobacco Action initiative. The priority areas for the Lung Association are establishing a smoking cessation intervention at every contact with the health care system, engaging First Nations in tobacco control and cessation programs, and promoting smoking cessation for people with mental disorders and illnesses. The LAS provides smoking cessation services, smoking prevention programs in schools, information on tobacco hazards, and is currently developing a comprehensive smoking and smokeless tobacco resource package for use in Saskatchewan schools.

Chronic Obstructive Pulmonary Disease or COPD is the fourth leading cause of death in Canada. COPD is the fasted growing cause of death and will soon be number three. COPD kills more Canadian women than breast cancer. COPD is the leading cause of hospitalization of seniors. Even though there are an estimated 61,000 Saskatchewan people living with COPD, awareness is low. Many COPD patients do not have access to diagnostic tools and management programs that are the recognised clinical standard of care. A lung attack (which is a flare-up of COPD) is as deadly as a heart attack. The LAS provides patient support through the BreathWorks program and many on-line resources. Certified Respiratory Educators on staff provide expert consultations to COPD patients and their family members. COPD patient support groups and newsletters are also provided.

The LAS worked with the Health Quality Council of Saskatchewan on its collaborative on COPD to improve the quality of care for COPD patents in Saskatchewan. This included teaching family physicians and office staff to conduct and interpret spirometry. Spirometry is a breathing test which is used to diagnose COPD and to assess its severity, but less than half of COPD patients in Saskatchewan have had this test. The LAS worked with the Saskatoon Health Region to develop and implement COPD rehab programs and continues to provide group education sessions for the program. These programs are being expanded to other health regions in the province. A COPD Toolkit was developed to facilitate the establishment and enhancement of COPD rehab programs.

There are 96,000 Saskatchewan people living with asthma, including 35,000 children. Many asthma patients do not have access to diagnostic tools and management programs that are the recognised clinical standard of care. The LAS provides patient support and many on-line resources including the asthma handbook and the asthma in children handbook. Certified Respiratory Educators on staff provide expert consultations to asthma patients and their family members. The LAS worked with the Saskatoon Health Region to provide Certified Respiratory Educator consultations and spirometry for children in inner-city schools. These children have reduced access to health care and providing services in the school setting is beneficial.

The LAS has developed training courses for health care professionals to become Asthma and COPD educators. The RESPTrec program is managed across Canada from here in Saskatchewan where it was developed. This has become Canada’s leading respiratory training program both in terms of numbers who take the course and in how well RESPTrec grads score in national certification exams. A continuing education program is also provided to keep RESPTrec grads up-to-date. Currently, the LAS has trained over 200 asthma and/or COPD educators in Saskatchewan.

A recent survey indicates that 26% of adult Canadians are at high risk for sleep apnea. This implies that over 214,000 Saskatchewan people should be tested for sleep apnea. Saskatchewan does not currently have sufficient capacity to address this load. Waiting lists for overnight testing in a sleep lab are up to 2 years. Although untreated sleep apnea has very serious consequences, including an increased risk of death, awareness of sleep apnea remains low. With the increasing obesity epidemic there is a corresponding increase in sleep apnea.

The LAS provides patient support and many on-line resources including the sleep apnea handbook. A respiratory technologist on staff provides expert consultation to sleep apnea patients and their family members. Sleep apnea patient support groups and newsletters are also provided.

The LAS provides resource materials on TB. The Lung Association also develops the Canadian TB Standards in collaboration with the Public Health Agency of Canada.

The LAS provides extensive information on how lungs work and how to prevent lung disease. The LAS has on-line materials for school programs and conducts classroom visits to educate students about lung health. Community education and programming in the area of tobacco are conducted by the LAS's Lung Squad, a team of health experts specialized in tobacco cessation and education. The LAS is currently developing a new resource package for teachers.

MISSION, VISION, ROLE, AND VALUES

Our mission: To improve lung health, one breath at a time.

Our vision: Healthy lungs for everyone.

Our role: To improve respiratory health and the overall quality of life through programs, education, research, training, treatment, and prevention of lung disease.

To achieve our mission we shall:

- Enhance public awareness of the impact of respiratory diseases on the individual, family, community, and on the health delivery system;
- Advocate increased support for education, research, training programs and a healthier environment;
- Provide leadership in advocacy and programming;
- Promote and support research into all aspects of respiratory health and disease;
- Deliver effective evidence-based education materials, programs and services;
- Support ongoing professional education initiatives to ensure optimum numbers of trained professionals;
- Foster partnerships and collaborate with other organisations working towards lung health.

Our Values:

- We are an efficient, effective, professional organisation, known for our integrity, honesty and fiscal responsibility.
- We treat everyone with compassion, respect and dignity.

OVERVIEW AND ANALYSIS

According to the Canadian Institutes of Health Research report *Improving the Health of Canadians* (2004), life expectancy has risen for Aboriginal Peoples, but on this and on virtually every health status measure and for every health condition, the health of First Nations, Inuit and Métis is worse than that of the overall Canadian population. First Nations and Métis respiratory health is no exception. Many barriers exist within First Nations and Métis communities that reduce the availability, affordability, dissemination, and efficacy of effective management of chronic respiratory disease. Many First Nations and Métis people are disadvantaged compared to the total Canadian population in terms of health determinants such as income, education, and employment. Possessing lower status on these determinants correlates to higher rates of health risk behaviours and ultimately poorer health outcomes. Ill health, in turn, exacerbates or creates economic hardships. Missed income from illness, costs of medication, emergency visits, and repeated hospitalizations all impact the economic well-being of First Nations and Métis families. Also, many First Nations and Métis communities face poor access to health care and community supports due to inadequate transportation, and/or lack of facilities and health human resources.

The National Lung Health Framework (2008) describes how 15% of First Nations children and youth suffer from asthma. There is a slightly higher prevalence of asthma among First Nations adults than in the general adult population in Canada (10.6% compared with 7.8%). Most of the difference appears to accrue to First Nations 50 years and older. Chronic bronchitis would seem to be more common among First Nations youth than youth in the general population: 2.4% of First Nations youth have this condition compared with 1.4% of youths in general. Chronic bronchitis presents potentially serious long term health risks. 16.5% of First Nations youth with this condition are receiving treatment for it. Almost one half (48.5%) of First Nations in band housing reported mould or mildew in their home (nearly half of First Nations and Métis Peoples live in band housing). A lesser percentage (36.9%) of respondents in other types of accommodation reported mould or mildew. This further exacerbates the respiratory problems for these individuals.

Between 1995 and 2003, the hospitalisation rate for COPD was four times higher in Northern Saskatchewan, where the population is largely First Nations and Métis, compared to the province as a whole. In Northern Saskatchewan, women were more than seven times more likely to be hospitalised for COPD.

Because there is less available data, the National Lung Health Framework (2008) had difficulty identifying issues specific to the Métis population. In the available data, some respiratory illnesses also reported to afflict Métis more often than First Nations (and off -reserve First Nations and Métis more than on-reserve). Self-reported bronchitis revealed an interesting pattern: only 4% of on-reserve First Nations reported this condition. Métis adults also reported higher rates of asthma: 8% among Métis city residents, compared to 5-6% for Métis outside the city and off-reserve First Nations, and to just 3% on reserve.

A 2002 report from the Regina Qu'Appelle Health Region stated that "Aboriginal people within the former [Regina Health] District experienced much higher rates of hospitalization – 298% higher for respiratory diseases."

Issues of social exclusion and historical trauma are important factors to address when examining health disparities in the First Nations and Métis population. Social exclusion is most consistently defined as the general denial of individuals from participating in the activities normally expected of members of their society. It occurs whenever the environments where people grow up, live and work, and the institutions that govern them, systematically limit their opportunity to participate in society. Social exclusion coupled with historical trauma resulting from colonialism and traumatic colonial policies, such as residential schools, which combined has created the “perfect storm” for the health inequalities within First Nations and Métis communities. Any health programs need to consider this backdrop if they are to be effective for First Nations and Métis people. Information and services that are not culturally relevant and culturally safe can create barriers for those seeking resources to improve First Nations and Métis respiratory health and well-being.

Some of the work that LAS is currently doing specifically to improve First Nations and Métis respiratory is as follows:

Asthma management in inner-city schools. LAS provides a certified respiratory educator with a spirometer to visit St Mary’s School, Saskatoon every Wednesday morning. Working in cooperation with a pediatrician, children can be referred by a teacher or caregiver to the program. Spirometry is used both to diagnose and assess asthma and other breathing problems. Children who otherwise have minimal access to such health care are able to receive asthma treatment and education. LAS has also explored expanding this service into other venues such as events at the Central Urban Métis Federation Incorporated (CUMFI) in Saskatoon.

Training for health care workers. LAS has just completed a project in cooperation with At-Your-Side, a distance learning program for health care providers working with First Nations and Métis people. LAS re-developed a module for COPD management in efforts to improve access to practical, relevant and culturally appropriate information for First Nations and Métis communities. LAS in cooperation with a First Nation community developed video-clips and case scenarios related to lung disease which it plans to integrate into the RESPTrec program. LAS is exploring the possibility of providing a mentoring program to improve and enhance the respiratory care skills of health care providers currently working with First Nations and Métis people.

Research. In order to properly interpret lung function tests, the results must be compared to normal values from a representative healthy population. While normal values exist for mainstream Canadians, they do not exist for First Nations and Métis populations. LAS has supported and initiated research into acquiring the necessary data.

CASE PROBLEM

Through its affiliation with the Canadian Thoracic Society, the Lung Association has access both to evidence-based clinical guidelines for the treatment of lung diseases and to the experts who developed the guidelines. LAS has taken the next step of developing training programs (RESPTrec) based on this science to train health care professionals how to educate people with lung disease to better manage and control their lung disease. These guidelines and training programs, however, are designed with mainstream Canadians in mind and do not consider the specific history and health status of First Nations and Métis people. The programs use case studies and scenarios that are not always applicable to the challenges faced by First Nations and Métis people. The LAS needs to engage in research to address this gap in its services.

Examine the situation and prepare a plan of how you would approach the problem.

Appendix A

Board of Directors:
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Major Paper Assignment
August 12, 2011

Developing a Process for a Knowledge Translation Strategy

I. Introduction

There is a significant research opportunity in Saskatchewan to address health inequity[1] experienced by First Nations and Métis people in relation to respiratory health through the development of a knowledge translation (KT) strategy. In comparison to other population groups within Saskatchewan, First Nations and Métis people are experiencing increasing rates of respiratory disease and ailments such as asthma, emphysema, chronic obstructive pulmonary disease (COPD) and tuberculosis (Saskatoon Health Region, 2008). Awareness and education is vital to improving lung health among First Nations and Métis people within Saskatchewan. For any health program to be effective, the historical context must be addressed as history provides a powerful lens for understanding the origins of current health inequity and the manifestation of the colonial relationship that underpins Aboriginal policy within Canada (Alfred, 2009; Hackett, 2005).

The Lung Association of Saskatchewan (LAS) created an educational program to train health professionals to help people with lung disease better manage their lung health. However, the LAS has recognized a gap in their services and noted that their training programs do not address First Nations and Métis people within Saskatchewan. The objective of this paper is to establish a process for developing an effective knowledge translation strategy to support

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[1] Health inequity refers to unfair, avoidable and remediable differences in the health among populations and this differs from health inequality, which may refer to differences that are neither avoidable nor remediable (Labonte et al., 2009).

education and awareness of respiratory health among First Nations and Métis people within Saskatchewan. Moreover, this approach provides a fiscally sustainable model by developing a process for a knowledge translation strategy designed to correspond with grant applications.

II. Background

This paper builds on the Lung Association of Saskatchewan (LAS) Case Study work conducted at the Weaving the Tapestry: Community-Based Health Research Summer Institute held at the University of Regina from June 19-24, 2011. The LAS Case Study group met a total of eight times over the institute, with the first two meetings co-chaired by Jan Haffner from the Lung Association of Saskatchewan and Jo-Ann Episkenew from the Indigenous People's Health Research Centre (IPHRC). During the preliminary meetings with the group, the members' initial reactions were to try and develop a simple solution by providing a list of recommendations that highlighted different mediums and messages. However, once discussions progressed the group collectively realized that preliminary groundwork such as building partnerships, establishing a champion and conducting institutional critical reflection was necessary prior to the development of a knowledge translation strategy.

This paper aims to establish a process to develop a knowledge translation strategy to increase awareness and education of respiratory health among First Nations and Métis people. Moreover, this plan provides a potentially fiscally sustainable approach designed to correspond with grant application funding. This action plan is not all-encompassing but is intended to inform the work of the Lung Association of Saskatchewan and serve as an initial guide in developing a process for a KT strategy. However, it is important to note that the development of a comprehensive KT strategy will have to be created in close consultation and input from First Nations and Métis people within Saskatchewan.

This paper provides an effective knowledge translation strategy for the Lung Association of Saskatchewan through three separate research grant opportunities funded by the Canadian Institutes for Health Research (CIHR), these include: the Knowledge Synthesis Grant; the Planning Grant; and the Knowledge Translation Supplement Grant (CIHR, 2011). The aim of this approach is to have each grant build on the previous grant's findings. This process will take approximately three years to establish, as each grant will take one year to complete. This timeframe will allow for the development of partnerships and help to build trust over the long-term.

A potential challenge to this approach is that it is founded on research grants that may be unsuccessful and thereby may tarnish the character of the partnerships developed through this strategy. Another potential challenge is that community partner expectations may exceed the capacity of the research funding (Elias and O'Neal, 2006). However, if these funding grants are unsuccessful or become unavailable, this process is still significant as the framework required within each of these grant proposals provides a strong basis for establishing a plan of action. There are three main benefits in utilizing this funding grant approach. First, this approach has the possibility of being fiscally sustainable and can be used to build resources and capacity which is important for most community-based organizations (CBO). For example, funding sustained from research grants can help community organizations hire research staff, expand their work, and communicate their results to a larger audience. Moreover, since few monetary resources are required to write a grant, and with the helpful assistance of a partnering academic organization (such as the Indigenous Peoples' Health Research Centre or Saskatchewan Population Health and Evaluation Research Unit), this approach could be replicated by other community-based organizations. Second, funding applications often recognize the importance of integrated knowledge translation and collaboration with team members such as community leaders; for example, if there are no letters of support from the community partners, the application will often be rejected. Third, funding applications can help to ensure that roles and responsibilities of each team member have been defined and their roles are evidenced within the application (usually under the section on project feasibility and contributions) and by letters of support.

III. Establish the Foundation

Prior to the development of an action plan, key elements must be recognized in order to develop a foundation that will help to sustain and support the KT Strategy over the long term. We suggest that there are three foundational elements, which would include critical self reflection, establishing a champion, and developing partnerships. For example, by developing partnerships and working collaboratively with stakeholders from different sectors and backgrounds we are able to develop a more comprehensive and robust KT strategy than could be achieved by a single actor or organization. Although these three elements are not explicitly referred to under each grant, these components are essential and provide the foundation for the plan of action.

Critical self-reflection

Prior to developing partnerships or beginning to develop a process for a KT strategy, it is important to recognize our positionality as researchers (Hopkins, 2007; Jackson, 1993; McIntosh, 1989). Critically self-reflecting on our positions and power relations as researchers and more broadly as organizations such as the LAS, enables us to recognize the influence that our different identities can have in influencing our decisions, practices and outcomes (Jackson, 1993). A potential challenge with conducting critical self-reflection is that it may be difficult and uncomfortable for one to engage in internal critical reflection; however, this is a necessary step to foster openness and shared knowledge (Hopkins, 2007).

When conducting critical self-reflection, researchers and community- based organizations (CBOs) should consider questions related to the research objectives, research methods and why they are conducting the research in this manner (Pain and Francis, 2003). There have been issues related to different knowledge paradigms and beliefs about what counts as ‘true’ or scientific knowledge (Israel et al., 1998). Accordingly, it is important for researchers to recognize that there are different types of knowledge and multiple ways of knowing (Adams et al., 2004; Guba & Lincoln, 1994). We suggest that the LAS should conduct critical self-reflection prior to developing partnerships, establishing a champion, or engaging in the development of a KT strategy. Critical self-reflection will allow the LAS to develop a more comprehensive understanding of potential challenges that may exist within their own institution and that may hinder their development towards increasing awareness of respiratory health among First Nations and Métis people. For example, self-reflection within the LAS could begin by examining the organization’s mission statement, hiring strategy and whether it promotes a diverse work force that supports Aboriginal employment.

Establishing a champion

Establishing a champion dedicated to the cause can play a vital role in developing partnerships, engaging community members and spreading awareness about health issues such as respiratory health. Scheirer (2005) found that having a champion with strong leadership skills increased the likelihood of an initiative’s success and sustainability. Scheirer (2005:339) also suggests that a champion not only provides communication support and advocates for the project but can also help to secure resources for program continuation. Accordingly, we propose that the

LAS consider employing or contracting a champion who would be able to perform the communication duties of a knowledge exchange officer. Establishing a champion of First Nations or Métis origin could provide a key role in helping to develop culturally informed initiatives; however, it is important to note that Aboriginal peoples' culture and historical backgrounds are diverse (Hunter et al., 2006).

A potential challenge to establishing a champion is that it may be difficult to locate a person who has a strong interest in respiratory health; however, this knowledge and interest can be fostered through different initiatives such as photo contests, scholarships, essay competitions and art awards. Laverack (2001) suggests that community champions and partners can include anyone who has a positive reputation in the community such as elders and youth role models. Some suggestions of potential champions for the LAS include Leah Dorion and Alika Lafontaine. Leah Dorion is a Métis author, curriculum developer, lecturer, researcher, and artist who won a competition for her painting entitled "Sacred Breath" (LAS, 2010). Alika Lafontaine is a Métis physician and motivational speaker who was raised with strong connections to his Aboriginal roots (Aboriginal Human Resource Council, 2009). Moreover, these champions could play an essential role in communicating awareness and developing partnerships between LAS and First Nations and Métis communities.

Developing partnerships

In order to develop an effective KT strategy to increase awareness and education on respiratory health among First Nations and Métis people, this plan must be developed in close collaboration with both Aboriginal and non-Aboriginal community leaders, activists, scholars, health care professionals (nurses, social workers, family physicians), elders and relevant organizations such as the Indigenous Peoples Health Research Centres, Métis Nation –

Saskatchewan, Saskatoon Tribal Council, Federation of Saskatchewan Indian Nations, Indigenous Peoples' Health Research Centre, First Nations and Inuit Health Branch (FNIHB), File Hills Qu'Appelle Tribal Council. Developing partnerships and collaborating with diverse stakeholders, will help to ensure integrated knowledge translation[2] and provide insight into the development of a culturally informed knowledge translation strategy.

Potential challenges related to developing partnerships include mistrust, limited timeframes, insufficient funding, and change in leadership within community-based organizations, government and research units. For example, the issue of mistrust of researchers is especially problematic for communities who have been 'over-researched' or exploited by the research findings (Adams, 2004). It is important that partnerships establish trust and co-production of knowledge where the community partners will feel ownership of the research which builds bridges over significant obstacles such as translating research findings into action (Adams et al., 2004; CIHR, 2007; Christopher et al., 2008).

When developing partnerships with Aboriginal people the issue of mistrust is further augmented by the impact of Canada's historical colonial injustices and oppression towards Aboriginal people (Alfred, 2009). Accordingly, when creating partnerships with Aboriginal people it is important to follow and respect the principles of *OCAP: Ownership, Control, Access and Possession* (First Nations Centre, 2007), the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (CIHR et al., 2010) and the *CIHR Guidelines for Health Research Involving Aboriginal People* (CIHR, 2007**.** Following these principles will help to ensure that the partnership proceeds in a way that is culturally informed, respectful and equitable (CIHR et al., 2010).

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[2] Integrated KT refers to conducting research with researchers and knowledge users working together throughout the entire research process- starting with collaboration on the research questions, the methodology, involvement in data collection, data analysis and dissemination of research findings (CIHR, 2010).

IV. Plan of Action

Following the establishment of the research foundation, based on the elements of critical self-reflection, establishing a champion and developing partnerships, the plan of action is designed to correspond with research grant funding opportunities (please refer to Appendix A, page 15). Moreover, it should be recognized that these elements such as developing partnerships are continuous and ongoing throughout all stages of the plan of action process. This section outlines specific activities that provide a process for developing an effective knowledge translation strategy.

Stage 1: CIHR Knowledge Synthesis Grant (Year 1)

The initial aim of the CIHR Knowledge Synthesis Grant is to facilitate the development of partnerships and stakeholder consultations to help foster knowledge translation and the development of a research team consisting of Aboriginal and non-Aboriginal researchers, health practitioners, elders and community leaders. In order to accomplish this aim, an integrated KT approach is necessary as it will promote collaboration from the onset of the project with knowledge users and collaborators who are actively engaged in helping to shape the design of the synthesis and the pilot project. It is anticipated that the partnerships developed in the Knowledge Synthesis Grant (Stage 1) will evolve and continue over the different stages of the action plan. The Knowledge Synthesis Grant focuses on achieving three objectives:

1. To conduct an environmental scan (and work in collaboration with the community partners throughout the research process) to identify the best practices for knowledge translation methods to increase awareness of respiratory health among First Nations and Métis people

2. To identify best practices for engaging and training health practitioners and community leaders in sharing lung health messages
3. To establish an incidence map of lung disease among Aboriginal and First Nations Peoples within the province of Saskatchewan

A place to begin the environmental scan is to review successful KT methods identified by other health organizations such as the Public Health Agency of Canada (2005). The Asthma Association of Canada also provides a good example of a review exploring the different communication initiatives to increase awareness among First Nations, Métis and Inuit people (Asthma Association of Canada, 2010).

The parameters developed for the environmental scan will need to be made in consultation with the community partners in order to ensure that the synthesis objectives are representative of both the LAS and the First Nations and Métis partners. The community partners will also have a vital role in helping to identify and locate relevant informational sources such as community documents, elders, newspapers, oral histories, winter counts, key contacts or policy documents. The parameters of the environmental scan should identify specific communication challenges and opportunities in working within different contexts of place (urban, remote and rural) at the population level. The importance of different communication styles, mediums, language and terminology should also be explored.

The second objective of the Synthesis Grant is to identify best practices for engaging and training health practitioners and community leaders in sharing lung health messages. It is important to engage health professionals and community leaders as both collaborators and knowledge users in the research process to help to inform the parameters and objectives of the research synthesis. In addition, support from health practitioners and community leaders will play a key role in uptake and provide guidance in the development of the KT strategy.

The third objective is to establish an incidence map of lung disease among First Nations and Métis within Saskatchewan. An incidence map will help to locate the communities with the highest incidence of poor lung health which would help to tailor the knowledge translation methods to the specific communities. If no existing incidence maps of lung health can be located, maps could be created based on existing statistics on First Nations and Métis health. Some potential places to look for Métis statistical data include the Aboriginal Peoples Survey and the Métis Centre. For example, in 2006 the Aboriginal Peoples Survey (Statistics Canada, 2006) incorporated a Métis supplement into this survey (Métis Centre, 2010). The Métis Centre a population-specific centre located within the National Aboriginal Health Organization (NAHO) has been working to develop analysis of Métis specific data (Métis Centre, 2010). However, since it is well documented that few health statistics exist for Métis people within Canada (Krieg & Martz, 2008), lung health statistics among Métis could be identified as a significant knowledge gap that needs to be addressed in future research.

Stage 2: Planning Grant (Year 2)

The primary aim of the Planning Grant is to pilot test the best KT methods identified in the Knowledge Synthesis Grant (Stage 1). The Planning Grant will address the following three objectives:

1. To support the development of new and existing partnerships among Aboriginal and non-Aboriginal community leaders, activists, scholars, health care professionals (nurses, social workers, family physicians), elders and organizations such as the Indigenous

Peoples Health Research Centres, Métis Nation – Saskatchewan, and the Federation of Saskatchewan Indian Nations.

2. To develop, implement, and test the most effective KT methods identified from the Synthesis Grant (Stage 1) to increase awareness and education of respiratory health among First Nations and Métis people.
3. To pilot test the proposed KT methods within two different communities to explore the impact of the context of place (urban, rural or remote) at the population level.

This Planning Grant will work to renew and sustain existing partnerships from the Synthesis Grant, as well as develop and build new partnerships. The development and implementation of the pilot study will be based on the guidance and input from the community partners in combination with the best KT methods identified from the Synthesis Grant. Ideally, the pilot study would be conducted within two communities to test the proposed KT methods within different locations of place (such as rural, urban and remote) and population groups (First Nations and Métis). It is anticipated that the communities used in the pilot study would be identified by the incidence maps from the Synthesis Grant; however, community input and support will also play an important role in determining the location of the pilot study.

Stage 3: Knowledge Translation Supplement (Year 3)

The primary objective of the Knowledge Translation Supplement Grant is to develop a KT strategy that incorporates the best practices identified in the Knowledge Synthesis Grant (Stage 1) and the findings from the pilot study in the Planning Grant (Stage 2) to provide a model for a KT strategy that could be replicated and used within different contexts (urban, rural, remote) and communities (First Nations, Métis).

The three main objectives of the Knowledge Translation Supplement Grant are to:

1. To form a LAS Knowledge Translation Advisory Committee to guide the development of a LAS KT strategy
2. Develop a KT strategy that incorporates the best practices identified in the Knowledge Synthesis Grant (Stage 1) and the findings from the pilot study in the Planning Grant (Stage 2) to provide a model for a KT strategy that could be replicated within different communities
3. To evaluate the proposed KT strategy and associated KT activities

The development of an LAS KT Advisory Committee would help to provide advice and overall guidance in the development of the KT Strategy. The development of the Advisory Committee would enable more partners to become involved in the strategy who may not have enough time to commit as a full team member. The committee would meet with the full team, approximately once every three to four months to first confirm the KT strategy and then to oversee the development of the knowledge translation strategy and assist with the evaluation.

The development and implementation of the KT strategy will be informed by the research findings uncovered by the Knowledge Synthesis (Stage 1) and the Planning Grant (Stage 2). Moreover, the Advisory committee will have a key role in modifying the initial findings from the previous to grants to develop the proposed KT Strategy.

The evaluation plan for our KT strategy will be developed in consultation with the full team and Advisory Committee. A proposed strategy for evaluation incorporates two methods that will assess 1) the dissemination of the KT strategy and 2) the quality of the KT materials and activities. Evaluating the dissemination of the KT strategy can be conducted by documenting the distribution of the KT materials (Danseco et al., 2009). The quality of the KT materials and activities can be evaluated through the usage of focus groups, paper evaluations (Tetroe, 2007).

The community partners will play a key role in providing suggestions to help ensure that the methods of evaluation are well suited to the community.

V. Conclusion

Throughout this paper, I have argued that an effective process for developing a KT strategy to increase awareness of respiratory health among First Nations and Métis people can be established through developing a solid foundation and an action plan based in research grant funding opportunities. Not only does this approach provide a process for developing a KT strategy but it also provides a fiscally sustainable model that is designed to correspond with grant applications. Further, by developing a solid foundation based on critical self-reflection, establishing a champion, and developing partnerships, this plan of action will have support and sustainability over the long-term.

In order to develop an effective KT strategy it is essential for community level input and involvement from First Nations and Métis people. An effective LAS KT strategy needs to acknowledge Canada's history of colonial injustice as well as respect First Nations and Métis' diverse culture. Accordingly, integrated KT should be used to promote collaboration from the onset of the project as this will help to foster trust and ownership of the KT strategy.

This paper is intended to help inform and provide initial guidance to the Lung Association of Saskatchewan as it moves forward in the development of a comprehensive knowledge translation strategy to increase awareness and education of respiratory health among First Nations and Métis people. It outlines specific activities that will help to provide a process for developing an effective knowledge translation strategy. Moreover, by building on the findings from each of the research grants, the ultimate goal of this approach is to develop a knowledge translation strategy that can be replicated and used within different communities (First Nations and Métis) and locations of place (rural, urban and remote).

Appendix A: Process for KT Strategy Work Plan

Process for KT Strategy Work Plan	Current Funding Available	Actions	Timeline	Additional Information
A) Building the Foundation				
Critical Self-Reflection		-Conduct critical-self reflection of different roles and identities -Consider issues related to power, voice and context - Ask questions related to the research objectives, research methods and research process (i.e. who is benefitting from the research?) -Need to recognize different types of knowledge and multiple ways of knowing	Continual and Ongoing	-When conducting self-reflection and exploring 'positionality', a good resource to draw on is the McIntosh (1989) article.
Establishing a Champion		- Establish a champion or a passionate leader dedicated to the cause -Identify potential champions or help foster potential champions through: scholarships, art awards, essay competitions, photo contests,	Continual and Ongoing	-Potential champions include: Leah Dorion and Alika Lafontaine
Developing Partnerships		i) Begin partnership process by: -Face to face meetings - Telephone conversations -Invitations to lunch and learn sessions - Attending community events -Contacting community organizations -Identifying a common goal or objective -Mutual or existing contacts with organization -Work with organizations such as IPHRC or SPHERU to help establish contacts	Continual and Ongoing	-Potential partners include: Aboriginal and non-Aboriginal community leaders, activists, scholars, health care professionals (nurses, social workers, family physicians), elders and relevant organizations such as the Indigenous Peoples Health Research Centres, Métis Nation – Saskatchewan, Saskatoon Tribal Council, Federation of Saskatchewan Indian Nations, Indigenous Peoples' Health Research Centre, First Nations and Inuit Health Branch (FNIHB), File Hills Qu'Appelle Tribal Council

		ii) Develop and maintain partnerships through: -Continual communication through newsletters, emails, phone calls, group meetings. -A memorandum of agreement to negotiate each team member's roles and responsibilities -Discuss and negotiate concerns related to information management and ownership of data -Discuss ethical issues such as community consent, confidentiality, power, and voice.		-When developing partnerships, introductions that share your multiple roles, identities and background are important to helping establish trust; one should avoid brief phone conversations disclosing little information about oneself.
B) Plan of Action Stages				
Stage 1: CIHR Knowledge Synthesis Grant	$100,000			
		-Team meeting to initiate project - Negotiate roles and responsibilities of team members -Collaboratively develop synthesis questions and research process -Identify initial data sources to search for relevant information	Year 1, Month 1	
		-Develop parameters of synthesis -Collect relevant data for Objectives 1 & 2	Year 1, Month 2-3	
		-Collect relevant data for Objective 3	Year 1, Month 4	
		-Team meeting to review progress and discuss initial findings -Complete a draft summary of findings for objectives 1, 2 & 3	Year 1, Month 5-8	
		-Team meeting to review initial summary of findings	Year 1, Month 9	
		-Complete revisions to summary of findings -Develop KT materials for communication and knowledge exchange -Team meeting to review KT materials and provide direction on dissemination -Discuss synthesis findings and begin to reflect on research questions for the stage 2 research proposal	Year 1, Month 10-12	

Stage 2: CIHR Planning Grant	$ 25,000			
		-Team meeting to initiate project and review findings from synthesis on best KT methods identified to test in a pilot study in two different communities (urban, rural, remote, First Nations or Métis) - Negotiate roles and responsibilities of team members -Collaboratively determine the research process to pilot test the most effective KT methods identified in the synthesis -Collectively determine the proposed location(s) for pilot project	Year 2, Month 1	-Collectively determine the proposed location(s) for pilot project. Ideally, it would work well if the pilot communities were also identified from the incidence map data from Synthesis Grant. However, community partners and local support for the project will also play a role in determining the communities of the pilot study.
		-Conduct pilot study depending on KT methods identified from the Synthesis and also collaboratively determined by group	Year 2, Month 2-5	
		-Team meeting to discuss preliminary findings and approach to data analysis - Complete data analysis and begin draft of data findings	Year 2, Month 6-7	
		-Team meeting to review initial findings on the pilot study of the KT methods used within the different communities	Year 2, Month 8-9	
		-Team meeting to develop materials for KT dissemination -Review pilot findings and begin to conceptualize objectives for stage 3	Year 2, Month 10-12	
Stage 3: CIHR Knowledge Supplement Grant	$ 100,000			
		-Team Meeting to establish KT Advisory Committee -Initial Advisory Committee meeting with full team to review findings from synthesis pilot study and begin to develop KT strategy and specific activities -Determine roles and responsibilities of team members	Year 3, Month 1	
		-Advisory and full team meeting to determine KT Strategy based on findings from pilot study in combination with the guidance and input provided by the Advisory committee	Year 3, Month 2-4	

		-Work with Advisory committee to modify the KT Strategy to provide a model that can be used within other First Nations and Métis communities. Develop evaluation plan to assess KT strategy and associated materials -Develop work plan		
		- Perform KT strategy and activities	Year 3, Month 5-9	
		-Advisory meeting to discuss findings from KT strategy and activities -Conduct evaluation of KT strategy and activities - Compile evaluation data and prepare report summarizing outcomes -Provide necessary modifications identified in the evaluation to improve the KT strategy model for replication within other First Nations and Métis communities.	Year 3, Month 10-12	

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Case Study #3

Play It Safer Network

Facilitators:

Dr. JoLee Blackbear and Carrie Pockett

Community-Based Research-Summer Institute
Play It Safer Network

Facilitators: Dr. JoLee Blackbear and Carrie Pockett

History

Started in 1992 as the NOR-MAN AIDS Working Group, the Play It Safer Network is a community based network in northern Manitoba and southeastern Saskatchewan covering a geographical area of over 72,000 km. Our goal is to put into service a community based approach to address Human Immunodeficiency Virus (HIV) /Acquired Immune Deficiency Syndrome (AIDS), Sexually Transmitted Infections, (STIs) Hepatitis C, and healthier lifestyle choices through education, prevention, treatment, and medical and social supports

The Network welcomes anyone who lives in northern Manitoba/Saskatchewan (NorMan/NorSask) and is living with, affected by, or has an interest in issues related to HIV/AIDS, STIs, and Hepatitis C. The Network strives to have broad representation from all communities and sectors. Currently, the PISN consists of more than 40 members including health care professionals, service providers, and community members within the region.

Living in a rural area with limited support, the opportunities for partnerships are paramount. Network goals are made possible through partnerships and support of existing STBBI prevention organizations, the dedication of the community-based volunteers and the in-kind contributions of the Regional Health Authority. The Network has made huge advancements within the community through our ability to reach our target populations, create community awareness, reduce barriers to accessing service through outreach campaigns, and to research and evaluate programming of both the Network and the project.

Organizational Structure

The Network consists of one paid project coordinator to complete specific project work plans, and a management team consisting of community members- chair, secretary, treasurer, finance, liaison representative with funders. The Network consisting of community stakeholders meets once a month via teleconference with Flin Flon, The Pas, and Cranberry Portage. There are also outlying community representatives within NorMan/NorSask. To allow flexibility in the commitment to the PISN, we have three types of membership:

1) Full Membership - includes individuals/organizations who commit a minimum amount of time to the Network. This would include attendance at meetings and participation in some other type of activity related to the Network.

2) Members at large - includes individuals who do not participate on a regular basis, but continue to receive information from the Network. Minutes from the meetings and special announcements are sent to members at large to keep them informed as to the activities of the Network, allowing them to participate on an “as needed” or relevant basis.

3) Project Partners – Theses are individuals/organizations who participate on specific projects only, such as Building Community Around Hepatitis C and Play It Safer Phase II.

Target Populations

The target populations of the Play It Safer Network include:

- Community Stakeholders including health care professionals, service providers, and community members
- Youth aged 15-24
- Persons living with or affected by HIV/AIDS or Hepatitis C

Strategic Priorities

There are eight strategic priorities of the Play It Safer Network. Annually the committee decides on two priorities to highlight for the year.

1. To secure funding dedicated to HIV/AIDS, Hepatitis C, STIs, and Healthier Lifestyle Choices
2. Develop a Public Awareness Strategy for HIV/AIDS, Hepatitis C, STI, and Healthier Lifestyle Choices information & services
3. Facilitate HIV/AIDS, Hepatitis C, STI, and Healthier Lifestyle Choices education programs
4. To consult with and develop partnerships among community stakeholders. A stakeholder may include anyone who is infected or affected by HIV/AIDS Hepatitis C and/or STIs. This includes agencies and organizations that provide community services.
5. To increase community (s) ability to address the issues of HIV/AIDS, Hepatitis C, STIs, and Healthier Lifestyle Choices by using an approach that includes all stakeholders in the community.
6. To participate in Provincial and National HIV/AIDS, Hepatitis C, and Risk Reduction based organizations
7. To recruit and maintain members who are actively involved in the Network, from different communities in NorMan/NorSask by creating a supportive environment
8. To advocate on behalf of or encourage others to advocate individually and systemically

Sources of Funding

The Network has successfully received annual funding by Public Health Agency of Canada under the AIDS Community Action Program since 1999. Funding has also been successful through the Manitoba government for time specific projects and the development and distribution of resources.

Partnerships with specific programs allow additional opportunities for building capacity and strengthening partnerships within the Network. Financial contributions have provided access to some opportunities we may have otherwise had to decline. Without the contributions of these programs, we would have had to overlook some incredible opportunities. Some of the external organizations we have partnered with include:

Teen Talk North
595 Prevention Team (formally known as the Manitoba Harm reduction Network)
CATIE (Canadian AIDS Treatment Information Exchange)
Prairie HIV Community Based Research Program
Manitoba PHA (Persons living with HIV) Caucus

The contributions offered through these programs are invaluable and has allowed effective program/project delivery to the NorMan/NorSask region.

How do we use community-based research?

Through successful federal and provincial funding, the Network has been able to participate in a variety of community-based research projects.

1999 – Building community around Hepatitis C project

- To form partnerships with groups and organizations with similar goals, such as schools, youth centres, correctional institutions and Red Prairie AIDS Project, to improve the promotion of Hepatitis C awareness and prevention.
- Research was conducted through…
  - A needs assessment and research inventory specific to Hepatitis C at schools, youth centres, and service provider locations
  - Pre and post test including an educational presentation for staff and students/youth to determine the knowledge levels of Hepatitis C in schools, youth centres, and correctional institutions and service provider locations

2001 – Hepatitis awareness community partnerships

- Community Youth Resource Centre (Youth Centre) for the development of a community drama production based on Hepatitis C education-created by youth
- Community members-development of Hepatitis awareness campaign materials-display boards and pamphlet
- Research was conducted through…
  - Research on the Hepatitis virus, facilitator feedback forms and meeting/practice session statistics, a evaluation following the drama performance and distribution of related information and resources

2006 – Knowledge, attitude, and behavior (KAB) survey

- Determine the issues affecting youth and their sexual health in the region
- Research was conducted through…
  - Survey distributed throughout region (schools, youth centres, post-secondary institutions) for youth aged 15-24
  - Data analysis of survey results-seven themes emerged
  - Focus Groups to verify the collected information, identify key messages, slogans, and delivery strategies based on the themes that emerged from the survey

2007 – Graphic Novel Project

- Partnership with high school students to develop a by-youth-for-youth graphic novel
- Research was conducted through…
  - Development of a graphic novel as a delivery strategy of sexual health information-based on the focus groups performed for KAB survey
  - Photo contest to include community pictures in the background
  - Distribution database of graphic novels including promotions, on-line surveys for service providers, and informal five question surveys for youth to measure effectiveness of information and accessibility

2008 – Development of ÙnWANTED Resources

- Development of large community based posters based on characters from the novel, locker posters based on themes from the novel, on-line animation and availability of the graphic novel on the Play It Safer Network website, 12 month calendars, magnetic trading cards, and mouse pads.

- Research was conducted through...
    - The themes and slogans previously identified through the focus groups allowed the development of the resources
    - Resource distribution databases allow tracking record of distribution

2008 – Identify the social support needs of people living with or affected by HIV/AIDS and/or Hepatitis C

- To address the social support needs of people living with or affect by HIV/AIDS and/or Hepatitis C who live in the NorMan/NorSask region
- Research was conducted through...
    - 1:1 interviews with individuals to determine the social supports needed when given a positive diagnosis including housing, employment income assistance, medical and social supports, income and education
    - Researched and developed a list of social supports available locally, regionally, and provincially

2009 – Safer Sex Kit Evaluation

- To measure the effectiveness of the community distribution of safer sex kits1 including service provider locations, and local bars and lounges
- Research was conducted through...
    - Outreach project to perform surveys and 1:1 interviews with the target populations in their locations, during the time of preference
    - Recommendations/changes made to program delivery strategies

1 A *Safer Sex Kit* is a 3x5 inch brown envelop with condoms, lubricant, community resources and 1-800 help line information, directions on how to apply a condom/use a dental dam, and a contact number for access to testing. These kits are distributed by the PISN to schools, youth centres, post-secondary institutions, service provider locations, and bars/lounges with NorMan/NorSask

2010 – Development & Delivery of UnWANTED Drama Production

- Partnership with high school for the development of Drama Production based on the UnWANTED project, characters, and themes
- Research conducted through...
    - Youth developed script based on the characters and themes from the developed graphic novel and past research
    - Facilitator feedback forms used at each session for a period of over nine months
    - 1:1 interviews following the production with the youth involved in all aspects of the project-script development, filming process

Note: Resources developed from the UnWANTED project are available through the CATIE (Canadian AIDS Treatment Information Exchange) website at www.catie.ca

Community-Based Health Research Summer Institute
Case Study

Project title:

What's hot and what's not...?
Ensuring the community input and investment of a
community-based organization

Research Topic:

Although we have qualitative data and evaluate all projects we do to determine success, we have never considered the "impact" of the Play It Safer Network. The ability to determine the effectiveness of our projects, awareness campaigns, access to resources, delivery strategies, and if we are reaching our target populations would help to strengthen the Network as a community-based organization. Through the collection of community feedback we will be able to improve programs in the future that are successful at reaching our priority populations and include the delivery of effective programming.

Project Objectives:

- To determine the extent communities receiving our services are invested in the PISN and if so, how are they invested?
- To verify that our target populations (youth, service providers, community) have input into the Network
- To determine the effectiveness and impact of community projects and program delivery
- To determine if we are reaching current priority areas and populations
- To determine alternative sources of information and resources where key populations in need access information or resources
- To identify how can we improve our services in the future

Through this research project, we hope to identify a useful tool that can assist in determining the community investment of the PISN, has our past work had any impact on the communities we serve, and concrete evidence that shows how we are a community-based organization.

Carrie Pockett
Project Coordinator
Play It Safer Network

A Community-Based Research Strategy for the Play it Safer Network

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University of Regina

August 2011

Introduction

Community-based research (CBR) is increasingly becoming a prevalent way of educating the public about health. CBR is an effective approach to creating knowledge integrated with an action plan to meet community needs for health research and community education (Israel, Schulz, Parker, & Becker, 1998). CBR can also provide an effective change in methodology for researchers who find their work is unapplied or underappreciated. By doing research with actively involved community members at all stages of the project, the process of doing research is shared. One of the strengths of CBR is that it is open to many sources of knowledge and ways of understanding. Reid, Brief, & LeDrew (2009) refer to CBR as a process of democratizing knowledge. Instead of knowledge coming from only experts in the field, CBR uses community and individual sources of knowledge as equal contributions to a research endeavor.

During the week of June 19-24, 2011 the project coordinator from the Play it Safer Network came to the Summer Institute for Community Based Health Research at the University of Regina. As a case study group for this institute, the Play it Safer Network's objective was to develop an impact evaluation of their programs and services. However, after discussing the evidence that had previously been gathered by the Network it became apparent that an impact evaluation was not needed. The Network already had a number of pieces of evidence gathered that had not been originally identified as evaluations of their programs. A higher priority was revealed to be funding for the next fiscal year. The case study group re-oriented its focus for the week and created a working document that could be referenced when the Network applies for upcoming funding.

Although the case study group focused primarily on the creation of a working document to help the Network prepare for upcoming calls for grant proposals, this paper will focus on further suggestions for the Network in four key areas of CBR. The areas of community engagement, research ethics and methodology, information management, and knowledge translation, are addressed in this paper as they apply to the Play it Safer Network. Given the importance of seeking out funding, the working document for future funding applications will be presented at the end of this paper.

As a whole, the Play it Safer Network has done an outstanding job of delivering services to its target audience. Although currently unrecognized, many of its education strategies could be considered CBR. For the Play it Safer Network to be more effective and appropriate in its programming and increase its potential to receive funding for future projects, the organization needs to advocate for itself and its network as community-based researchers. By recognizing the value of its work as research, and enhancing the principles and practices of CBR in their organization, the Network will become an outstanding example of CBR and enhance its profile as a service provider.

What is the Play It Safer Network?

The Play it Safer Network is a group of individuals, organizations, and community groups who are interested in, living with, or affected by Human Immunodeficiency Virus (HIV)/Acquired Immune Deficiency Syndrome (AIDS), Hepatitis C, and Sexually Transmitted Infection (STI) awareness and prevention. The organization's goal is to use a community-based approach to build education, prevention, and healthy lifestyle campaigns. Youth (15-24) are the primary focus of the Network's programming. Initially known as the NOR-MAN AIDS Working Group, the organization is now known as Play It Safer Network. This community-based network started in 1992 and serves northern Manitoba and northern Saskatchewan, known as the NorMan/NorSask area.

Community Engagement

Working with a community that is engaged in the research process is a fundamental component of Community Based Research (CBR). Specifically, Israel notes there should be an “emphasis on the participation and influence of nonacademic researchers in the process of creating knowledge” (Israel et al., 1998). The Play it Safer Network has a well-documented history of engaging community in their past projects, both on research and education campaigns. As a result of this engagement, the Network has many members who hold different areas of expertise. A successful CBR project would involve a community, such as the Play it Safer Network coming together and sharing each other’s resources, strengths, and relationships (Israel, et al., 1998). This process of working collaboratively is supportive to all parties involved and has many advantages.

The outcomes of a research project or an awareness campaign are heighted by engaging the community that is being served. When communities work in partnership with community based organizations (CBOs) (or a researcher), there is an opportunity for both parties to learn from and influence one another. This work environment also allows for all involved to learn skills and competencies in terms of professional development (Hartwig, Calleson, & Williams, 2006). Above all, when the community is involved in creating and contributing to what campaigns are being delivered in their regions, they will be more successful than if they were designed without the voice of the community members.

The Play it Safer Network is currently engaged with a diverse group of members from the community it serves. Membership is increasing across the service area, including Flin Flon, The Pas, Creighton, Snow Lake, and Cranberry Portage. There is a strong representation from varied service providers including educational institutions, healthcare professionals, Friendship Centres, youth centre, and women's resource centres. However, one area where partnerships could be enhanced is with Aboriginal communities within the Network's service area.

The Network has over 10 Aboriginal communities in its NorMan/NorSask service area. Although there are several strong connections with some of these communities and local Friendship Centres, there could be more collaboration with these groups. Because one of the Network's strategic goals is to recruit and maintain members from different communities in NorMan/NorSask, making an effort to invite more Aboriginal community representatives in the service area should be a priority.

The case study group suggested that the Network seek out a connection with Chiefs and Councils from the communities in the NorMan/NorSask area who are not currently involved in the Play it Safer Network. As an alternative, if the Chief and Council are not accessible, the council member with the health portfolio would also be an appropriate person to contact. During the week of the summer institute the Network's coordinator, Carrie Pockett, noted that she has an existing working relationship a woman at the Cree Nation Tribal Health office. This would be the starting place for discussions about how to build relationships with local Aboriginal communities. This contact person may be able to offer assistance and information regarding which council member may be interested in the objectives of the Play it Safer Network.

As relationships are built with these groups, there may be a number of areas of common ground where the groups could help each other. The Network is doing invaluable work for free of charge in these communities. By building relationships with the Aboriginal communities it is hoped that this will generate a positive working relationship for all parties involved. There are a number of resources available online that may be of assistance to the Network when it is beginning to develop a new partnership.

The Association of Asian Pacific Community Health Organizations (www.aapcho.org) has an “Community Based Participatory Research Toolkit” (AAPCHO, 2009) on their website that contains resources that could be helpful to the Network. The section that entitled “Developing and Maintaining Partnerships” describes the “Partnership Trust Tool”(CDC, 2009) as a useful resource to use to help build trust between CBOs and communities. The Play it Safer Network could use this toolkit to negotiate a relationship with a new organization that is joining their network. If appropriate, this document could be a good guide to follow to build the trust with a new partner organization. There are other resources on this website that may be useful to the Network when they are interested in documenting more specific aspects of a collaborative relationship, such as the “Sample Memorandums of Understandings” (Community-Campus Partnerships for Health, 2011).

It is in the best interest of the Network to approach the Aboriginal communities who are not yet involved with their programming. By having more voices to contribute to the direction and future programming of the Network, the Network will be better able to direct their focus to those who they serve. The Aboriginal community representatives may be very helpful in developing strategies to reach youth who are currently being underserved by the Play it Safer Network, such as youth who are not attending school. Finally, it is important for the Network to know that their programs are appropriate for their Aboriginal clientele. Including more Aboriginal representatives in their Network’s activities may be helpful to get a sense of how the Aboriginal communities could best be reached. For an extensive group such as the Play it Safer Network increasing community engagement should be a constant objective. At this time, developing collaborations with Aboriginal communities in the Network's service area is a high priority.

Research Ethics and Methodology

The ethics and methodological considerations of CBR are some of the most important elements to review when planning a project. The Tri-Council Policy Statement guides ethical decisions of all researchers at universities in Canada (CIHR, 2011). This is a document that outlines standards for research involving humans and it is expected that all researchers follow this policy. The core principles of the Tri-Council Policy Statement are respect for persons, concern for welfare, and maintenance of justice. The goal of this policy is to protect the Canadian public and the integrity of its researchers. Ethical research means that the project has value and validity. It will also have been reviewed independently, will have received informed consent from participants, and have fair participant selection (Martz, 2011). However, for CBOs who are not affiliated with a university or a publicly funded research institute, research ethics standards may not be upheld to the same level of expectation as they are under the Tri- Council Policy Statement.

With future research projects of the Play it Safer Network in mind, it would be helpful for the Network to begin to seek out a research partner. An individual who is associated with a university or college could work collaboratively with the Network coordinator (Carrie Pockett) to explore future research ideas. Working with an academic partner could offer the Network a variety of resources. Depending on the academic's skills and area of expertise, this person may be able to help the Network apply for long term funding to carry out a research project, or to help prioritize areas that are in need of investigation. As an example, if the Network was able to connect with a professor or a graduate student these individuals may be interested in starting a new community based research project and have a source of funding in mind that would suit the programming of the Play it Safer Network.

If the Network chooses to seek out a potential academic partner, it is important to ensure that the new academic partner is an appropriate fit to the Network's goals. A researcher who is willing to help out, but only wants to pursue areas of interest to them and not have the best interests of the Network in mind would not be appropriate. Dr. JoLee Blackbear, who was a member of the case study group and is currently a faculty member at the University of Regina, has suggested that she could help the network explore appropriate connections with the University College of the North. Dr. Blackbear would be a strong resource for the Network to utilize in finding an academic partner.

When an academic partner is found, hopefully this partner will be able to help the Network establish a community based research methodology for future projects. If this partner is currently connected with an academic institution, the research ethics board from this school will be helpful in ensuring appropriate ethical guidelines and considerations are met and upheld. Creating ethical guidelines and considering different methodologies will help the Network become a capable and prepared organization for future community-based research projects.

Information Management

A well-managed research project has a detailed data management plan in place before data is collected. To keep files and any type of data stored in an orderly fashion, especially in a team setting, there must be an agreed upon plan for how the information will be handled (Reid, Brief, & LeDrew, 2009). How this information is handled may depend on what type of data it is.

There is a wide range of what may be considered data in CBR. As Reid, Brief, and LeDrew (2009) note, data refers to a “collection of information or facts usually gathered as the result of experience, observation, or experiment. Data can come in the form of numbers, words, or images. Qualitative data are usually words or chunks of text that are gathered and then woven together to make meaning of a particular phenomenon” (p. 42). Today’s researchers have many diverse, multi media methods of doing research. Video interviews, photo essays, and digital story telling are a few examples of inventive research that has been done in CBR (Abonyi, 2011).

The Play it Safer Network has completed a number of innovative educational campaigns in the past. One priority for the Network is to organize and catalogue all material that could be considered evidence for what they have achieved thus far. If an academic collaborator joins the Network his or her skills in information management would be an asset to the great work the Network has been done in the past. From the discussions with the program coordinator, there seems to be a substantial amount of evidence that has been gathered on the value of their programs. However, when this work was done the Network was not aware that their work could be considered research data as defined above by Reid, Brief, and LeDrew (2009). This is a challenge for CBOs who are working hard to be progressive organizations, and engage their clientele. If staff members are not trained in CBR, they may not have the expertise to create a research project with comprehensive information management. In the case of the Play it Safer Network, they have done a number of exceptional projects they understood to be awareness campaigns, while in terms of CBR their work is absolutely also considered research.

In 2007, the Network collaboratively created a graphic novel with youth as a knowledge translation strategy of sexual health information. The novel, *unWANTED* was printed and over 4 000 copies have been distributed in the NorMan/NorSask region to date (KL Consulting, 2009b).

After the wide success of this text based translation strategy, in 2010 the Network partnered with a high school to create a drama production of the novel. To investigate to impact of these projects, surveys and focus groups were completed with youth who had read the novel.

The survey of the youth who had read the novel found encouraging results. The majority of youth surveyed either "agreed", or "strongly agreed" that they could: a) relate to the characters, b) relate to the way the characters speak, and c) use the information contained in the novel. The same group also agreed that the novel portrayed the truth faced by youth in the NorMan/NorSask region (KL Consulting, 2009b). Further details on the focus group results and online survey results are available in the "Graphic Novel Evaluation Report" (KL Consulting, 2009b). These organized results show the youth who read the novel valued the material. This data is strong evidence that should be referenced in future grant proposals and annual reports to show how valuable this project was for the Network. As the Network learns more about CBR and potentially collaborates with a researcher to organize the information that has previously been collected, it will have the opportunity to reclassify some of the data previously collected so that it can be managed according to the principles of CBR.

Knowledge Translation

Knowledge translation (KT) and knowledge exchange are similar terms used to describe how community-based researchers use the findings of their research projects (Reid, Brief, & LeDrew, 2009). Sharing the findings of a CBR project is fundamental to this type of research (Reading, 2011). Putting the research into action, or using the findings for practical applications is the end goal of most CBR projects. However, there are many ways to convey research findings to an audience.

The Ontario Ministry of Agriculture, Food and Rural Affairs (OMAFRA), (2010) has a useful toolkit to assist in creating a successful plan for KT. Using the OMAFRA toolkit enables researchers to develop key areas of a KT strategy. Reviewing the target audience for the research findings, considering who would be interested in the findings, and considering the methods of communication needed to reach the target audience are the areas addressed in the OMAFRA toolkit (2010). This is a good resource for the Play it Safer Network to use as a guide for future research or educational projects.

The Play it Safer Network has two KT projects they would like to begin exploring. The first is to translate some of their educational materials into the Aboriginal languages that are spoken in the NorMan/NorSask region. The Network is interested in making their materials available in other languages to increase the accessibility of their educational materials on HIV/AIDS, STIs, and Hepatitis C.

The second KT project idea is to create a Youth Advisory Committee, the members of which would serve as resident advisors on future initiatives, as well as future KT strategies. Youth committees are an increasingly popular approach to ensuring the voice of youth is heard, and are included in public and private sector programming. For an example of the challenges and successes of a Youth Advisory Committee refer to Hohenemser and Marshall (2002). Both of the proposed initiatives of KT are suitable strategies for the Network. These are both intensive approaches of KT, but have the potential to be rewarding and effective when they are in place.

Ongoing Funding Strategy Recommendations

The Play it Safer Network does not currently have funding in place for the next fiscal year. Although they have had success in the past with funding that has been renewed annually, their funding is not guaranteed for the upcoming year. Not having core funding that a CBO can rely on for more than one year into the future is a common struggle for organizations that rely on grant money to fund their operations. Grant writing is a well-developed skill at the Play it Safer Network: however there are areas of funding that have not yet been sought out. The Network's service delivery area is within the NorMan/NorSask area. Therefore, funding applications should be made it both Saskatchewan and Manitoba. It seems that in the past the Network has relied on money from Manitoba. To build the network to its fullest capacity applications should be submitted to both provinces.

Funding applications should also be made to Aboriginal health agencies. The Network has not been clear in the past that Aboriginal individuals are in their target audience. Although they do not focus their programming only for Aboriginal individuals, it is still important to be transparent on funding applications about all the populations the Network serves. There have been numerous success stories from the Network in the past years; these need to be celebrated and reported to funding sources.

In attempt to aid the Network prepare to be ready to respond to a call for funding applications a working document was created be the case study group (Appendix). This document is organized by headings that are taken from previous calls for applications from the AIDS Community Action Program (ACAP) under the Canadian Strategy on HIV/AIDS (CSHA) at the Public Health Agency of Canada. The Play it Safer Network has received funding from ACAP in the past and plans to respond to a call for applications if one is available this Fall.

The Appendix is intended to be a collection of facts and statements that the Network may choose to reference in future funding applications. The needs of the network, and volunteer contributions, and a detailed budget are outlined. Finally, there is a letter of support at the end of the appendix signed by all members of the case study group. This letter is the best example of what the case study group accomplished at the Summer Institute. The letter makes a strong case for how beneficial and needed the Play it Safer Network is, yet is struggling with funding constraints.

Conclusion

The Play it Safer Network is an exceptional CBO that has many successes to celebrate. The projects that have been carried out by the Network have taught youth about sexual health, HIV/AIDS, Hepatitis C, and healthy lifestyle choices. In a rural area with communities that are relatively small, this Network has delivered services that are essential to the healthy development of its youth.

By following the recommendations made in this paper, the Network will become a CBO with a developing CBR priority. Investing in CBR practices will be highly beneficial for the Network in future funding competitions. A funding agency will be pleased to see that the Network has reached out to collaborate with Aboriginal representatives, and academic researchers. Organizing information management strategies and ethical guidelines will also stand out to a funder as examples of the Network being an organization with a keen interest in CBR.

The proposed knowledge translation strategies will contribute to the Network increasing its profile as a service delivery agency. Building a youth advisory committee, and translating Network materials into Aboriginal languages are major steps forward in the strategic direction of the Network. These activities will help the Network continue to be respected by other CBOs and perhaps contribute to the Network becoming a leader in the field one day.

Choosing to participate in CBR and democratizing knowledge is a choice health researchers can choose to make (Reid, Brief, & LeDrew 2009). The principles and practices of CBR offer the researcher and the communities involved an opportunity to do research that is meaningful, valid, and respectful. As we see CBR gain momentum in the field of health research, researchers and CBOs will increasingly include this methodology in their practice. The suggestions made in this paper for Play it Safer Network are suitable examples of how a CBO can take steps towards becoming an outstanding example of how CBR can be used in community.

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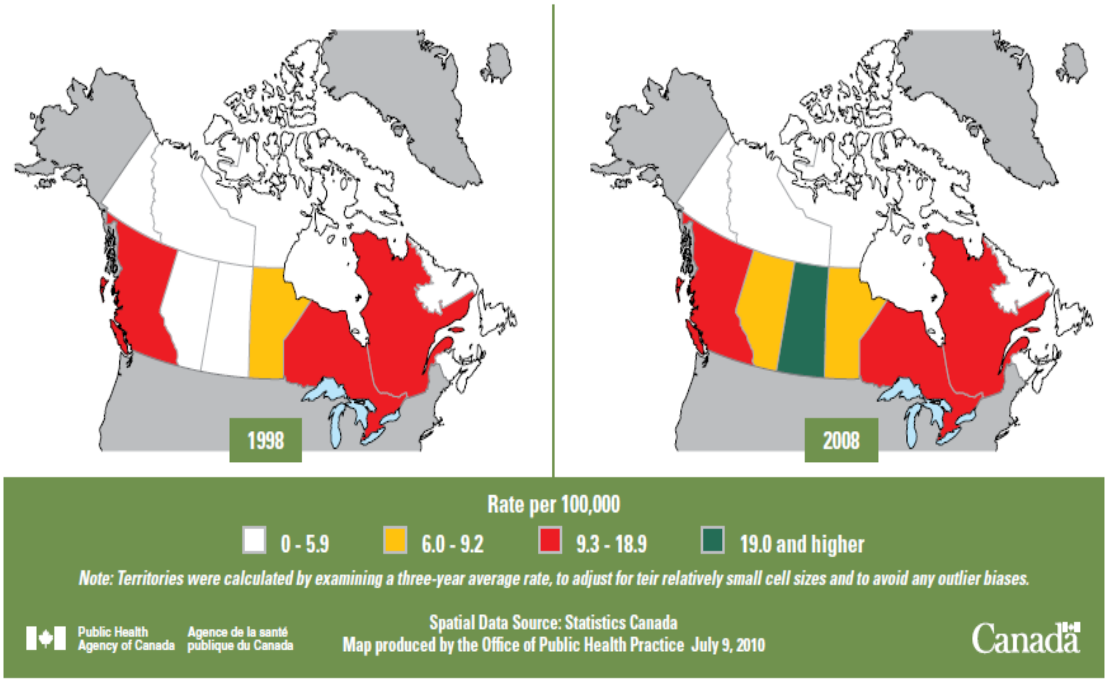
Appendix. Working Document for Future Funding Applications

Note: This document is to be referenced by the Play it Safer Network in future funding applications as needed. The formatting is following the structure of previous calls for applications from the AIDS Community Action Program (ACAP).

1.) What are the needs of the Network?
    a. Prevalence rates?

Since 2002, HIV rates have steadily increased in Saskatchewan (Saskatchewan Ministry of Health, 2010a). Rates per 100 000, show Saskatchewan being the province with the highest rate of new infections. These rates are more than double the new infection rate in the provinces of British Columbia, Ontario, and Quebec. The figure below illustrates the changes in rates per 100 000, from 1998, to 2008.

Rate (per 100,000 population) of Diagnoses of HIV Infection in Canada, 1998 and 2008 (both sexes, ages >= 15)



Note: Territories were calculated by examining a three-year average rate, to adjust for teir relatively small cell sizes and to avoid any outlier biases.

Public Health Agency of Canada Agence de la santé publique du Canada

Spatial Data Source: Statistics Canada
Map produced by the Office of Public Health Practice July 9, 2010

Canada

Although the exact rates of individuals living with HIV in Saskatchewan, the Public Health Agency of Canada estimates the rates to be 1 420 individuals (Saskatchewan Ministry of Health, 2010b).

b.) Previous Consultation Reports

In March 2009, the Network hired an outside consultant to review the overall effects of the phase II project, which occurred in the fifth year of operation under the current network name (Play it Safer Network). The evaluation was organized around specific goals, and future recommendations were made accordingly. Two of these goals are still in progress today. The first goal was "To develop a communication strategy to promote and maintain partnerships in the Play It Safer Network". Regarding this goal, the consultant made the following four recommendations (KL Consulting, 2009a):

1. To hire a part time position to support the coordinator and the Network administratively.
2. To continue to work towards expanding the Network through the region.
3. To continue to increase focus on education by sharing information with schools.
4. To develop and implement a process to ensure regular maintenance of the website.

The second goal (which was the third goal of the initial report) was to "Identify social support needs for individuals living with or affected by HIV/AIDS and Hepatitis C who live in NorMan/NorSask". The consultant suggested the following recommendations:

1. Review current HIV, HCV, and STI data.
2. Host and coordinate a harm reduction education workshop on safer sex practices for high-risk clients for health care professionals.
3. Host and coordinate a "munch and learn" workshop for high-risk clients at the Homeless Shelter and the Friendship Centre.

2.) Volunteer Contributions

a. Number of volunteer hours

The Play It Safer Network has a substantial base of volunteers who assist with the Network's activities around the year. For the period of April 1, 2010 - March 31, 2011, 426 volunteer hours were recorded with 43 volunteers. Most recently, for the period of April 1, 2011 - July 31, 2011, 414 volunteer hours were recorded with 32 volunteers.

3.) Management

a. Budget

In line with the external reviewers recommendations to hire a part time staff member to support the Network coordinator, out case study group also felt the Network needed more employees. The following is a detailed budget for what the Network will need to accommodate these expansions.

Play It Safer Network DETAILED BUDGET	**DOLLAR AMOUNT**	**EXPLANATION**
EQUIPMENT AND MATERIALS		
Learning materials and resources	5,000	
Office equipment and furniture	12000	Copier lease, fax, desks, file cabinets, printer, etc
Office space rental	12000	
Outreach Van lease @ 3 years	45000	
Van insurance, maintenance	7000	
Laptop computers @ 5 (one per staff, one student)	6000	
Software and Licenses	1500	
Equipment and materials sub-total	**88,500**	
SUPPLIES		
Office supplies	6000	
Postage	1500	
Supplies sub-total	**7500**	

SALARIES		
Project Director	45509	
Project Assistant	32000	
Project Assistant	32000	
Project Administrator	35132	
Teen Peer Leader	5000	
Teen Peer Leader	5000	
Teen Peer Leader	5000	
Salary sub-total	159,641	
Benefits @ 15%	13056	Benefits of salaried staff
Salary w/ benefits sub-total	**172,697**	
TRANSPORTATION / TRAVEL		
	5,000	Travel and presentations/ trainings to conferences
Van outreach costs	5,000	
Travel sub-total	**10000**	
Other		
Drama program	5,000	
Special events	8,000	community engagement / volunteer support
Communication	3000	
Student Success Initiatives	3,000	
Summer Youth Program	5000	
Specialized training	5000	
Other sub-total	**29,000**	
Play It Safer Network sub-total	**307,697**	
Administrative costs @ 15%	**46,154**	
Play It Safer Network Total Request	**353,851**	

4. Letter of Support

This letter was written in support of the work the Network has done, and may be used as appropriate.

June 22, 2011

To Whom It May Concern:

I am writing on behalf of the Play It Safer Network (PISN) located in Flin Flon, MB. During the 2011 Community Based Health Research Summer Institute sponsored by the Indigenous Peoples Health Research Centre, Saskatchewan Population Health and Evaluation Research Unit, and the Prairie Community-Based HIV Research Program at University of Regina, the Play It Safer Network was accepted to be examined as a case study. Program Coordinator, Carrie Pockett brought forth issues facing her organization to participate in a case-study analysis. This analysis brought together health researchers at the graduate student and faculty levels as well as community based professionals with expertise within the public and private sectors.

During the case study analysis, several observations, insights and recommendations were brought forth. First we would like to identify that the Play It Safer Network is a community based organization that has a community based service approach to address the Human Immunodeficiency Virus (HIV), Acquired Immune Deficiency Virus (AIDS), Sexually Transmitted Infections (STIs), Hepatitis C and healthy lifestyle choices through education, prevention, treatment, and medical and social supports. They do this on a programming budget only and have no operational funding. Further, they cover an area of over 72,000 sq. km including northern Manitoba and northeastern Saskatchewan. PISN has only one paid staff member and works the rest of its staff through in-kind or volunteer support.

The amount of work, community collaborations, outreach, research, education and prevention, in particular with engaging youth, is quite impressive. Considering the financial limitations, PISN has made huge advancements within the community through their ability to reach their target populations by creating community awareness, reducing barriers to accessing service through outreach campaigns, and conducting thorough and thoughtful research evaluating their programs on Network and project levels.

The Play it Safer Network has made valuable partnerships and community connections. In the past 12 years of operation PISN has delivered services to youth in their service areas which includes 10 First Nations communities and outlying northern communities with limited access to HIV/AIDS, STI programming.

The Public Health Agency of Canada (PHAC) and the AIDS Community Action Program (ACAP) currently provide PISN programmatic dollars, however this funding is slated for termination at the end of the 2011-2012 year. Therefore, it is a recommendation of this CBHR Analyst Team that dollars for operational funding be prioritized immediately.

Further, since 1996, there has been an increase in new HIV-positive cases in Saskatchewan. There were 26 new cases in 2002 and an increase to 200 new cases in 2009 (Ministry of health database 2010). Additionally, Manitoba has experienced increases. Between 1985-1996 there were 574 newly diagnosed cases of HIV and from 1997 to 2002 an increase of new cases grew to 412 with a dramatic increase occurring with IV drug users (An Aboriginal Strategy on HIV/AIDS, 2004). With the increasing epidemiological shifts in HIV/STI this is not the time to allow an organization such as the Play It Safer Network come to a close. In fact, it is a moral imperative that this organization at long last receives operational funding to move into an era of expansion, education, service development, health education and prevention. Additionally, we must honour the work conducted by this organization that has existed on the backs of volunteerism and community concern and recognize that community changes will come through grass roots efforts. Everything must be done to keep this organization and those like it growing and expanding serving the outlying areas not afforded the services urban areas offer.

We offer this letter as a sign of our strongest support of the Play It Safer Network and implore your organization as funding agent to deeply consider the ramifications of funding or not funding this organization. We implore you to recognize the need in both Manitoba and Saskatchewan for education and prevention of these much preventable diseases. We ask that you support the efforts of community people addressing community-based issues in a grass roots manner. I have offered to be the contact for this team if you should have further questions.

Respectfully,

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Case Study #4

Paths to Living Well for Standing Buffalo Youth: Sharing the Learnings

Facilitators:

Dr. Pammla Petrucka and Leanne Yuzicappi

PATHS TO LIVING WELL FOR STANDING BUFFALO YOUTH: SHARING THE LEARNINGS

Facilitators: Dr. Pammla Petrucka and Leanne Yuzicappi

Introduction

The community of Standing Buffalo First Nation (SBFN), a small rural reserve in southern Saskatchewan, hosts this community-research partnerships, which includes the community and a collaboration of academic researchers from the University of Saskatchewan, First Nations University of Canada (FNUC), and University of Regina. The partners began with a shared vision to explore societal, cultural, and environmental influences impacting on the 'being' or 'becoming well' for members of SBFN – a direction named 'Ocanku Duta Amani' which is Dakota for Paths to Living Well (PTLW).

As the partnership evolved, it was decided that an initial focus would be best directed towards the health of youth in the community of SBFN. This decision was rooted in the realization that research literature is filled with issues facing Aboriginal youth ranging from disease incidence (i.e., diabetes, obesity), mental health challenges (i.e., suicide), and substance abuse issues (i.e., smoking, illicit drugs), further demonstrating that the dominant biomedical model has been unresponsive and unsuccessful in removing the burden of health experienced by Aboriginal youth. It was apparent that it is critical to go to the youth themselves to understand individually and collectively how historical, social, cultural, and environmental factors impact on their health.

Goal of this Case Study

As this project is nearing completion, the team would like to consider the 'Knowledge to Action' aspects of this research, using the following three guiding questions:

- What are the opportunities and challenges to implementing research results from this study?
- What approach(es) might improve the success of the knowledge to action agenda?
- What is the difference between a 'knowledge to action' agenda and a dissemination plan?

Activity Detailed Description

<u>Summary of Evidence</u>

The community based participatory research project entitled Ocanku Duta Amani: Paths to Living Well – Youth focuses on exploring "paths to being or becoming well" from the perspective of Aboriginal on reserve youth. Through audio and visual methods (such as photo-voice, murals, and wintercounts[1]), the community and academic research team explored the societal, cultural, and environmental influences on wellness. Dialogues and

---

[1] Wintercounts are a traditional calendar (on animal hide) which the Dakota/Lakota people used to capture memorable events in the life of their people/community. This was replicated in our project by having youth participants depict memorable events during their lives which have contributed to their wellness and wellbeing.

interpretations related to participants' **past**, **present**, and **future** health realities were co-facilitated by elders and research team members. Each of the generated research outputs was considered individually and collectively at various stages of this project in order to inform and affirm learnings and future directions.
In terms of rigour and trustworthiness, we recognized the potential of the combination of the community based participatory approach and artistic methods to give voice and validity to local knowledge. Both photographs and art (in our study murals and wintercounts) have been demonstrated to raise social consciousness in a culturally and ethically responsive manner. In this study, all three data collection approaches (i.e., photovoice, murals, and wintercounts) were independently analyzed and then comparatively analyzed by the participants and research team.

> Photovoice
> Through a series of photovoice collection/dialogue sessions, the youth contributed over 700 pictures.During the photo-elicitations, the participants reviewed three to five photographs which they felt best represented what 'made or kept them well/unwell' as on-reserve youth. The participants individually selected three to five personal photographs for photo-elicitation. (See Appendix I)
>
> Mural
> As the photovoice phase proceeded, Chief and Council requested the use of the insights from the photographs to design a mural to hang in the powwow grounds. The research participants along with summer culture camp attendees created a mural consisting of four panels representing youth's perceptions of 'paths to living well'. (See Appendix II)
>
> Wintercounts
> As the project continued, we had intended on some type of digital presentation of findings. However, the community leaders (Chief, Council, community researcher, and Elders) suggested the potential for use of wintercounts – which are traditional historical calendars which pictorially capture a key annual community event on an animal hide. The research partnership team agreed this was both a culturally and community appropriate approach. We recognized that, although wintercounts are traditionally linked to the Dakota/Lakota peoples, pictograms have appeared in most First Nations peoples in Canada and, more broadly, in most indigenous groups. (See Appendix III)

Three major research themes have been explicated through this research process. *"Living and Caring for Our Environment"* was the most prevalent theme represented visually as water, plants, and animal life and described as life-giving, sustaining, and a gift. The second theme, *"People across the Generations"*, included depictions of ancestors and family/community members and emphasized connections through the ages and belonging. Finally, *"Participating in Our Culture"* was illustrated in this research through depictions of leather/beadings, cultural activities (i.e., powwows), and hunting/fishing. This theme was often described in terms of actions such as dancing, singing, drumming, and building.

Knowledge Translation (KT)

The intended KT strategies are an extension and expansion of work already done and found to have significantly contributed to our project's relevance and significance to the participants and the community. Strategies #1 and #2 have been considered by the community and will be approached through future funding. The emphasis for discussion on this case will be to consider Strategies #3 and #4 which have been revealed in the latter stages of the project, but are in the early stages of discussion by the partnership.

Strategy #1

The first KT strategy proposed is to enable a number of the participants to travel to the Smithsonian Institute to work with Dakota/Lakota expert curator Emil Her Many Horses. During the project, a short study tour of the Dakota holdings was undertaken by three students (one community participant, one undergraduate research assistant, one graduate research assistant) and the principal investigator. During this opportunity we were exposed to remarkable historical/archival holdings and interpretive dialogues with experts in the area of traditional wintercounts. This experience highly informed the direction of the research collection and analysis related to the participant created wintercounts. In this iteration, four participants, an elder, graduate research assistant, and principal investigator would work with the aforementioned curator in the process of naming and revisiting their wintercounts under his tutelage. This process would be used to inform their descriptive accounts to appear in a proposed publication and secure Mr. Her Many Horses contributions. It is important to note that linking of the participants' wintercounts with cultural artifacts will enrich and strengthen their KT capacities and relevance.

Strategy #2

The second KT strategy proposed is the co-creation of a photo journal book using a self-publishing environment. This publication will include photographs selected in collaboration with the participants, elders, and research team. Each photo will be augmented with quotations and elicitations by the participants and elders to bring their lens to the consideration and interpretation of the contribution. Through culturally informed and respectful presentation this book will showcase the themes, perspectives, and future priorities for Aboriginal youth wellness. It is anticipated that the work done with the Smithsonian curator will be critical to the presentation of this document; further, anticipating his contribution in the book's forward as an expert in Dakota ways of knowing.

Strategy #3

The third KT strategy proposed is a consideration of the learnings, adaptations, and co-creation of innovative research methods. We have seen the use of murals and wintercounts as potentially challenging the elitist structures which permeate the Western notions of knowledge production and knowledge translation. Our concern is how to properly contextualize and ‘reveal’ the emergent research approaches which are respectful, reflective, and inclusive of all members of the community-academic partnership. This aspect of the KT was not anticipated at the onset of this research relationship (as indicated in the discussion of the evolution of the research process).

Strategy #4

The fourth KT strategy concerns the‘knowledge to action’ component. According to CIHR, “new knowledge is socially constructed, negotiated, and adopted: 1) through both communication and by people of influence, and through social networks that link peers and similar organizations; 2) by the presence of peers, opinion leaders and champions; and 3) especially by tailoring the message to the language, values and needs of the organization” (*Greenhalgh 2004*). Essentially this strategy will require the clarification of the ‘who’, ‘what’, and ‘how’ of the knowledge to action plan (*De Civita, 2007)*.

Team Members

Ms. Leanne Yuzicappi(co-facilitator)
Elder Wayne Goodwill
Ms. Deanna Bickford
Dr. Pammla Petrucka (co-facilitator)

Chief Roger Redman
Dr. Sandra Bassendowski
Dr. Bonnie Jeffrey
Ms. Bev McBeth
Mr. Andrew Salgado

Acknowledgements

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This case is dedicated to the Elders of SBFN whose wisdom and guidance have been invaluable – especially the late Elder Ken Goodwill who is sadly missed.

Appendix I
Photovoice

Appendix II
Mural

Appendix III
Wintercounts

The Paths to Living Well Spread Through the Media

Stephanie R. Miller

University of Regina

Background

The phrase “Ocanku Duta Amani,” Dakota for “paths to being and becoming well,” should be examined in finer detail before moving forward. The term wellness incorporates many areas of livelihood and can be characterized by a sense of well-being reflected in optimal functioning, health-related quality of life, and a contribution to society (Corbin, Welk, Corbin, & Welk, 2009). Broken into dimensions, wellness is categorized as emotional, intellectual, physical, social, spiritual, and total outlook. One’s optimal health, then, is the highest level of the aforementioned dimensions within the limits of heredity and personal abilities (Corbin, et al., 2009).

Looking into the lives of Canadian Aboriginal youth and teens it becomes clear that the uphill battle they face is much steeper than those of any other ethnic group in Canada. According to Formsma & Formsma (2005), Aboriginal youth face higher risks for negative health factors than any other ethnicity in Canada. A factor is categorized as “risk for negative health” if they encourage or are associated with behaviors that might lead to a negative health outcome or discourage behaviors that might prevent them (Blum, 2004). An example of negative risks could be smoking tobacco, engaging in unprotected sex, or disordered eating. Furthermore, when it comes to health and wellness promotion, Aboriginal youth receive less funding, less programming, and have access to fewer resources than the average young person in Canada (Formsma & Formsma, 2005). Consequently, those involved in the knowledge to action process aimed at increasing the overall health and wellness of Aboriginal youth need to be creative in how they use their resources to best serve the youth. In addition, those individuals need to be cognizant of the specific ethical limitations of the community they are working with. One strategy may work for one community but may be deemed inappropriate by another.

The Paths to Living Well Spread Through the Media

Introduction

This submitted paper is based on information attained during the Community-Based Health Research Summer Institute. The case study being addressed and examined is the research project titled "Ocanku Duta Amani: Paths to Living Well." This project was lead by Dr. Pammla Petrucka, along with researchers from the University of Saskatchewan, University of Regina, First Nations University of Canada, and a community researcher from Standing Buffalo First Nation.

At the urging of the elders within the community, the research team focused their efforts on exploring the social, cultural, environmental aspects affecting the health of the Standing Buffalo youth. The researchers presented the elders with the idea of using Photovoice as their main research methodology. Photovoice is a participatory-based research method that uses photographic images taken by individuals who otherwise may not have the platform to express their daily experiences, needs, and opportunities (Strack, Magill, & McDonagh, 2004). The researchers noted during the Institute that the elders were in full agreement of using this method because using the camera provided the youth with a life-skill. Also, much like focus groups, sharing circles were used, respecting the preference for Aboriginal oral tradition (Petrucka, 2008). It became clear, listening to Dr. Petrucka, that she and her team made conscience efforts throughout the research study to include and engage the Standing Buffalo community during every step of the research process, an action she termed "collective sharing." This not only helped the research team to gain access to the community during this project but also has set the stage for several more years of Researcher-Community interaction. One of Dr. Petrucka's research assistants noted that another project has already been approved for funding, and in her terms, "the connection is not done."

As stated in Dr. Petrucka's research proposal, the research team planned on showcasing the photovoice photos at various venues in the reserve area (Petrucka, 2008). However, this plan did not come to fruition as the elders were now telling them that photographs could not be used or displayed. Speaking directly to us at the Institute was Standing Buffalo Elder Velma, and she offered this explanation while quoting a now deceased elder, she stated, "taking photos is not our way, it kills the spirit." With this realization, the research team had to think of other means to display the images caught on camera by the youth. In the end, the youth were able to produce winter counts and murals that depicted "living well," which are displayed in the community.

The challenge presented to our group was not developing a research strategy, but rather, what to do with this information now that the study was complete, and how to bring it to life. More specifically, we were asked, how can the knowledge gained by and about the youths' "paths to becoming well" be turned into action, and how can this best be achieved?

This paper will propose three strategies, which aim to turn the knowledge gained from Patrucka's study into action by the youth and young adults of Standing Buffalo. These three strategies will focus on "paths to being and becoming well" and will offer the youth and young adults opportunities to showcase and promote "wellness" in their community and to other communities, both Aboriginal and Non-Aboriginal. The scope of these strategies reaches beyond Standing Buffalo in order to accommodate the wishes of the Standing

Buffalo chief, who according to Dr. Petrucka, wants to spread the word to outer Aboriginal Canada and the Eurocentric populations.

The strategies also take into consideration the words of Standing Buffalo Elder Velma, and community researcher, LeeAnn. Elder Velma felt the focus of the original research study should be on their youth. She felt they were more impressionable, willing to learn, and have more time to make a positive impact on their community. She felt they could pass down behaviors to younger children in the community as well. The proposed strategies continue to focus on the youth and young adults, as they will continue to be the main driving force behind the knowledge to action process. Community researcher LeeAnn believed the use of photovoice was a benefit to the youth because it was a form of counseling without appearing to be so. The participants were learning and passing on information to their community without it feeling like a lecture or therapy session. Once more, the proposed strategies will allow the youth and young adults the opportunity to share information with others, but doing so in a creative, fun, and comfortable ways that are also help to develop life skills relevant in today's technological society.

Proposed Knowledge to Action Strategies

Health and Wellness Segments on CTV News

The first proposed strategy is to take part in several airings of CTV Regina News' Indigenous Circle. This special segment takes a weekly in-depth look at news and issues facing the First Nation and Metis population of Saskatchewan (CTV Regina News, 2011). Such segments would discuss upcoming recreational programs, special community events, community trips and group classes all aimed at the wellness dimensions. This would be a way for the youth to discuss what is happening in Standing Buffalo to make them "well," while also reaching a larger audience, both Aboriginal and Non-Aboriginal.

The Indigenous Circle mission statement reads, "Our mission is to foster, in a holistic way, greater understanding between Aboriginal and Non-Aboriginal people as to traditional values, current issues and future directions of First Nations and Metis communities" (CTV Regina News, 2011). Their mission fits perfectly with what the researchers hoped to disseminate; what factors contribute to youth being well on reserve, and now the youth would have the opportunity to discuss these factors, and what actions they are taking to be well.

The youth would also be able to use this time to possibly discuss issues in their community that prevent them being well. For example, if there is lack of funding for sports equipment, they could be the voice that ultimately reaches out to policy makers.

Taking part in such a well-established program--the series first aired in 1993-- would have many benefits to the youth and young adults involved. For example, the youth would be able to see first-hand what it takes to put a news production together, from sound, camera angles, editing, hosting, to the final product we see in our homes.

With these segments airing throughout the province, the Standing Buffalo's chief's wishes to spread the word would be achieved. Given the in-depth look these segments take as well, the approval from the Elders of the community should be attained.

While the segments may reach policy makers, one disadvantage of this strategy is it may not reach the youth and young demographic, who may not watch this news series. If this is the case, then unfortunately the programs and events the on reserve youth participate in to "be well" may not extend to other on and off reserve youth. However, the Indigenous

Circle has their own Facebook page, which contains videos of previously aired segments. As will be noted later on, youth and young adults spend a great deal of time on social networking sites (SNS), like Facebook, so this may be a way to reach this demographic.

Public Service Announcements (PSA) on The Creek FM

The next strategy option is to air public service announcements (PSA) on the radio station 95.3 The CreekFM. The CreekFM, according to its website, is a community-based radio station operating on the Okanese First Nation in Saskatchewan, Canada. It has unprecedented reach for a community radio station with a generated signal of 50,000 Watts, reaching a significant portion of southeast Saskatchewan. CreekFM can be tuned in from Pilot Butte to Yorkton and from Indian Head to Raymore, reaching an estimated 20,000 listeners (The CreekFM). Clearly, the listening audience not only reaches the Standing Buffalo First Nations reserve, but stretches across southern Saskatchewan.

Unlike a standard advertisement, which promotes a certain product, a PSA is intended to change the public interest, by raising awareness of an issue, affecting public attitudes, and potentially stimulating action (Public Service Announcement, Wikipedia, 2011). Much like the Indigenous Circle strategy mentioned above, the CreekFM PSA would be used to announce upcoming community events and programs promoting wellness. The PSA could also be used to state quick facts regarding health and wellness. For example, a PSA could be developed regarding wearing bicycle helmets, an anti-bullying campaign, and raising self-esteem. As a reference, the Concerned Children's Advertisers have a great website full of information about public service announcements targeting Canadian youth (http://www.cca-kids.ca/psas/index.html).

There are several benefits to creating a PSA. First, the youth and young adults developing the PSA will have the opportunity to improve their writing skills. According to the National Institute of Justice (2007), a written made for radio PSA should be creative, concise, and include the 5 W's, who, what, when, where, and why. Again, just as the Standing Buffalo elders wanted the use of cameras for skill development, creating the PSA will also help enhance the youth's writing skills. Another advantage of using a PSA is that they are free, and would not cost the community any monetary expense. When properly created, a PSA can help educate, inform and motivate the community and the public on a variety of wellness issues.

The development of public service announcements should not be aired just one time. To be most effective, the PSA should be repeated and heard over and over again. Having the time to produce a large number of PSA may be one disadvantage. The Standing Buffalo youth, along with the research team may need to choose one to two wellness related issues (i.e. drinking and driving and active living) they want to target, and focus on airing those for a few months. In the mean time, they can also work on producing a PSA for any upcoming community events. The research team could seek the assistance from a teacher at the local school, who can help with the writing process and do so before, during, or after school hours.

The CreekFM is also community-based programming, so the listening audience is mostly comprised of Aboriginal listeners. In contrast, CTV News is watched by Aboriginal and Non-Aboriginal viewers, so the scope of their audience is wider.

Social Media

The final strategy, and the one being recommended for use is utilizing social media to promote "being and becoming well." Social media can be defined as web-based technologies or mobile technologies to turn communication into interactive dialogue (Wikipedia, 2011). Examples of social media include text messaging on a cellular phone, instant messaging (IM), social networking sites (SNS), blogs, Youtube, and email.

Based on a number of statistics, the use of social media by youth and young adults is significant. For example, 93% of teens ages 12-17 go online, with 63% reporting daily usage. The percentage of teens owning a cell phone was a reported 71% in 2008, up from 45% in 2004. Most importantly, 61% of teens send friends messages through SNS, and 73% of teens have their own SNS profile or page, such as the very popular Facebook (Lenhart, 2009). By these numbers, one can see that youth are using social media at a high rate to communicate with one another, often communicating more using the computer than they do face-to-face.

While the use of the internet and other social media sites may be novel and threatening to some older individuals with far less exposure and experience, the same cannot be said for most youth. According to the RCMP, for youth, using and communicating through the computer is not a distant environment but rather another medium to engage friends, follow interests, and gain information (RCMP, 2011).

The plan for this strategy is to use social media to pass along information using the technologies most utilized by today's youth and young adults. The Standing Buffalo youth would be responsible for using social media to distribute wellness tips, events, stories, programs, etc. to other youth and young adults within and outside their community. An example would be creating a Facebook group, which allows free communication within a specified group of people. On a Facebook page, all members can list upcoming events, post messages, upload videos, connect to more individuals, create blogs and share information.

A quick search of Facebook reveals there are 62 members of an already established Standing Buffalo Dakota Nation Facebook group (http://www.facebook.com/group.php?gid=21378650540). An audience is present and out there, with the potential for even greater growth.

The benefits of using this method contain some of the benefits of the previous two strategies. First, the youth involved will be responsible for writing, producing, and distributing information. This will of course involve keyboarding on a computer, and this is a skill that should not be undervalued. An article from the Vancouver Sun further illustrates this point. It states that 48 U.S. states are currently transitioning from an old curriculum of handwriting to one with an emphasis on keyboarding. The article further adds that much of our daily personal and business correspondence occurs through email and text massaging (Baziuk, 2011). Again emphasizing the need to develop keyboarding skills to keep up with the rest of the population.

The second benefit of this strategy is the instantaneous and constant messaging that can occur. Individuals can send and receive messages in a matter of seconds and at anytime of the day. In contrast the previous strategies could only occur on a weekly basis, or at the scheduling discretion of the television and radio companies.

The target audience is also ideal for reaching the demographic intended by the Standing Buffalo elders at the onset of the research project. Elder Velma stated during the Summer Institute that the impact of this project should come through the youth, some now young adults, and for them to carry on the work by teaching the younger children. Therefore the continued focus of the knowledge to action plan is utilizing the youth of Standing Buffalo.

Using social media has the potential of reaching a far greater number of individuals. The internet is not bordered by radio wattage or television viewing rights; it is accessible to all people, all over the world.

This fact however can also be a negative, especially with youth and young adults involved. Many adults may be concerned with the type of people having access to the sites and its members. It is important to have an adult moderator to help manage the messages coming in and going out. Many SNS allow you the opportunity to block certain members as well. There are also many sites, such as Microsoft's "Protect Children Online" that offer tips to help make SNS safe for young users (http://www.microsoft.com/security/family-safety/kids-social.aspx).

Conclusion

The research project, Ocanku Duta Amani: Paths to Living Well, examined aspects affecting the health on-reserve youth. The challenge posed to those in the case study was to determine how knowledge to action could best be achieved. Using the information from the head researcher and those from the Standing Buffalo community, I have presented three such strategies that directly engage the youth, provide them with opportunities to develop technological and life skills, and enable the youth of Standing Buffalo to spread their word to outside communities.

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Case Study #5

595 Prevention Team

Facilitators:

Paula Migliardi and Albert McLeod

The 595 Prevention Team

Facilitators: Paula Migliardi and Albert McLeod

The 595 Prevention Team is a coalition of over 100 member organizations interested in addressing the determinants of health and preventing the transmission of sexually transmitted infections (STI) and blood borne infections (HIV/AIDS and HCV) in Manitoba.

Mandate

The mandate of The 595 is to work with peers[1], community members, policy makers, and leaders to make recommendations regarding the development, implementation and evaluation of sexually transmitted and blood borne infection prevention initiatives based on evidence and best practice with priority populations.

Values

The 595 has four core values. The first, using a client-centered approach, speaks to the importance of the client being engaged in their health and wellness regardless of where they are at along their path. The second value of the 595 is to develop a practice that is, at the core, non-judgmental. Thirdly, the 595 values relationship building as the foundation of strong therapeutic relationships. Lastly, the 595 supports the development of supportive environments that provide all kinds of people with comfort and the capacity to contribute and engage in their communities.

Vision

The 595 is a broad and diverse network of peers, service providers, administrators, and policy-makers collaborating to provide province-wide access to services, materials and resources rooted in the principles of health promotion for priority populations. We are committed to using and promoting evidence-based practices. We are peer driven with peers having strong representation in all aspects of the network.

Strategic Priorities (See Appendix A)

1. Welcoming peer input and meaningful peer involvement. Building capacity of peer member organizations. Specifically involvement of PHAs, People living with Hepatitis C, sex trade workers, and injection drug users.
2. Increase the promotion and education of resources rooted in principles of harm reduction for Peers and professionals in Manitoba.
3. Increase access to harm reduction services, materials and resources to those in need.
4. Broadly integrating the philosophy of evidence based practice in STBBIs.
5. Marketing The 595 Prevention Team.

Involvement in Community-Based Research

The 595 is committed to utilizing research to guide our work. Over the past few years, we have made community-based research part of our operations. A number of peer researchers

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[1] A peer is an individual who self identifies as a member of an affected community and has/is working in a formal or informal peer support capacity to reduce the rates of HCV, HIV & STIs.

have been engaged and mentored in research and have conducted research to assess the role of peers in community organizations. This research has led to securing funding to support the Prevention Team. We are completing a project on peer led distribution of harm reduction supplies, including drug use resources.

Community Based Health Research: Summer Institute

Case Study Description

Project Title: **What Goes Around: How Peers Use their Social Networks to Share Safer Drug Use Resources**

Research Topic:

One of the most effective methods of ensuring vulnerable populations have access to information and resources regarding HIV and HCV prevention and safer drug use is through peer-to-peer knowledge exchange. But further research is required to have a greater understanding of how peers use their social networks to share information, particularly when this information is shared "informally" and without initiation from service providers. As well, what does "safer drug use" mean to peers? Is HIV and HCV prevention information of highest priority to peers or is other "safer drug use" information more important? This project will explore the processes in which peers share safer drug use information within their social networks.

Objectives

1. To identify the scope of peer social networks.
2. To describe the processes in which peers share information, resources, and tools regarding safer drug use and HIV/HCV prevention, in their social networks.
3. To determine what information and resources are most important to peers for sharing.
4. To make recommendations for peer-to-peer knowledge exchange services based on the data gathered through this project.

Rationale

Evidence supports the inclusion of peer-to-peer knowledge exchange as a key component to HIV/HCV prevention and safer drug use messaging. However, "peer-to-peer knowledge exchange" may mean something different to service providers than to peers themselves. To service providers it often means training peers to provide education and resources in a formal setting (workshops, outreach, supply distribution) and often the peers doing the work are not actively street involved or drug users. This project seeks to explore what peer-to-peer knowledge exchange means to peers themselves, particularly in an informal setting. Some issues to be explored in this project are: in which social networks does information get shared, what information is most important to share, how are information and tools exchanged, where do peers access accurate information, and what does "best practice" mean to peers.

Procedures and Action Plans

- Meetings with Peer Forum members
- Identify key researchers from Peer Forum
- Develop interviews/survey/focus group tools.
- Identify and contact participants
- Conduct interview/surveys/focus groups.
- Workshop developed
- Dissemination plan

Data analysis plan

Data analysis will be conducted throughout the project, with the assistance of the MHRN evaluator. The researchers and staff (Education Coordinator, Evaluator) will develop the tools to gather the information (surveys/interviews/focus groups for example). After each session the researchers analyze the data, identify common themes, surprising/interesting comments, and make recommendations for further action.

Milestones

- Grant approved for project.
- Research (Interview/focus group/survey) tools are developed.
- Participants for interviews/focus groups/surveys are recruited.
- Interviews/focus groups/surveys are conducted.
- Research results analyzed, recommendations for further action identified.
- Method for dissemination developed.
- Workshop developed.
- Information is disseminated through Manitoba.

Participants

The 595 Peer Working Group members, members of peer networks, and staff at the 595 (Education Coordinator, Coordinator, and Evaluator) will be involved in the project in all aspects of the research.

Relevance

The information gathered through this project will support peer-to-peer knowledge exchange programs/services to ensure that peer voices are heard and their recommendations for priority issues and services are put forward. As well, this project will gather information on how peers share information in an informal setting so that more formalized programs can build off on existing knowledge exchange among peers.

Case Study #6

Saskatoon Poverty Reduction Partnership: Community-Based Research Case Study

Facilitators:

Dr. Sylvia Abonyi and Dr. Mary Hampton

Saskatoon Poverty Reduction Partnership: Community-Based Research Case Study

Prepared by: Christine Thompson and Jennifer Cushon

Introduction:

For more than a decade, poverty has been an issue of concern in Saskatoon (refer to Appendix A). *Health Disparity in Saskatoon: Analysis to Intervention* (Lemstra & Neudorf, 2008), catalyzed further momentum around the issue of poverty reduction in Saskatoon. This report presented extensive local data on health outcomes. Findings showed that in comparison to high-income residents, Saskatoon residents of low-income neighborhoods were:

- 1389% more likely to have chlamydia
- 3360% more likely to have Hepatitis C
- 1549% more likely to have a teen birth
- 448% more likely to have an infant die in the first year
- 1458% more likely to attempt suicide, and
- 1186% more likely to be hospitalized for diabetes.

The report also considered possible solutions. Based on an extensive review of strategies pursued elsewhere, it identified 46 policy options which evaluation research had shown to be effective at reducing poverty.

After discussing the report, the Saskatoon Regional Intersectoral Committee (the SRIC) concluded that concerted action was required. It identified three priorities for its work: a community action plan for poverty reduction, sustainable housing, and Aboriginal employment. While housing and Aboriginal employment warranted dedicated attention, they were also viewed as key elements of an overall poverty reduction plan.

In addition to securing support from the SRIC, the report also put new energy behind the efforts to mobilize broad community involvement in poverty reduction. In May 2009, the United Way, Community-University Institute for Social Research (CUISR), the Saskatoon Anti-Poverty Coalition (SAPC), the Saskatoon Health Region (SHR), and other community partners organized the Saskatoon Community Well-Being Design Charette, an intensive planning process intended to turn research and dialogue into action. Over two and a half days, 100 diverse participants from Saskatoon outlined a vision for a poverty free Saskatoon and strategies for accomplishing it.

Over the next several months, the SRIC, SHR, the United Way, and CUISR joined forces to build on this beginning through: a) focus groups with parts of the community not fully represented at the charette (business, faith community, Aboriginal community, people in poverty, and youth); b) all stakeholders in the focus groups were asked to indicate which of the 46 Health Disparities Report policy options they supported, which they could not support, and what other strategies they would recommend; and c) investigating other Canadian communities pursuing comprehensive, collaborative approaches to poverty reduction.

On November 24, 2009, the SRIC sponsored a follow-up meeting to consider the results of this work and to determine an initial set of strategies – those with the greatest agreement and support (refer to Appendix B). After this follow-up meeting, the SRIC and a range of community partners came together to form the Saskatoon Poverty Reduction Partnership (SPRP). The SPRP aims to create and implement a poverty reduction action plan, scheduled to be released in September 2011. A governance model for the SPRP was also created (refer to Appendix C). The governance model includes a Leadership and a Coordinating Group, which include representatives from different sectors (refer to Appendix D). Action Groups were a key component of the SPRP's original governance model and were intended to encourage community mobilization around issues that had been identified at the November 2009 meeting. However, Action Group progress and engagement has been problematic.

Overview/Analysis:

Action Groups were formed to address the specific issues of: health, child care, education, housing, income assistance, and employment. These Action Groups were assigned three immediate tasks: 1) inventory of what is already happening on the issue; 2) identify where there are gaps that need to be addressed; and 3) outline the steps needed to achieve desired outcomes. Terms of Reference for the Action Groups were drafted (refer to Appendix E). Some of the Action Groups met a limited number of times, and others did not meet at all. At this point, the Action Groups are not a strong component of the SPRP's governance model. It is unclear how the SPRP will encourage community mobilization around specific issues without the inclusion of the Action Groups.

The SPRP is an excellent example of intersectoral action, bringing together a broad variety of sectors and actors. The literature has found that intersectoral action is most effective when action is both top-down and bottom-up (PHAC & WHO, 2008). In other words, mobilization and change needs to occur at both the top (i.e., policy level) and bottom (i.e., community level). Baum (2007) points out that one of the most common challenges with promoting greater health equity is ensuring that top-down action is linked to bottom-up action to 'crack the nut' of inequity. At this point, the SPRP is heavily focused on top-down action (i.e., policy change), and bottom-up change is not well represented.

Case Problem:

The Leadership and Coordinating Groups of the SPRP would like to further community well-being and poverty reduction through community engagement and mobilization. The Action Groups of the SPRP were originally intended to encourage and accomplish community engagement and mobilization. However, maintaining momentum within the Action Groups has been problematic. The majority of Action Groups never met or only met a limited number of times. It is not clear why this occurred. Some anecdotal reasons cited are: a) lack of clarity around the purpose of the Action Groups; b) lack of operational support; and c) Action Groups were duplicating work already being carried out in the community.

Prepare recommendations on how to encourage community engagement and mobilization for the SPRP.

Appendix A

Poverty Reduction in Saskatoon Timeline

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
Core Neighbourhood Development Council	■	■	■							
SAPC Roots of Poverty Project	■	■								
Saskatoon Anti-Poverty Coalition (SAPC)	■	■	■	■	■	■	■	■	■	■
CUISR Quality of Life Research	■	■	■	■	■	■	■	■	■	■
Urban Aboriginal Strategy – Poverty Work							■	■		
Wellness Design Charette and Working Group									■	
SHR Health Disparity Report								■		
United Way Community Conversations								■		
Post Charette work - SRIC and Charette group									■	
SRIC Poverty Forum and Planning Group									■	
SRIC Poverty Forum Working Groups										■
Saskatoon Poverty Reduction Leadership Group										■

Appendix B

Saskatoon Poverty Reduction Partnership
Initial Action Groups
November 24, 2009

On November 24, 2009, the Saskatoon Regional Intersectoral Committee convened a community forum to support the development of a Saskatoon action plan for poverty reduction. Based on research and consultation undertaken in preparation for the forum, participants identified the following items as the starting points for detailed planning:

1. *Health*: increase health resources in low-income neighbourhoods; increase public understanding of the social determinants of health.

2. *Child Care*: develop universal child care for low-income parents; increase support for parents on leave.

3. *Housing*: expand affordable housing projects; expand not-for-profit housing authorities; increase support for home ownership; develop a long-term, consolidated, comprehensive, inter-agency social housing system for hard-to-house individuals; renew federal responsibility for social housing.

4. *Education*: reserve education placements for people with low incomes; increase support for community schools.

5. *Income Assistance*: index social assistance rates to inflation; increase monthly shelter allowances; change lower limit tax exemptions.

6. *Aboriginal Employment*: expand employment opportunities for Aboriginal people.

7. *Welfare to Work*: develop comprehensive return to work programs; remove work earning claw backs.

8. *Coordination of Efforts:* develop a multi-year, targeted plan to reduce poverty.

Appendix C

Governance Structure Description

Saskatoon Poverty Reduction Partnership

The governance model for the Saskatoon Poverty Reduction Partnership is based on the Centre for Social Innovation's (CSI) Constellation Collaboration Model[1]. The Constellation model is a complexity-inspired governance framework for multi-organizational collaboration. It is a way of organizing a group of various partners to meet a need and work toward a joint outcome without having to create a new organization to 'hold' the issue.

The strength of the model is in its balance between a strong base of roles, responsibilities, vision, strategy and planning that still allows emergence or flexibility among the 'constellations' or action groups.

Energy and intentionality are the underlying forces that support the model. Energy is the recognition of people and organizations' motivations, priorities, strategic goals and sense of urgency around an issue. Intentionality is the consciousness of the work of the partners toward the shared vision. Not everyone involved needs to be conscious of how they are working in the model, but the core leadership partners need to be operating intentionally. Intentionality is the wisdom behind the energy.

The following are descriptions of the model components:

Community Roundtable

- The overall governance structure evolved as a result of a group of people recognizing a need in which working together could achieve both individual and shared outcomes. The need is the most important part of the model as its draw will determine the level of priority that the partners will give it within their broader scope of work. It determines the level of energy that drives the success of the model.
- It is essential to be connected into the broader network of community partners, individuals and organizations working to reduce poverty and improve community well-being.
- Gatherings will be held 2 – 3 times per year with an open invitation to attend.

Leadership Group

- Overall decision-making and direction setting
- Accountable to take information back to and be a liaison with relevant sectors/organizations
- Includes key influencers and organizations, those with lived experience, and those with credibility in organizations and/or community
- Leads strategic planning, with input from the Action Groups
    - outlines a clear set of assumptions or guiding principles, vision and a plan that identifies how the partners will work together

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[1] Surman T. Constellation Collaboration: A model for multi-organizational partnership. Toronto: Centre for Social Innovation, 2008.

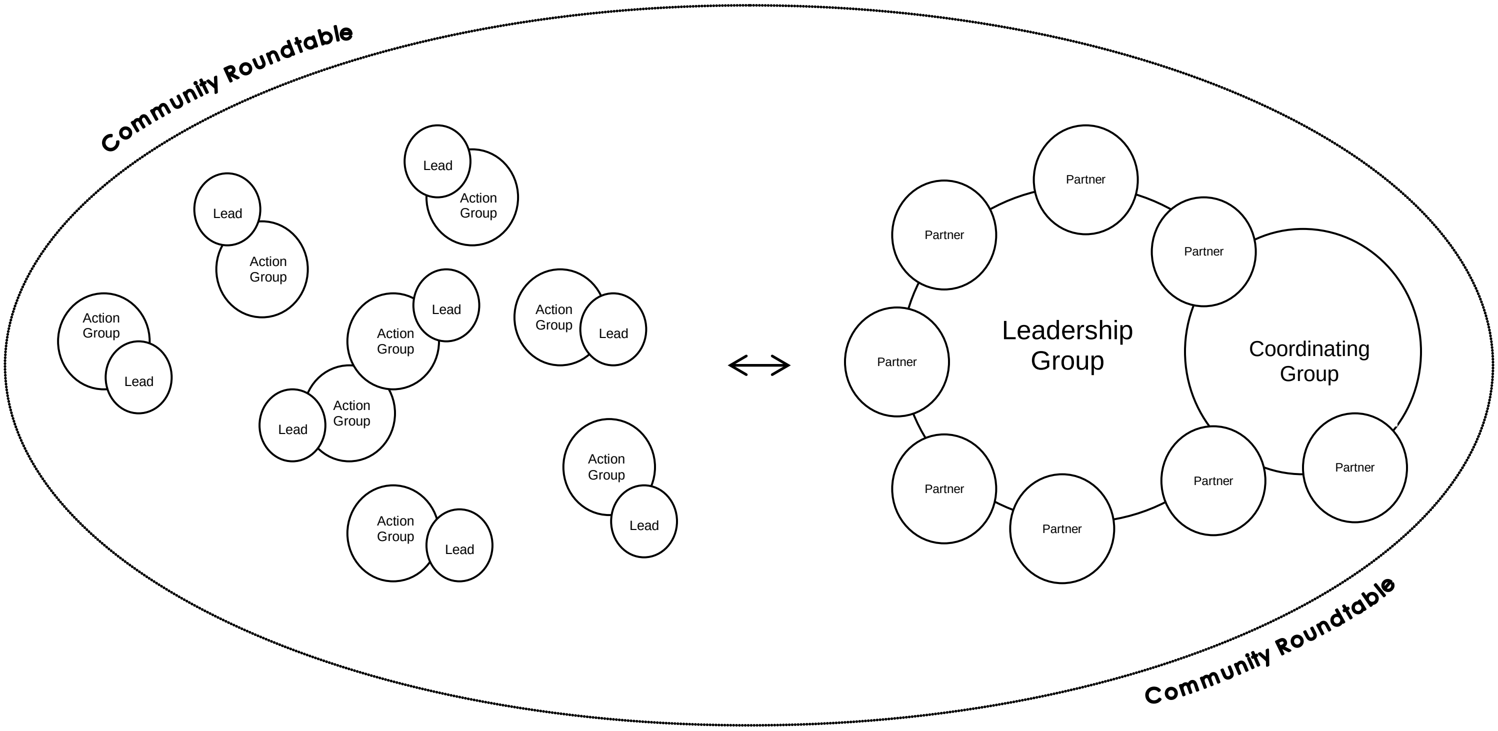
  - builds on assets, core competencies and interests of the partners
  - specific enough to mobilize action and measure success but flexible enough for new structures and initiatives to emerge
- Self-interest exists primarily in the arena of the Action Groups; collective interest is stewarded by the Leadership Group
- Ensures overall health of the Partnership and Action Groups
- Assesses current assets, successes, gaps and needs in the community
- Balances the flow of leadership and money among partners
- Invites new partners to be a part of the collaboration
- Scopes the nature of how and why the group should work together
- Assesses the gaps and evaluates the progress of the partnership and how the issue is transforming within the broader community
- Meets every 2 – 3 months
- Size ~ 15 members
- Membership:
  - Business
  - Faith
  - Provincial government (Social Services, Advanced Education)
  - CUISR
  - Saskatoon Health Region
  - United Way
  - CBO
  - First Nations and Métis
  - City of Saskatoon
  - Saskatoon Anti-Poverty Coalition
  - School Divisions
  - SRIC
  - Action Group leaders

Coordinating Group

- Acts on behalf of the Leadership Group re: implementation of decisions
- Size 7 – 10 members
- Meets every four to six weeks
- Membership:
  - CUISR
  - Saskatoon Health Region
  - United Way
  - City of Saskatoon
  - Saskatoon Anti-Poverty Coalition
  - SRIC
  - Staff, if relevant

Action Groups

- Drive the model
- Work in an enabling environment in which accountability and coordination are in place, as established by the Leadership Group and Coordinating Committee
- Plan and implement specific poverty reduction strategies in concert with the broader strategic vision
- Are self-organizing around a common framework; they are clusters of activity in which a subset of the partners and others in the community voluntarily participate
- Can be based on formal projects, opportunistic initiatives or committees that guide particular aspects of the work of the partnership
- Members do not need to be aware that they are part of this governance structure
- One partner takes a lead role and acts as the fiscal and accountable authority on the activity (e.g., leadership, linkage to Coordinating Group, provides Action Group secretariat support)
- The lead is determined on a case-by-case basis, as determined by the partner's interests, competencies and fit with potential funders
- Liaise with the Leadership Group to ensure efforts are coordinated and duplication is avoided
- May be long-term or short-term, depending on the energy and shared interest of those involved
- Are created by a recognition of a need or opportunity which is matched with the energetic leadership to move a particular issue forward; anyone can ignite an Action Group



Partnership Secretariat and Human Resources

- United Way provides secretariat support for groups other than the Action Groups
- Tanya Dunn-Pierce, Manager of Health Promotion, Saskatoon Health Region, is seconded for two days per week to work with the Saskatoon Poverty Reduction Partnership to develop the action plan
    - Tanya is working Thursdays and Fridays until February 2011
    - Tanya's time will be covered by some of the HSIF dollars received for this initiative
- Christine Thompson, Director of Community Impact, United Way, is dedicating one day per week for the Partnership
    - Christine is working on Fridays until February 2011
    - Christine's time is part of her regular role at United Way and will not be expensed to the Partnership
- Short term consulting opportunities will be explored as needed.

Guidelines for Managing the Flow of Money and Power

- The partnership is not a legal entity so fiscal and legal responsibility rests with the partners.
- The Action Groups drive the model so project leadership and resources are constantly coming from different places and going to different organizations.
- The Action Group leads have the authority to make legal and fiscal decisions; however, the conflict resolution process will outline the consultation and decision making process taken to protect other partners.
- The Leadership Group has the authority to make legal and fiscal decisions related to their scope of work (e.g., staff contracts); authority may be deferred to the Coordinating Group on some matters.
- Core, long term funding for the Leadership Group level will be sought so as it does not compete for funding sought by the Action Groups (e.g., grants).

Guidelines for Communications and Transparency

- The Leadership Group will identify communication tools needed to facilitate group communications and feedback.
- Clear, regular communications from and to the partners is foundational to the model.
- Specific communication responsibilities will be deferred to the Coordinating Group.

Appendix D

Saskatoon Poverty Reduction Partnership

Updated Jan 4 2011

Leadership Group Membership*

Anti-Poverty Coalition
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City of Saskatoon
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Christine Thompson
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Tel: 975-7705

Ministry of Social Services Linda Gaudet Senior Policy Analyst, Child and Family Services - Centre Region Linda.Gaudet@gov.sk.ca Tel: 933-6577	** This membership list is not exhaustive. Additional linkages are being explored with the Business, First Nations & Métis and other communities.*

Coordinating Group Membership

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Appendix E

Saskatoon Poverty Reduction Partnership

Action Group Terms of Reference (DRAFT) *Updated Sept 30 2010*

Background

The Saskatoon Poverty Reduction Partnership (SPRP) is developing a community plan to reduce poverty in Saskatoon. The plan will guide the implementation of poverty reduction initiatives in Saskatoon which holds partners mutually accountable.

The partnership is based on multi-organizational collaboration; various partners work together toward a joint outcome without having to create a new organization to 'hold' the issue. The model balances a strong base of roles, responsibilities, vision, strategy and planning that also allows emergence or flexibility among Action Groups.

Energy and intentionality are the underlying forces: energy is the recognition of people and organizations' motivations, priorities, strategic goals and sense of urgency around an issue and intentionality is the consciousness of the work of the partners toward the shared vision.

The partnership is governed by a Leadership Group and a Coordinating Group.

Objective

Action Groups will make evidence-based recommendations to the Leadership Groups on priority poverty reduction issue areas. The recommendations will inform the development of a Saskatoon Action Plan to Reduce Poverty.

Action Groups will assess current assets, successes, gaps and needs in the community related to the particular issue area, outline the steps needed to achieve desired outcomes, and potentially implement these steps. This work is completed in concert with the SPRP's broader strategic vision.

Timeframe

The expected timeframe for initial steps is September 2010 – March 2011. Action Groups may decide to continue meeting beyond this timeframe depending on the energy and shared interest of those involved. May be short term or long term, depending on the energy and shared interest of those involved.

Meetings

Frequency of meetings will be determined by the Action Group members. It is expected regular meetings will be every 2-3 weeks.

Authority

Self-interest exists primarily in the arena of the Action Groups; collective interest is stewarded by the Leadership Group. The partnership is not a legal entity so fiscal and legal responsibility rests with the partners. The Action Group leads have the authority to make legal and fiscal decisions; however, the conflict resolution process will outline the consultation and decision making process taken to protect other partners.

Regular Communications Action Groups will provide monthly updates to the SPRP Coordinating Group and quarterly updates to the SPRP Leadership Group, and may be requested to report at 1-2 Community Roundtables. Action Group Leads will come together at regular intervals. These assist efforts to be coordinated and avoid duplication.

Membership Membership is determined by each Action Group. Members may include stakeholders from a mix of sectors and interest groups including:

- Community service agencies
- Aboriginal
- Health
- Provincial government
- City/municipal government
- School divisions
- Business and Labour
- Faith
- Poverty advocacy groups
- Poverty self-advocates
- University
- Funding bodies

Roles: *Organization Champion*: Convenes and leads and facilitates the Action Group (plans meetings, documents discussions & recommendations, communicates with Action Group members). Facilitation support is available through the SPRP if required. The Organization Champion is the main reporting contact to the Leadership and Coordinating Groups.

SPRP Staff: Provide planning and troubleshooting support to the Action Group, mainly through the Organization Champion.

Research/Evidence Staff Support: May be available through the SPRP if required.

Funding: An operational budget is not available for the Action Groups. Action Groups members are requested to provide in kind support for meetings (space, refreshments, secretariat support, etc.). Action Groups may choose to pursue funding (e.g., grants), in coordination with the SPRP Leadership and Coordinating Groups, to support their work.

Evaluation: Action Groups may be requested to participate in evaluation activities related to the SPRP being conducted through the Measurement & Evaluation Working Group.

Saskatoon Poverty Reduction Partnership Action Group Template

Identify Action Group Name/Issue Area:
List Action Group Members (include names & organizations/groups):
Identify Organization Champion and Contact Person:
Identify Meeting Facilitator(s):
Outline the strategies that are shown by existing evidence (including research evidence) to be effective in addressing this issue area. A good starting point is reviewing relevant sections of the Saskatoon Health Region's *Health Disparity Report*.
Identify the stakeholders in the community that are affected by and influence this issue area.
Describe the current assets and successes in the community related to this issue area.
Identify groups and/or plans that already exist to contribute to action around this issue area (include local, provincial and national groups & plans).
Describe the gaps and needs in the community related to this issue area.
Identify any data currently being collected in the community related to this issue area.
Outline recommendations for next steps to achieve desired outcomes in this issue area.
Describe commitments needed by different stakeholders.
Describe the barriers and potential solutions to these barriers related to the recommendations for desired outcomes.

Saskatoon Poverty Reduction Partnership Analysis

Sheryn D. Peterson

University of Regina

The poor are not the problem, rather, the problem lies in the societal relationships and processes leading to and perpetuating impoverishment. Health inequities are crafted by unfair and unjust policies and practices that preferentially reward certain groups, economically and socially at the expense of others (Krieger, 2007).

Introduction and Background

This paper will supplement case study #6 final report that was completed on July 14, 2011 by students from the Community Based Health Research Summer Institute. The final group report and individual student papers will be submitted to the Saskatoon Poverty Reduction Partnership (SPRP). The information provided by the SPRP indicates that a concerted effort has been made to address poverty over the past ten years through a partnership of approximately twenty agencies that are a combination of government, faith base and community organizations. My paper will focus on the SPRP priority to use a community action plan for poverty reduction; in addition I will elaborate on the following three recommendations from the final case study report:

1. Use focus groups to determine why action groups are not working
2. Do a critical review of the governance structure and model of SPRP
3. Explore the larger social and political context

The three aforementioned issues are lack of community engagement with the action groups, governance structure, and the larger social and political context surrounding poverty reduction. It is important to define poverty and why a community based research approach is needed. Poverty, as defined by Webster is “the state of one who lacks usual or socially acceptable amount of money or material resources” (Merriamwebster 2011).

For the purpose of this paper I will refer to the statistics and health outcomes documented in the Saskatoon Health Disparity Report in regards to social and health disparities within Saskatoon, Saskatchewan. Because there is no operational definition for poverty reduction it is my assumption that the longitudinal data on health outcomes for Saskatoon will be one measure that the SPRP uses to evaluate success on whether or not poverty has been reduced.

According to Health Canada, income and social status are the most important determinants of health because people at each level of the income scale are healthier and live longer than those at the level below (Braun, 2008). As such, one can assume Saskatoon residents can improve their health by increasing their income. Therefore when considering poverty reduction strategies a public policy perspective must be addressed. SPRP must consider both a short and long term approach to poverty reduction. David Hay with Citizens for Public Justice explains that it seems likely that current health status depends more on the cumulative effect of income over time than the effect of present income on present health status. Hay concludes that policy making in the improvement of the conditions for children in lower income families is a public policy challenge (deGroot-Maggetti, 2009). This idea of thought encourages the idea that SPRP must work at both the micro and macro level to address the issue of poverty. The micro level approach will promote programs and interventions for healthier outcomes, whereas the macro approach will work with policy makers and funders to address systemic issues and bias. Therefore can a CBR approach work to address both long term and short term programs to deal with health outcomes?

With proper techniques and execution CBR is a method that can work well. CBR emphasizes collaboration, relationship, trust, and respect. From the beginning resources must be invested to develop collaborative relationships between stakeholders and politicians to ensure project success. A community based approach values the grass roots or bottom up style of community engagement.

Based on the information available it is likely that a traditional top down approach has been implemented with the SPRP. The Saskatoon Health Disparity Report states an extensive literature review has been completed with 46 recommendations for policy options to reduce poverty or social and health disparities within the general categories of health care, education, income, employment, and housing (Lemstra & Neudorf, 2010). A randomized telephone survey was completed in Saskatoon to find out what people's opinions are on reducing poverty and the findings indicate strong public support. The SPRP state that both the evidence based research and the community of Saskatoon are supporting a move forward with poverty reduction strategies. However, the dilemma that SPRP has is how to get the action groups working within the organizational structure to move the poverty reduction strategies forward. The action groups have been designed as a catalyst for community engagement within the SPRP to get partners from various agencies to work toward a common goal of poverty reduction.

Community Engagement

One of the key principles of CBR is equal partnership, which means walking together side by side, learning and sharing together. Action groups were established to be a voice in the community for the SPRP to engage the community; however, these action groups are not working well, possibly because they are separate from the SPRP Leadership and Coordinating Groups. Therefore, an equal partnership was not achievable. In spite of this the short term nature of some action groups may have impeded the ability of actual groups to do successful work towards sustainability. It appears that the action groups were set up to act more as a short term focus group rather than as a group able to coordinate, conduct and analyze a particular item for detailed planning. Some of the difficulties with focus groups according to Gehlert are that their transitory nature is a disadvantage because it precludes a long-term relationship (Gehlert, 2010). To be effective a CBR approach requires an investment of time into developing relationship and trust amongst group members.

To accomplish the goal of poverty reduction one must assess what is working and not working with the SPRP action groups. One approach identified is to conduct a qualitative study by using focus groups to determine strengths and weaknesses of the current action group model. Focus groups would be held with an unbiased, neutral, facilitator using a predetermined script of questions to gather further insight into issues regarding lack of engagement.

Another potential method for the SPRP to enhance community engagement of action groups is to use a six point checklist developed by kidSKAN for building effective partnerships. KidSKAN, or, Saskatchewan Knowledge to Action Network, is a provincial partnership receiving funding from the Canadian Institutes of Health Research. This six point checklist was designed by a team of early childhood professionals to be used as a resource for other partnerships or “communities of practice”; informal groups of people who share a common interest and come together to reflect on and improve their practice together (SPHERU, 2011).

The “communities of practice” approach closely resembles the principles of CBR as both methods boast collaboration, consensus building and inclusive approaches which work together for success. The kidsKAN tool has been developed by a community based agency and tested by community based agencies (SPHERU, June 2011). The following six point checklist provides an approach for developing and strengthening community engagement for action groups and is also a tool for evaluation and troubleshooting how the action groups are actually functioning.

The first step is to provide opportunities for regular interaction. Because the partnership has been stagnant for quite some time, momentum could be built with some face to face public events which will help to build trust and rapport amongst members. The second step is to allow participation to vary over time. The SPRP has long standing involvement with many partner organizations, so it would stand to reason that involvement of various groups will ebb and flow over time. New methods of involvement such as online media can be explored for members to easily follow the partnerships activities and contribute when they can. The third step is to provide public and private spaces for interaction. Partnerships need to have both public spaces where members can interact and private spaces for small groups. The environmental space is an important factor to consider when examining why the action groups have not been active. Group members need access to space that is accessible, comfortable and safe. Successful partnerships need to be transparent with their activities and business and online technology may be a means for accessible facilitation. The fourth step is to document activities, goals and outputs. There is great potential for partnerships to flourish through the use of online technology because of the vast group of individuals online in today’s day and age. However, on a cautionary note, ease of access and use may be an issue for some because some group members may not have access or the skills required to use online technology. The fifth step is to enlist a technology champion. With ever increasing access to technologies such as websites and discussion forums, partnerships have the opportunity to embrace the flexibility that social media offers. To efficiently utilize these outlets it is important to have someone who is skilled in online technologies and can assist agencies in developing and maintaining online support. The sixth step is to identify the value of the community itself. The SPRP is an intersectoral, interdisciplinary partnership of several community based organizations, holding much potential to be a rich organic group because of the knowledge sharing from all members. Stories told by community members can have the greatest impact and rewards because they are sharing their lived experiences on how the work accomplished by SPRP makes a positive difference in their lives.

Governance Structure

The SPRP case study document prepared by Thompson and Cushon sites the SPRP as an excellent example of intersectoral action which brought together a broad variety of sectors and actors. The writers use research to back their claim that in order to achieve health equity both a top down and bottom up approach are necessary to "crack the nut" of inequity (Thompson & Cushon 2011). However I argue that because the SPRP is focused on a policy change, or, top down approach, the bottom up change in the form of action groups, has not been well represented. It is important to note that often times top down approaches are seen as more efficient and a better use of time in comparison to the bottom up approach which requires more time for relationship and trust building.

SPRP recognizes the current organizational framework for getting action groups to function successfully is not working well for them; as such I am suggesting a closer look at CBR principles to guide the partnership between the agencies in meeting their common goal of poverty reduction. In suggesting that SPRP examine a CBR approach this holds the possibility that the current structure of Leadership Group, Coordinating Group & Action Groups be critically examined. Theory and practice need to be integrated so that each group functions as part of the whole system. It is noted by scholar Gehlert 2010 that:

> Achieving the multifactorial approach to eliminating disparities suggested by CHIN et al. (2007) requires that disciplinary scholars work more closely than they have traditionally done. Likewise, the culturally tailored interventions can be achieved only when academic researcher draw on the knowledge and resources of communities vulnerable to adverse health conditions. (p. 302)

Is the governance structure currently working and is there room to improve structural function ability that could be more inclusive of all partners?

At first look it appears that SPRP has all the key areas covered in their organizational structure, Leadership, Coordinating, and Action (Representing Community) groups. However the following issues the Case Study #6 group identified may have been avoided had a CBR approach been used. The first issue was concerning action groups not engaged with the development of working documents and terms of reference. In a true ‘partnership’ all stakeholder groups should have a say in the development of working documents. The second issue regards the structure of roles and responsibilities of the Action Group members which are loosely defined in comparison to the well-defined responsibilities of the leadership. A

CBR approach would have clearly defined expectations for all groups involved. The third issue identified was that no clear method of communication was identified for the SPRP groups for reporting to and from the partners. Again a CBR approach would allow for incorporation of various methods of knowledge translation for overall communication of goals and outcomes of the project either through contracts or memorandums.

Some CBR principles that will assist the SPRP groups to become mobilized in effectively reducing poverty are team & relationship building, knowledge translation to practice and policy, sustainable partnerships, culture and social classes, sharing of resources and decision making, conflict resolution, as well as having fun. It is important to emphasise the need for action groups to be involved at both policy and program levels. Researchers and outside experts also reject the idea that scientific objectivity demands creating a distance between themselves and their research subject, subsequently they are partnering with inside experts and community members who live with the issues being studied. Studies show that this approach will ignite new initiatives that lead to sustainable long term results through participation and involvement" (Horowitz, 2009). The SPRP could use the existing organizational structure of a Leadership group, Coordinating Group and Action Groups; however, an important factor of success will be the inclusion of community members as well as action groups on the leadership and coordinating committees.

Team and relationship building is one of the foundational principles of CBR which needs to be a shared responsibility. Building of relationships for the poverty reduction takes time, patience and stakeholders must recognize their common goal. Relationships in partners and projects are crucial to the success of poverty reduction efforts. Kennedy states in his article, that building relationships is a key goal of CBR, as relationships have the potential to develop into lasting partnerships that might improve relations between the community and the institutions, leading to additional future collaborations" (Kennedy, 2009, page 11). The action groups should have members from the leadership team participating in order to understand firsthand how poverty affects individuals, communities and society. Often people of privilege do not understand because they have no lived experience therefore it is important to walk side by side with each other in the partnership. A true partnership should have close cooperation between groups with joint rights and responsibilities. Horowitz 2009 study found the following:

> To form teams academics must supplement their scientific skills with humility, patience, curiosity, interpersonal skills, and the abilities to mentor inspire, share control, and focus on community interpersonal skills and the ability to focus on community concerns. Academics need to rely on community partners to teach them about the community, and point out if they inadvertently offend or discount community partners. (p. 6)

Knowledge translation is important when using CBR because it means that everyone will use language that can be understood by each member of the group. Knowledge translation must be discussed in the planning stages so the correct message will be translated to the larger group, the community, the media, policy makers and funders. A unified message from academics, community, and program staff is powerful because funders and policy makers will listen creating a potential for future funding. Policy makers value the CBR approach because it makes politicians look good when successful collaboration has produced a shared understanding of issues and solutions for social justice.

Knowledge translation is a learned skill that must be developed as such; members must be careful to choose the appropriate language of the community when describing each message, outcomes, and action plans. Emphasis should be placed on choosing the correct tool for the most effective communication, whether that is through the use of media, verbal or written reports, or community presentations. Knowledge translation should be discussed at the planning stages of the project so as to be clear what communication tools will be used, what goals and outcomes will be communicated and who will own the information. Stakeholder groups should be informed that knowledge translation templates are available to assist in guiding them through the important function of knowledge translation.

Culture and social class do exist within partnerships. This fact needs to be addressed from initiation to most effectively work towards the common goal. In my experience finding ways to work effectively with diverse groups bring much strength to the table such as noted by scholars. “Typically academics have evaluative competency and community members have cultural competencies” (Horowitz, 2009). Because CBR involves partnerships, such as the SPRP, that are cross cultural and span across social classes, issues of power and conflict will arise. Conflict, however, can provide an opportunity for growth which can expand perspectives of a diversity of individuals.

Conflict resolution is necessary for growth in developing problem solving strategies; as such the SPRP had developed a strategic conflict resolution model. It is important that all group members understand and feel empowered to use the conflict resolution tool because insight and a richer understanding can be achieved in finding solutions to conflict. It may be helpful to discuss with members which conflict resolution tool would be used. For some groups having a community member that is comfortable and confident in providing feedback to academics when a mistake is made can be crucial to the relationship building. Taking time to meet, having clearly written rules for how decisions will be made, and recognizing group member's strengths all contribute to the building of relationships. CBR calls for all members of a partnership to be responsible for their own actions and to look at their own misconceptions about other people from different walks of life. In order to continually move forward it might be necessary to include a clause which states that in some cases partners may have to agree to disagree. In addition, members must recognize that each individual processes and responds to information at different rates and must be aware that patience is indeed a virtue and understand that for an effective decision to be made people should not feel rushed to compromise on a decision. Sharing resources and decision making is about shared power and control; this means every member in every group has a shared responsibility in regards to funding and budget allocations. Sharing resources and decision making in a partnership means that each member has a voice and the power to contribute to the decision making process. However, as Horowitz states, we must be careful not to offer a token of marginal involvement but instead offer realistic and vital engagement in research (Horowitz, 2009). For success, researchers must genuinely be convinced that community partners have something to offer.

It is important that an element of fun be added to the group structure to ensure that meeting and working together can also mean having fun together. Having fun together will be helpful in understanding group members. In addition having fun can also be a good stress reliever from the daunting task of working through issues. Celebrating success both big and small should be a priority for SPRP.

Horowitz states that to inform and influence policy, teams must decide what specifically they want to advocate for, how to best frame the issue to make it compelling towards policy makers who are sympathetically receptive and influential in the defined area, and plan a strategy to approach them (Horowitz, 2009). Therefore, it is vital that the SPRP partnership mobilize its efforts and groups to become effective advocates for change. This becomes possible when a critical review has been completed and new approaches are adopted which engage the community at both a micro and macro levels in order to move the poverty agenda forward.

Social and Political Context

I have learned that policy makers and funders want to be at the planning table right from the beginning of the project and kept informed throughout the process. Because I am not familiar with the community of Saskatoon, I must inquire as to whether those policy makers that have the connections and drive to add value to poverty reduction efforts are present. To effectively address poverty Saskatchewan needs to have representatives at the table from various government departments including; health, social services, education and housing, in addition to representatives from First Nations governments. Kennedy states that several respondents noted that CBR was successful because it invested in the community or built community capacity. For example, investments in the community through the availability of health or social services, improving community health status, or hiring and training community members all contributed to social justice (Kennedy, 2009).

Krieger states that social remedies to the poverty-health debate will vary depending on political view; one side are proponents of the free market; on the other are those who seek a more democratically controlled and egalitarian economy (Krieger, 2007). SPRP has real authority to act on and change policies and programs, or whether it is just lip service and the action groups have become tired of hearing the same rhetoric.

In conclusion, CBR is an effective model that can be used to address the inequalities and health issues affecting most of our vulnerable population. Some of the approaches and principles are relationship building, trust, respectful and collaborative process, negotiate consensus of goals, communication, knowledge translation, sharing information, power dynamics in decision making and negotiate balance between academic and community relevance. CBR is about gaining new knowledge that has been produced from the findings and presenting it in a way that can contribute to social change in small and big ways. By employing these CBR principles, SPRP will reap the benefits of community engagement and that the important task of reducing poverty in Saskatoon will be achieved. I want to take this opportunity to thank SPRP for their transparency in sharing their working documents and their willingness to work with students. It has been an invigorating academic experience.

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COMMUNITY-BASED HEALTH RESEARCH: A Summer Institute

Weaving the Tapestry

SECTION 4 – READING LIST & RESOURCES

1. Reading List

The following is a list of resources provided by the session presenters.

Session I – Developing Relationships & Partnerships

Part 1: Collaboration

Bishop, R. (2008). Freeing ourselves from neo-colonial domination in research: A Kaupapa Maori approach to creating knowledge. In N. K. Denzin and Y. S. Lincoln (Eds.). *The landscape of qualitative research* (3rd Ed) (pp. 145-184). Thousand Oaks, CA: Sage.

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Reason, P., & Bradbury, H. (eds. 2008). *The Sage Handbook of Action Research: Participative Inquiry and Practice.* Thousand Oaks, CA: Sage Publications.

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Part 2: Research Ethics

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Community-Campus Partnerships for Health http://www.ccph.info/

Toronto Community-Based Research Network http://torontocbr.ning.com

Community Tool Box; Bringing Solutions to Light http://ctb.ku.edu/

National CBR Network Wiki http://cbrnet.pbworks.com/w/page/6418778/FrontPage

Centre for Urban Health Initiatives http://www.cuhi.utoronto.ca

Knowledge Translation Clearinghouse http://ktclearinghouse.ca

Community-Based Research Capacity-Building Programs

Prairie HIV CBR Program http://www.prairirecbr.com

British Columbia HIV CBR Program http://www.bchivcbr.org

Québec HIV CBR Program/ Le Programme de la Recherche Communautaire http://www.cocqsida.com

Alberta HIV CBR Program http://www.cbrAlberta.com

Aboriginal HIV CBR program at the Canadian Aboriginal AIDS Network http://www.caan.ca

3. Presentation PowerPoints

The following pages contain the PowerPoint presentations that were delivered on session topics at the Institute.

Developing relationships and partnerships: Collaboration

Gloria DeSantis, PhD
Saskatchewan Population Health & Evaluation Research Unit
University of Regina
June 2011

Who am I?

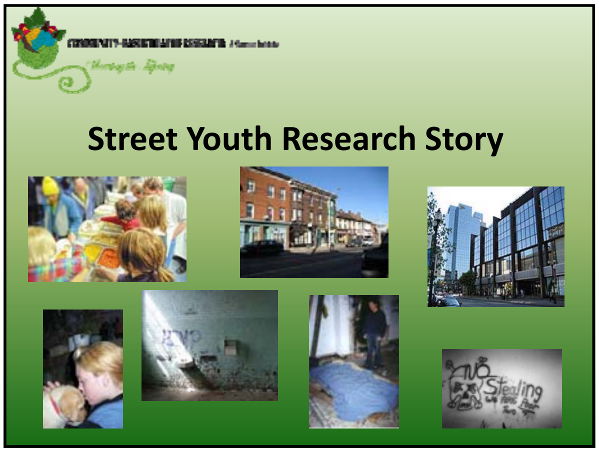
- 20 years doing CBR as a practitioner in urban & rural communities
- With diverse groups – people with disabilities, street youth, people living on low incomes, women experiencing intimate partner violence, isolated seniors ...
- Returned to academia recently

Overview

1. Defining "partnership"
2. Partnership-related issues <u>within</u> the group
   - barriers/tensions and facilitative factors
3. Partnership-related issues <u>outside</u> the group
4. Deconstructing some invisible elements
   - power and voice
5. In closing ...

1. Defining "partnership"

- "CBR involves a collaborative partnership in which all parties participate as <u>equal members</u> and <u>share control</u> over <u>all phases</u> of the research process" (Israel et al. 1998, p. 178)

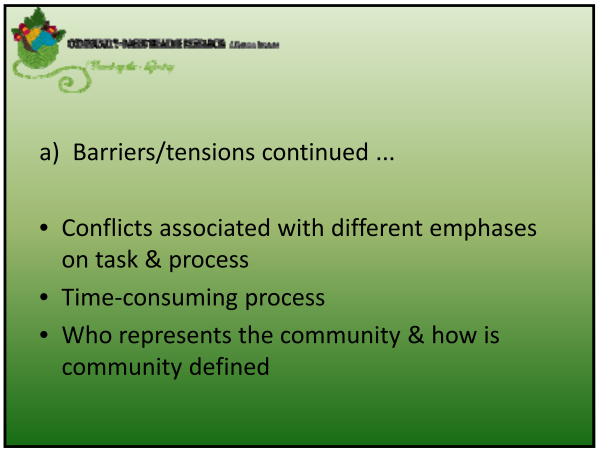


Street Youth Research Story

2. Partnership-related issues <u>within</u> the research team/committee (Israel et al. 1998)

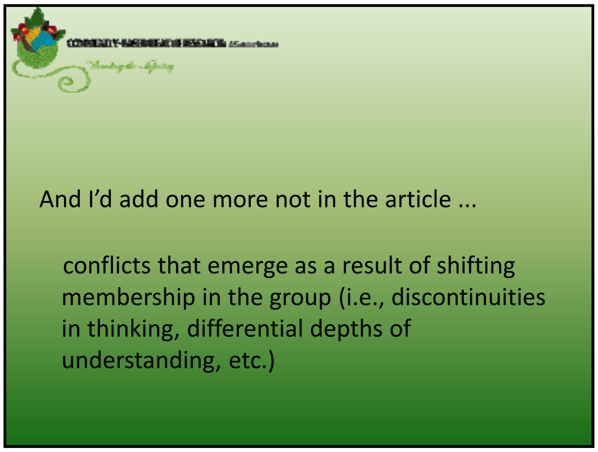
a) Some fairly visible barriers/tensions

- Lack of trust & respect
- Conflicts associated with differences in perspectives, priorities, assumptions, values, beliefs & language
- Conflicts over funding



a) Barriers/tensions continued ...

- Conflicts associated with different emphases on task & process
- Time-consuming process
- Who represents the community & how is community defined

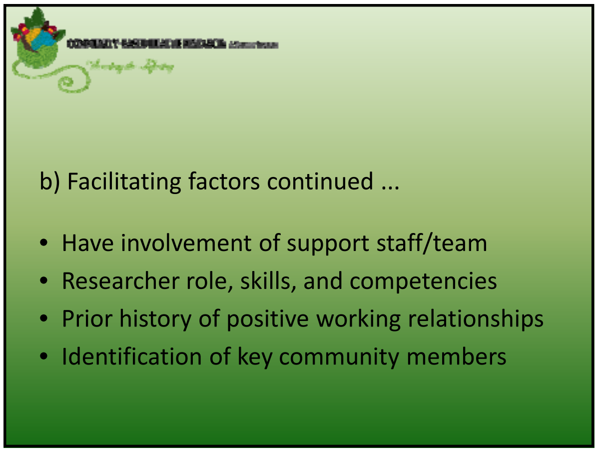


And I'd add one more not in the article ...

conflicts that emerge as a result of shifting membership in the group (i.e., discontinuities in thinking, differential depths of understanding, etc.)

b) facilitative factors toward healthy partnerships (Israel et al. 1998, p. 178)

- Jointly develop operating norms
- Identify common goals & objectives
- Have democratic leadership
- Have a community organizer



b) Facilitating factors continued ...

- Have involvement of support staff/team
- Researcher role, skills, and competencies
- Prior history of positive working relationships
- Identification of key community members

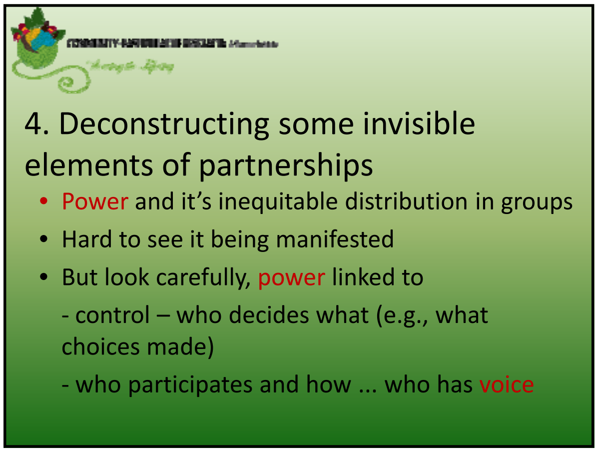
3. Partnership-related issues outside group

- Partnerships affected by goings-on in our organizations & communities (Israel et al. 1998, p. 178)

  - Multiple & competing demands in our organizations

  - Political & social dynamics within communities

  However, even after we work through all of this, things shift over time!



4. Deconstructing some invisible elements of partnerships

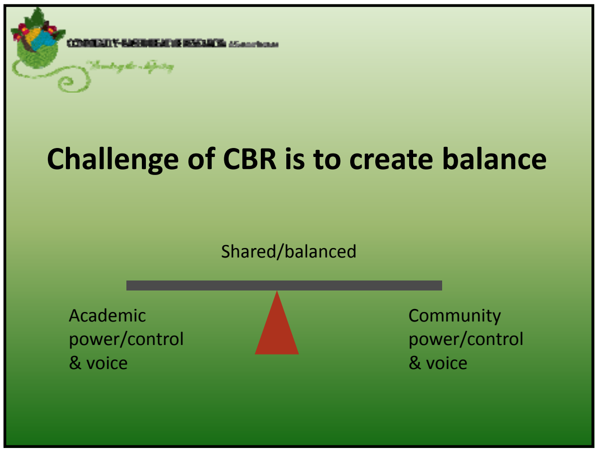
- Power and it's inequitable distribution in groups
- Hard to see it being manifested
- But look carefully, power linked to

  - control – who decides what (e.g., what choices made)

  - who participates and how ... who has voice

Power & voice continued ...

- Power is differential capacities and access to resources "which give rise to structured, asymmetric relations of domination & subordination among social actors" (Grabb, 2007, p. 211)
- Result is dominant & subordinate people in groups ... some speak and others do not
- Power is control of ideas, people &/or resources



Challenge of CBR is to create balance

Shared/balanced

Academic
power/control
& voice

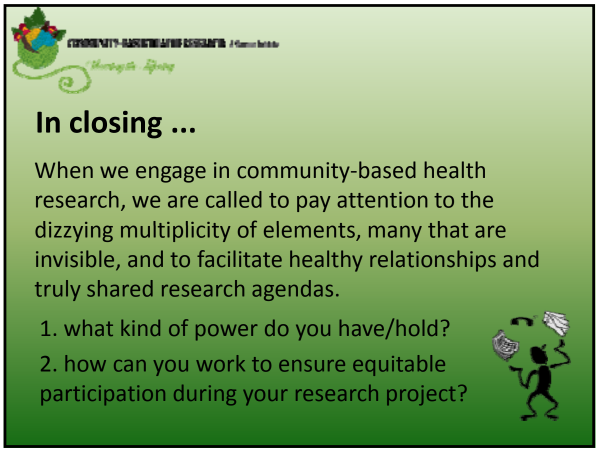
Community
power/control
& voice

- OK so let's talk about this at outset of our research project, and be done with it
- Ummm .... not so fast
- Let us look at a CBR list of tasks and how they may unfold in different models ....

Models of doing research – power & voice

Aspect of Research	Traditional	Academic-participatory	Facilitative group	Citizen-directed
Relationship to funder				
Budget & setting timelines				
Definition of problem				
Task organizing				
Decide on data collection & analyses methods				
Collect & transcribe data				
Analyse data & draw conclusions				
Write/re-write action recommendations & documents				

(Adapted from O'Connor & Williams, 1994, McMaster Research Centre for Promotion of Women's Health)



In closing ...

When we engage in community-based health research, we are called to pay attention to the dizzying multiplicity of elements, many that are invisible, and to facilitate healthy relationships and truly shared research agendas.

1. what kind of power do you have/hold?
2. how can you work to ensure equitable participation during your research project?

Models of doing research*

The following four research models are not pure types; there are numerous blurred boundaries between them. In general, the traditional research model is top-down with the academic "expert" playing a pivotal role. On the other extreme are citizen-directed research groups that are bottom-up and have citizens playing pivotal roles throughout the process.

Aspect of Research	Traditional	Academic-participatory	Facilitative/educative group or organization (emphasize learning opportunities)	Citizen-directed groups (in general, most aspects done by group with outside expertise as they deem necessary)
1. Relationship to funder	Funder gives money to academic "expert" .	Funder gives money to academic participatory researcher who involves citizens.	Funder gives money "in trust" to facilitator group. Citizen groups access money for their research.	Funder gives money to self-defined citizen group for research about their own issues.
2. Budget & setting timelines	Funder & academic "expert" decide. Expert requests changes as needed.	Academic participatory researcher may request input from citizen group on decisions; decides when to negotiate with funder.	Facilitator group assists citizen research group to set and control their own budget & timelines as well as to negotiate with funder.	Citizen-directed group controls budget and timelines, negotiates directly with funder, hires financial experts if necessary.
3. Definition of problem and conceptual work	Academic "expert" defines problem & does conceptual work based on literature & other studies.	Academic participatory researcher receives funding related to a subject area based on their conceptual work; invites citizen group to further define the research with them before making final decisions.	Facilitator group receives funding for broad theme and works with citizen group on further conceptual work and problem definition.	Citizen groups define their own research problem and conceptual
4. Task/work organizing (i.e., who will work on what?)	"Expert" supervises all research tasks.	Academic participatory researchers invite sharing of basic tasks – not advanced tasks (e.g., quantitative analyses)	Facilitator group co-leads most of research project with citizen group members in order to transfer skills/knowledge.	Citizen groups decide & share manual, clerical & other tasks according to principles of equality and recognition of work preferences and skills.

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* Prepared by Gloria DeSantis for CBHRSI, June 2011, based on an adaptation of Mary O'Connor & Karen Williams (1994), *Seminar on Theories and Methods of Participatory Research*, McMaster Unviersity Research Centre for Promotion of Women's Health, Hamilton, Ontario.

Aspect of Research	Traditional	Academic-participatory	Facilitative/educative group or organization (emphasize learning opportunities)	Citizen-directed groups (in general, most tasks done by group with outside assistance as they deem necessary)
5. Decide on data collection methods & analyses methods	Academic "expert" makes all decisions about methods.	Academic participatory researchers ask citizens for input on methods, but final decisions rest with academics. Usually ask citizens for feedback on completed analyses.	Facilitator group shares their knowledge & information about variety of methods, educates citizen group about options, then citizen group decides.	Citizen groups make decisions about data collection and analyses methods.
6. Collect & transcribe data	Academic "expert" usually employs research assistants who do data work.	Academic participatory researchers often hire research assistants who work with citizen group.	Facilitator group provides ongoing support & equipment so that citizen group can collect & transcribe data.	Citizen groups find supports they need and collect & transcribe data themselves.
7. Analyse data & draw conclusions	Academic "expert" does analysis.	Academic participatory researchers make interpretations & draw conclusions after input from citizen group.	Final interpretation rests with citizen group however, facilitator offers critique to help citizens see alternatives.	Citizen groups with necessary supports make final interpretations; they may request others to assist with analysis.
8. Write/re-write action recommendations & documents	Academic "expert" writes "scientific" document.	Academic participatory researchers write drafts based on collective deliberations among researchers and citizen group.	Facilitator group supports citizens to write document & educates them about funder expectations. Different sections sometimes written by different people including citizens.	Citizen group decides form of document & writes document. May engage someone to present the image they desire.

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* Prepared by Gloria DeSantis for CBHRSI, June 2011, based on an adaptation of Mary O'Connor & Karen Williams (1994), *Seminar on Theories and Methods of Participatory Research*, McMaster Unviersity Research Centre for Promotion of Women's Health, Hamilton, Ontario.

Community based research:

Relationships are foundational

Community Based Health Research Conference
June 20, 2011
Regina, Saskatchewan

Dr. Linda Goulet
Department of Indigenous Education
First Nations University of Canada

Who are you?
Who are your participants?
How will you and your participants enter that 'in between space' where knowledge is constructed and shared?

Context matters
in community based research

CONTEXT

Each community is positioned in a particular **socio-cultural history** (Vygotsky 1978; Cole 1996) that affects how they view health and health research and how they will participate in the research process

- First Nations communities are positioned within a context of historical colonization and ongoing racism so are suspicious of researchers because research has been used against them as a tool of colonization.
- Doctors historically have been the experts with access to health information and knowledge so had the authority. Patients deferred to their judgement regarding treatment.

Choosing a community

- Choose communities where you have connections already.
- Let people know your expertise and get invited by the community
- Find a community partner who has community connections.

Why Relationships? Process/product

- Research is a process of coming to know combined with product(s) to share that knowledge, interpretation and understanding.
- In community based research, the process is especially important because the process constructs new/shared understandings.

Why relationships?

Accuracy of information

- ☐ Groups traditionally marginalized in our society may not be willing to disclose certain information to people who may use the information to further oppress them (sex trade workers, Indigenous peoples, etc)
- ☐ Subcultures may find it more interesting to provide inaccurate data (youth data on sexual activity, drug use, etc)
- ☐ People may provide information that they think the researchers want to hear (what they know about healthy living as opposed to what they actually do in practice) (Goulet, Episkenew, Linds & Arnason 2009)

Maori researcher Russell Bishop says:

"Traditional research epistemologies have developed methods of initiating research and accessing research participants that are located within the cultural preferences and practices of the Western world, as opposed to the cultural preferences and practices of Maori people themselves. For example, the preoccupation with neutrality, objectivity, and distance by education research has emphasized these concepts as criteria for authority, representation and accountability and, thus, has distanced Maori people from participation in the construction, validation, and legitimization of knowledge."

(2008, p. 148)

Developing Community Relationships

Initial, ongoing, open communication and reciprocal negotiation

- Create time, space, and actions in your research plan to develop community relationships at the beginning of and throughout the duration of your project.
- Know your positionality - what are the knowledge and power dynamics involved and where are you positioned in relation to the research participants? In the broader society? In the research project?

Relationships

Respect

- Listen and be responsive (Goulet, Krentz & Christiansen 2003)
- ***Otootemitowin*** (respectful openness and acceptance of others) and ***weechiseechigemitowin*** (alliances for common action) (Goulet & Goulet in progress).
- Be open to community ways of knowing, ways of being, ways of communicating

Relationships

- **Reciprocity**
- Make an offer and let the community decide if it will accept your offer (Bishop 2008)
- Be clear about your research expectations, timelines, requirements (including the funder and the university)

Relationships

- Recognize community expertise, limitations, expectations
- **Trust** enhances **authentic participation** for the production of rich data

Respectful, open relationships

- Can help you ask the right questions/ develop your hypothesis
- Can familiarize you with the appropriate language and style for the community
- Can provide guidance to the direction of the research project
- Can facilitate effective Knowledge Transfer (KT) ie research findings can be articulated in the culture of the community (language and practices).

Questions

- What is your positionality (status, power, access to resources) as a health researcher and how will that affect research relationships? (Developing and maintaining?)
- Respond to the Bishop quote. What voices have not been well represented in health research and what has been the effect? What does reciprocity mean to you in CBHR?

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Developing Relationships & Partnerships: Part 2 - Research Ethics

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June 21, 2011

Outline

- Background on Research Ethics
- Core Principles of the TCPS
- Ethical Research in Aboriginal Communities

Context of the TCPS Ethics Framework and Principles

- Research benefits Human Society
- Underlying value = Respect for Human Dignity
- Participant-Centered Perspective
- Academic Freedoms and Responsibilities
- Ethics and Law
  - Jurisdictional and legal context (e.g. privacy, confidentiality, intellectual property, capacity, constitutional rights and freedoms)

What is Ethical Research?

Ethical Research has

- Value
- Validity
- Fair participant selection
- Favourable risk-benefit ratio
- Independent Review
- Informed consent
- Respect for participants

HEADLINES

U of S researcher cautions trial for MS 'liberation' therapy years away
Saskatoon StarPhoenix: Aug 25, 2010

Presidential Commission for the Study of Bioethical Issues Nov 09

From Disclosure to Transparency The Use of Company Payment Data Archives of Internal Medicine, Sept 2010

Doctor conducted secret clinical trial prescribing hayfever tablets for neck pain and earache Telegraph

Indian Tribe Wins Fight to Limit Research of Its DNA New York Times April 22, 2010

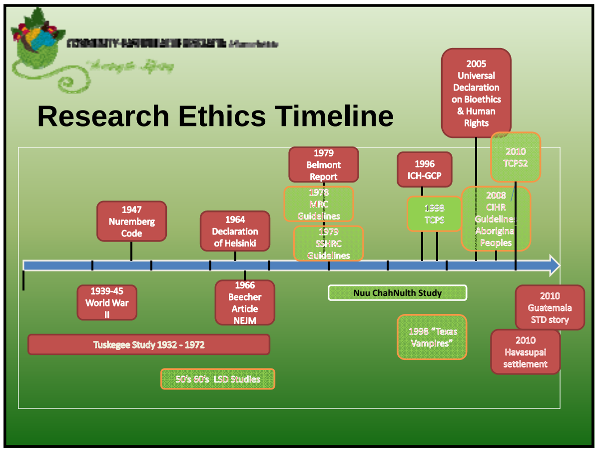
NEW YORK TIMES JULY 27, 2010
Center's Studies Suspended Due to Impure Injections

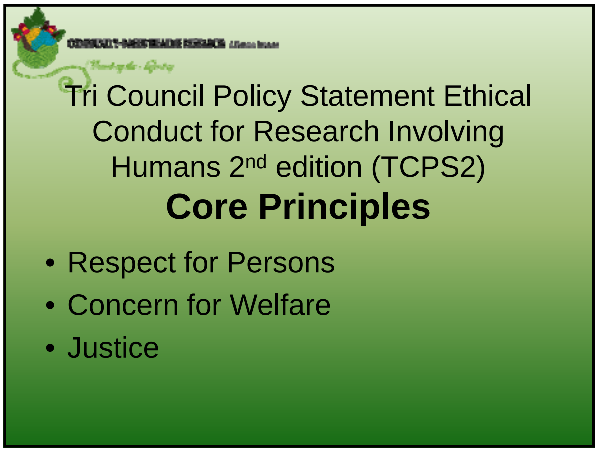
UW-Madison suspends researcher over animal welfare problems.

Pentagon questions drug study on troops
80 wounded American service members in Iraq alleged to be improperly used as subjects in a test of a possible treatment for brain injuries."

U.S. apologizes for STD experiments in Guatemala Oct, 2010

Research Ethics Timeline





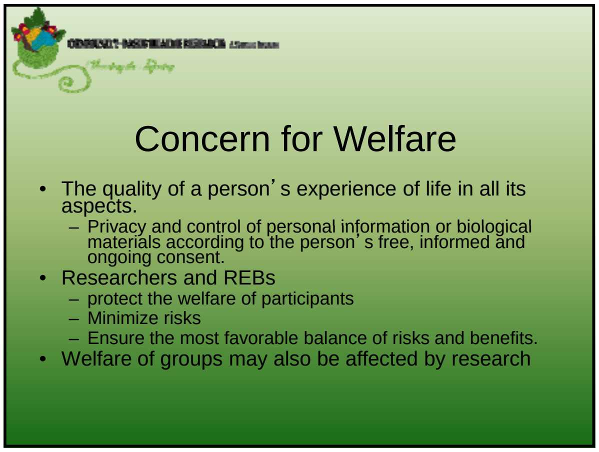
Tri Council Policy Statement Ethical Conduct for Research Involving Humans 2nd edition (TCPS2)

Core Principles

- Respect for Persons
- Concern for Welfare
- Justice

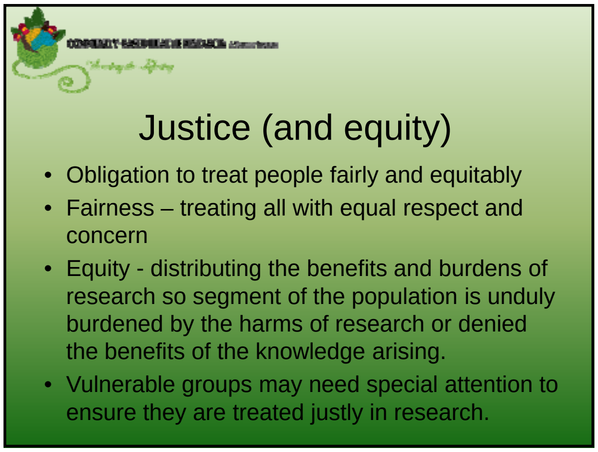
Respect for Persons

- Recognizes the intrinsic value of human beings and the respect and consideration they are due
- Dual moral obligation
  - to respect autonomy and
  - to protect those with developing, impaired or diminished autonomy.



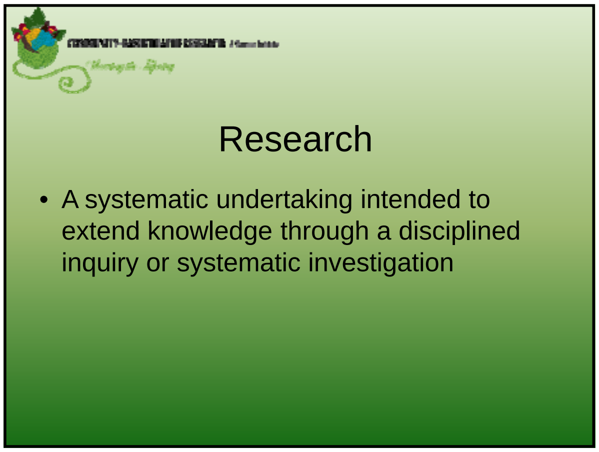
Concern for Welfare

- The quality of a person's experience of life in all its aspects.
  - Privacy and control of personal information or biological materials according to the person's free, informed and ongoing consent.
- Researchers and REBs
  - protect the welfare of participants
  - Minimize risks
  - Ensure the most favorable balance of risks and benefits.
- Welfare of groups may also be affected by research



Justice (and equity)

- Obligation to treat people fairly and equitably
- Fairness – treating all with equal respect and concern
- Equity - distributing the benefits and burdens of research so segment of the population is unduly burdened by the harms of research or denied the benefits of the knowledge arising.
- Vulnerable groups may need special attention to ensure they are treated justly in research.

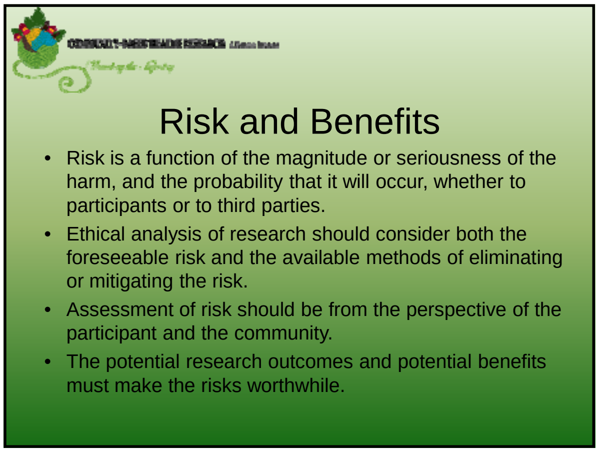


Research

- A systematic undertaking intended to extend knowledge through a disciplined inquiry or systematic investigation

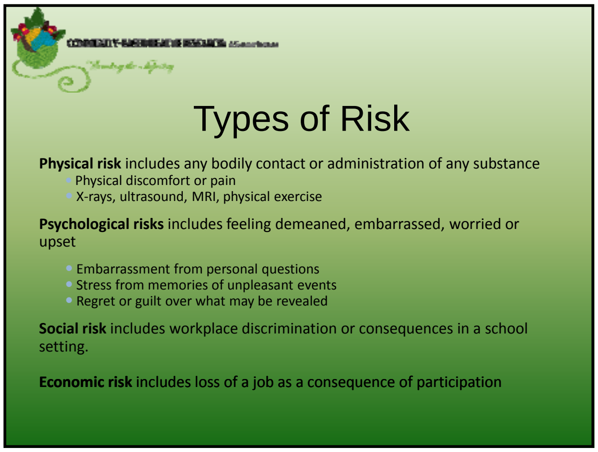
Research Requiring Review

- Research involving living human participants
- Research involving human biological materials as well as human embryos, fetuses, fetal tissue, reproductive materials and stem cells from both living and deceased individuals.



Risk and Benefits

- Risk is a function of the magnitude or seriousness of the harm, and the probability that it will occur, whether to participants or to third parties.
- Ethical analysis of research should consider both the foreseeable risk and the available methods of eliminating or mitigating the risk.
- Assessment of risk should be from the perspective of the participant and the community.
- The potential research outcomes and potential benefits must make the risks worthwhile.



Types of Risk

Physical risk includes any bodily contact or administration of any substance

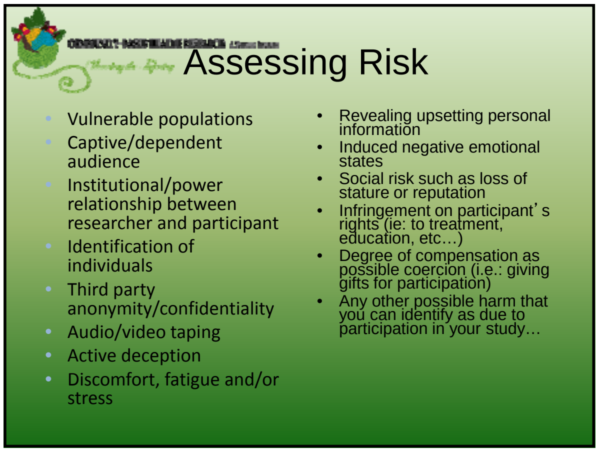
- Physical discomfort or pain
- X-rays, ultrasound, MRI, physical exercise

Psychological risks includes feeling demeaned, embarrassed, worried or upset

- Embarrassment from personal questions
- Stress from memories of unpleasant events
- Regret or guilt over what may be revealed

Social risk includes workplace discrimination or consequences in a school setting.

Economic risk includes loss of a job as a consequence of participation



Assessing Risk

- Vulnerable populations
- Captive/dependent audience
- Institutional/power relationship between researcher and participant
- Identification of individuals
- Third party anonymity/confidentiality
- Audio/video taping
- Active deception
- Discomfort, fatigue and/or stress

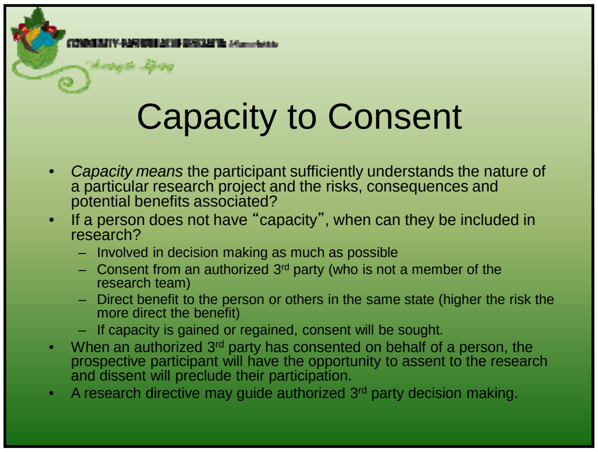
- Revealing upsetting personal information
- Induced negative emotional states
- Social risk such as loss of stature or reputation
- Infringement on participant's rights (ie: to treatment, education, etc…)
- Degree of compensation as possible coercion (i.e.: giving gifts for participation)
- Any other possible harm that you can identify as due to participation in your study…

Consent Principles

- **Consent Shall Be Given Voluntarily**
- **Consent Shall Be Informed**
- **Consent Shall Be an Ongoing Process**
- **Consent Shall Precede Collection of, or Access to, Research Data**

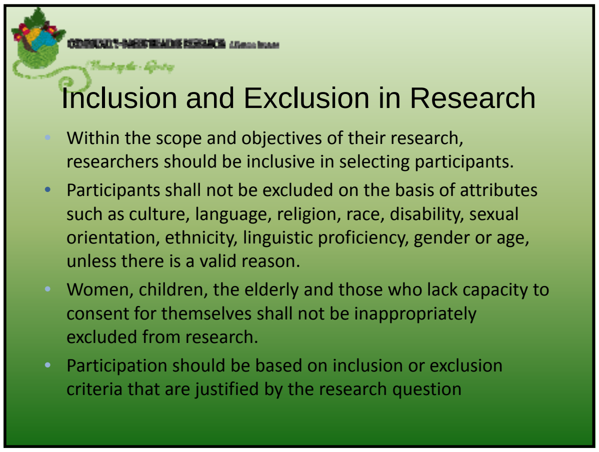
FREE, INFORMED, ONGOING & PRIOR

What do participants and communities need to know about a research project to ensure they are able to give <u>informed</u> consent?



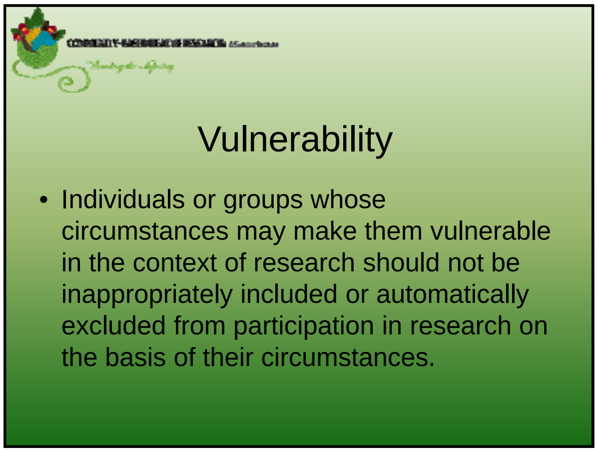
Capacity to Consent

- *Capacity means* the participant sufficiently understands the nature of a particular research project and the risks, consequences and potential benefits associated?
- If a person does not have "capacity", when can they be included in research?
  - Involved in decision making as much as possible
  - Consent from an authorized 3rd party (who is not a member of the research team)
  - Direct benefit to the person or others in the same state (higher the risk the more direct the benefit)
  - If capacity is gained or regained, consent will be sought.
- When an authorized 3rd party has consented on behalf of a person, the prospective participant will have the opportunity to assent to the research and dissent will preclude their participation.
- A research directive may guide authorized 3rd party decision making.



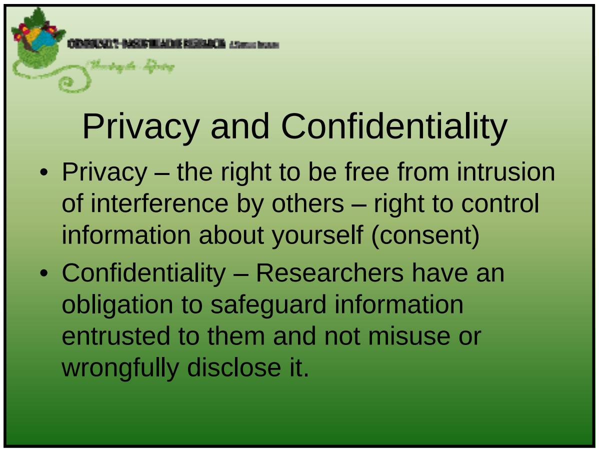
Inclusion and Exclusion in Research

- Within the scope and objectives of their research, researchers should be inclusive in selecting participants.
- Participants shall not be excluded on the basis of attributes such as culture, language, religion, race, disability, sexual orientation, ethnicity, linguistic proficiency, gender or age, unless there is a valid reason.
- Women, children, the elderly and those who lack capacity to consent for themselves shall not be inappropriately excluded from research.
- Participation should be based on inclusion or exclusion criteria that are justified by the research question



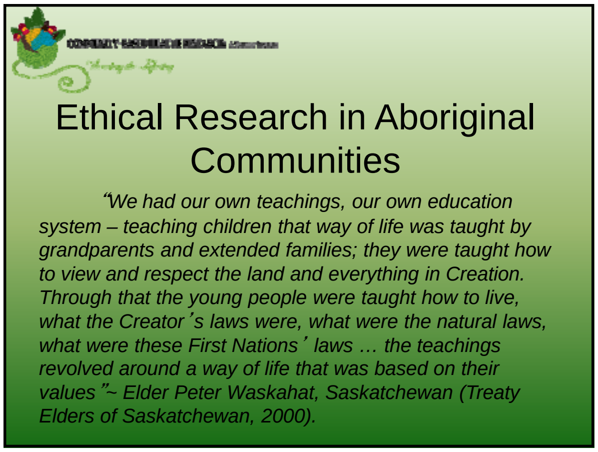
Vulnerability

- Individuals or groups whose circumstances may make them vulnerable in the context of research should not be inappropriately included or automatically excluded from participation in research on the basis of their circumstances.



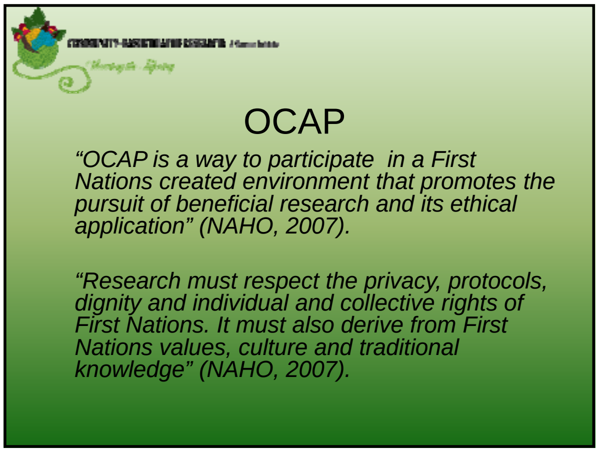
Privacy and Confidentiality

- Privacy – the right to be free from intrusion of interference by others – right to control information about yourself (consent)
- Confidentiality – Researchers have an obligation to safeguard information entrusted to them and not misuse or wrongfully disclose it.



Ethical Research in Aboriginal Communities

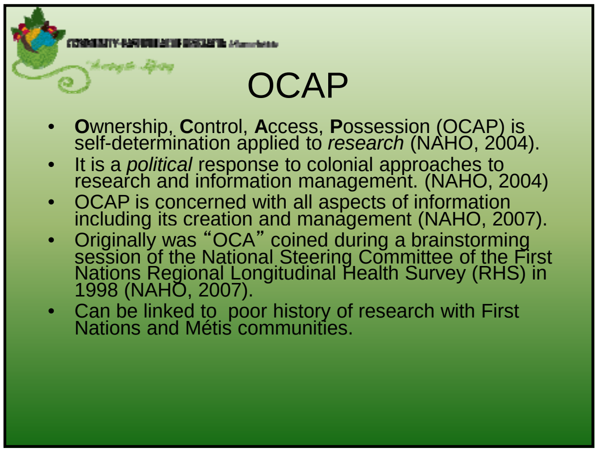
“We had our own teachings, our own education system – teaching children that way of life was taught by grandparents and extended families; they were taught how to view and respect the land and everything in Creation. Through that the young people were taught how to live, what the Creator’s laws were, what were the natural laws, what were these First Nations’ laws … the teachings revolved around a way of life that was based on their values”~ Elder Peter Waskahat, Saskatchewan (Treaty Elders of Saskatchewan, 2000).



OCAP

“OCAP is a way to participate in a First Nations created environment that promotes the pursuit of beneficial research and its ethical application” (NAHO, 2007).

“Research must respect the privacy, protocols, dignity and individual and collective rights of First Nations. It must also derive from First Nations values, culture and traditional knowledge” (NAHO, 2007).



OCAP

- **O**wnership, **C**ontrol, **A**ccess, **P**ossession (OCAP) is self-determination applied to *research* (NAHO, 2004).
- It is a *political* response to colonial approaches to research and information management. (NAHO, 2004)
- OCAP is concerned with all aspects of information including its creation and management (NAHO, 2007).
- Originally was “OCA” coined during a brainstorming session of the National Steering Committee of the First Nations Regional Longitudinal Health Survey (RHS) in 1998 (NAHO, 2007).
- Can be linked to poor history of research with First Nations and Métis communities.

OCAP

"The gathering of information and its subsequent use are inherently political. In the past, Aboriginal people have not been consulted about what information should be collected, who should gather that information, who should maintain it, and who should have access to it. The information gathered may or may not have been relevant to the questions, priorities and concerns of Aboriginal peoples. Because data gathering has frequently been imposed by outside authorities, it has met with resistance in many quarters" (RCAP, Vol. 3, Chpt. 5, 1996).

Some Common Grievances

- The majority of research projects are initiated, paid for and carried out by non-Aboriginal people from universities government and industry.
- • Researchers have selected subjects of personal or academic interest or of interest to the larger society, but have not been interested in First Nations priorities.
- • Researchers have essentially pre-empted meaningful community involvement by presenting completed research designs, often already funded, for community approval rather than collaborating from the start.

- Governments gather administrative and other data on First Nations without their knowledge or consent.
- Governments and researchers analyze, interpret and report First Nations data without consent, approval, review or input by First Nations representatives.
- Research funding is largely controlled by a few external agents and is generally not accessible to community groups and First Nations organizations.
- Human remains and cultural property have been taken for storage, display in museums, or sale (NAHO, 2004).

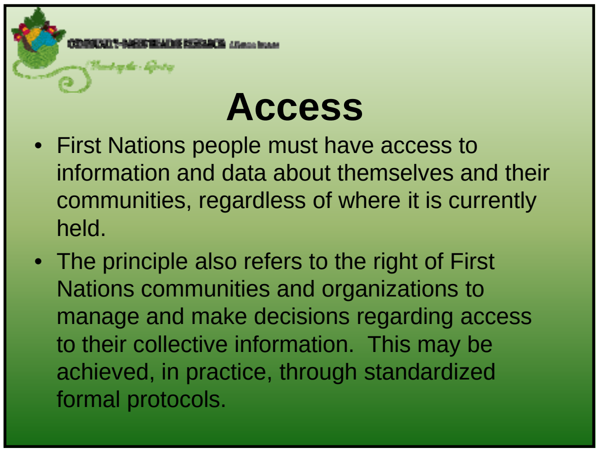
Ownership

- refers to the relationship of a First Nations community to its cultural knowledge/ data/ information.
- The principle states that a community or group owns information collectively in the same way that an individual owns their personal information. It is distinct from stewardship. The stewardship or care taking of data or information by an institution that is accountable to the group is a mechanism through which ownership may be asserted.

"First Nations' claim to ownership of their own data is not some strange new aberration. On the authority of their own institutions and laws, governments and academics have long possessed and owned data without really thinking twice about it. OCAP brings the illegitimate owners into the spotlight. Those who most strongly reject the notion of data ownership tend to have control or possession of considerable volumes of it" (NAHO, 2004).

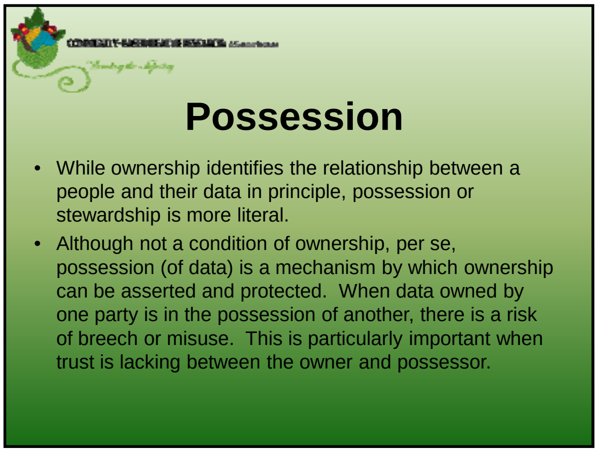
Control

- The aspirations and rights of First Nations people to maintain and regain control of all aspects of their lives and institutions extend to research, information and data.
- The principle of control asserts that First Nations people, their communities and representative bodies are within their rights in seeking to control all aspects of research and information management processes which impact them. First Nations control of research can include all stages of a particular research project – from conception to completion. The principle extends to the control of resources and review processes, the formulation of conceptual frameworks, data management and so on.



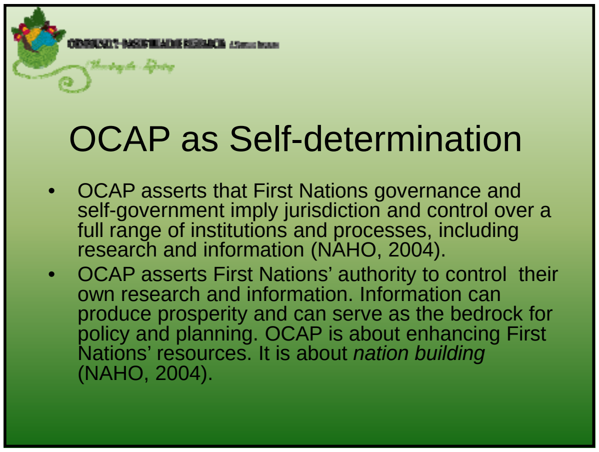
Access

- First Nations people must have access to information and data about themselves and their communities, regardless of where it is currently held.
- The principle also refers to the right of First Nations communities and organizations to manage and make decisions regarding access to their collective information. This may be achieved, in practice, through standardized formal protocols.



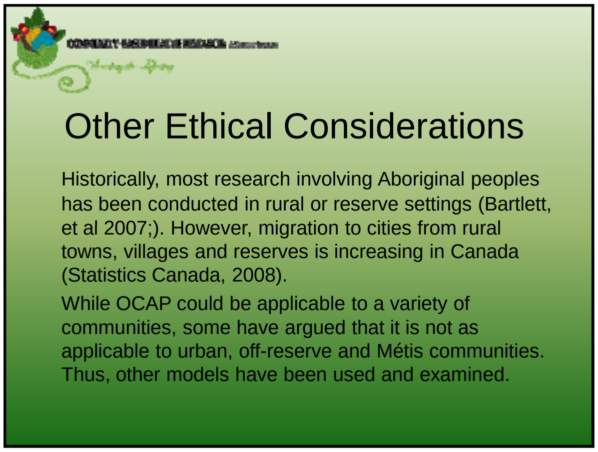
Possession

- While ownership identifies the relationship between a people and their data in principle, possession or stewardship is more literal.
- Although not a condition of ownership, per se, possession (of data) is a mechanism by which ownership can be asserted and protected. When data owned by one party is in the possession of another, there is a risk of breech or misuse. This is particularly important when trust is lacking between the owner and possessor.



OCAP as Self-determination

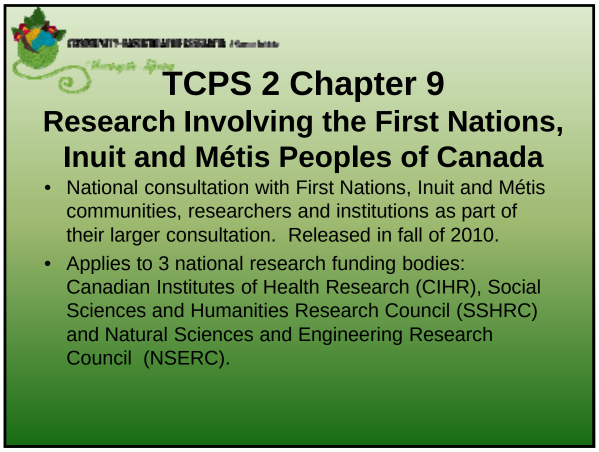
- OCAP asserts that First Nations governance and self-government imply jurisdiction and control over a full range of institutions and processes, including research and information (NAHO, 2004).
- OCAP asserts First Nations' authority to control their own research and information. Information can produce prosperity and can serve as the bedrock for policy and planning. OCAP is about enhancing First Nations' resources. It is about *nation building* (NAHO, 2004).



Other Ethical Considerations

Historically, most research involving Aboriginal peoples has been conducted in rural or reserve settings (Bartlett, et al 2007;). However, migration to cities from rural towns, villages and reserves is increasing in Canada (Statistics Canada, 2008).

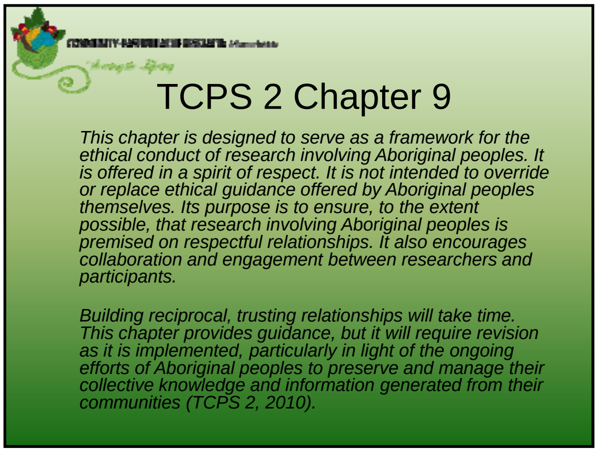
While OCAP could be applicable to a variety of communities, some have argued that it is not as applicable to urban, off-reserve and Métis communities. Thus, other models have been used and examined.



TCPS 2 Chapter 9

Research Involving the First Nations, Inuit and Métis Peoples of Canada

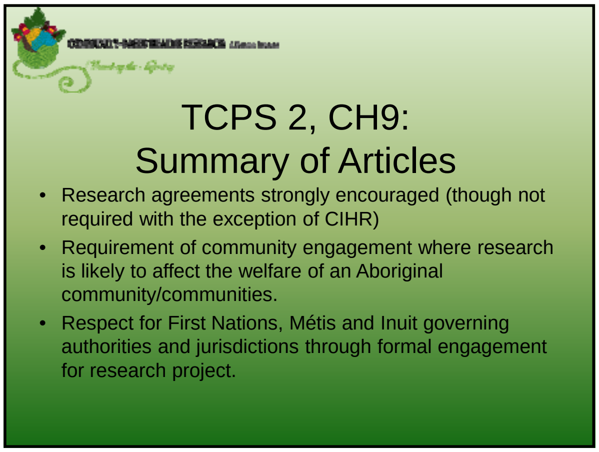
- National consultation with First Nations, Inuit and Métis communities, researchers and institutions as part of their larger consultation. Released in fall of 2010.
- Applies to 3 national research funding bodies: Canadian Institutes of Health Research (CIHR), Social Sciences and Humanities Research Council (SSHRC) and Natural Sciences and Engineering Research Council (NSERC).



TCPS 2 Chapter 9

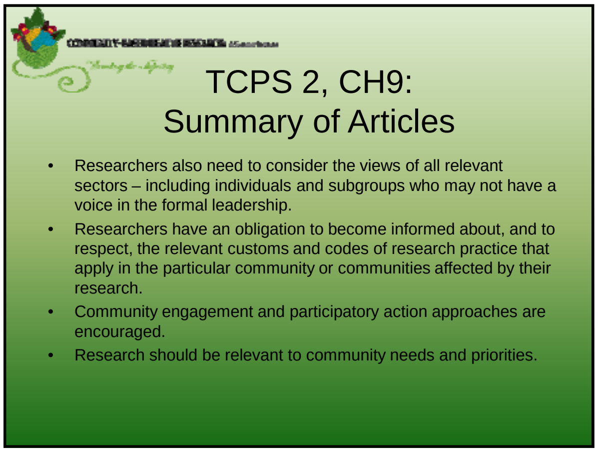
This chapter is designed to serve as a framework for the ethical conduct of research involving Aboriginal peoples. It is offered in a spirit of respect. It is not intended to override or replace ethical guidance offered by Aboriginal peoples themselves. Its purpose is to ensure, to the extent possible, that research involving Aboriginal peoples is premised on respectful relationships. It also encourages collaboration and engagement between researchers and participants.

Building reciprocal, trusting relationships will take time. This chapter provides guidance, but it will require revision as it is implemented, particularly in light of the ongoing efforts of Aboriginal peoples to preserve and manage their collective knowledge and information generated from their communities (TCPS 2, 2010).



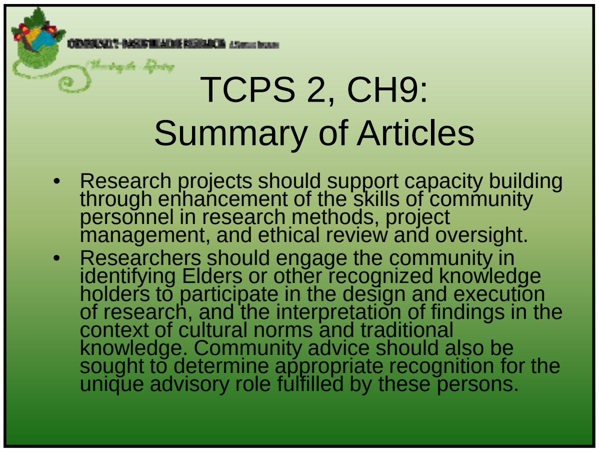
TCPS 2, CH9: Summary of Articles

- Research agreements strongly encouraged (though not required with the exception of CIHR)
- Requirement of community engagement where research is likely to affect the welfare of an Aboriginal community/communities.
- Respect for First Nations, Métis and Inuit governing authorities and jurisdictions through formal engagement for research project.



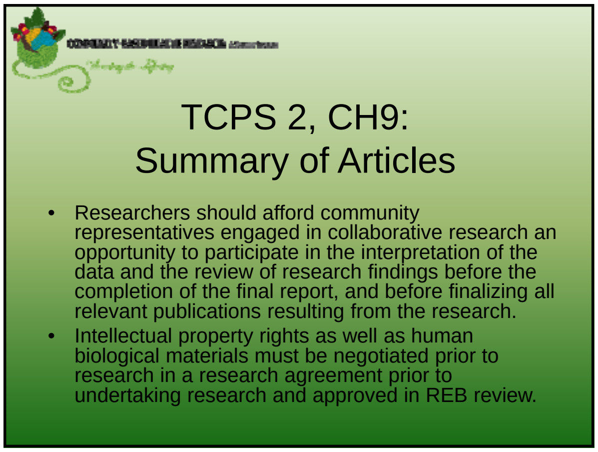
TCPS 2, CH9: Summary of Articles

- Researchers also need to consider the views of all relevant sectors – including individuals and subgroups who may not have a voice in the formal leadership.
- Researchers have an obligation to become informed about, and to respect, the relevant customs and codes of research practice that apply in the particular community or communities affected by their research.
- Community engagement and participatory action approaches are encouraged.
- Research should be relevant to community needs and priorities.



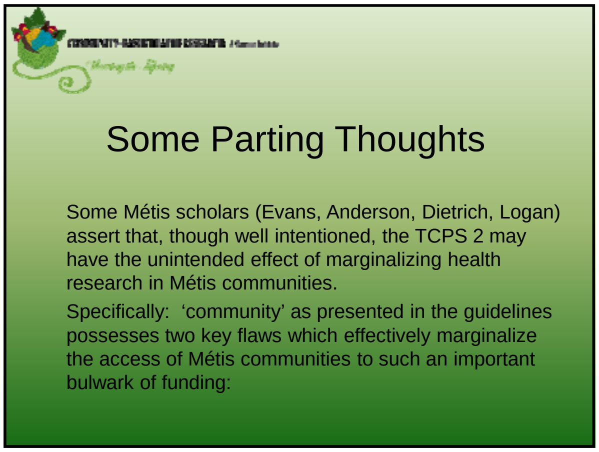
TCPS 2, CH9: Summary of Articles

- Research projects should support capacity building through enhancement of the skills of community personnel in research methods, project management, and ethical review and oversight.
- Researchers should engage the community in identifying Elders or other recognized knowledge holders to participate in the design and execution of research, and the interpretation of findings in the context of cultural norms and traditional knowledge. Community advice should also be sought to determine appropriate recognition for the unique advisory role fulfilled by these persons.



TCPS 2, CH9: Summary of Articles

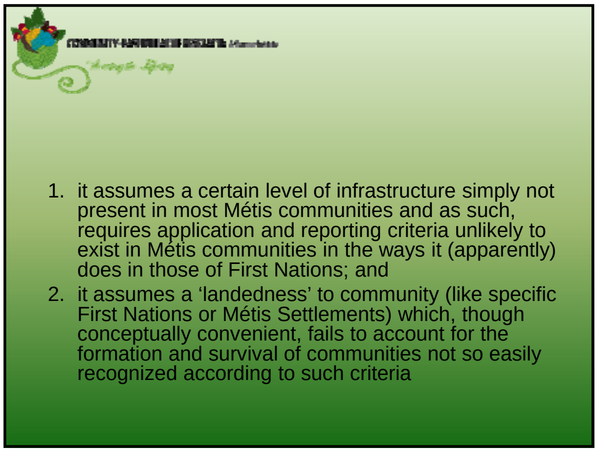
- Researchers should afford community representatives engaged in collaborative research an opportunity to participate in the interpretation of the data and the review of research findings before the completion of the final report, and before finalizing all relevant publications resulting from the research.
- Intellectual property rights as well as human biological materials must be negotiated prior to research in a research agreement prior to undertaking research and approved in REB review.



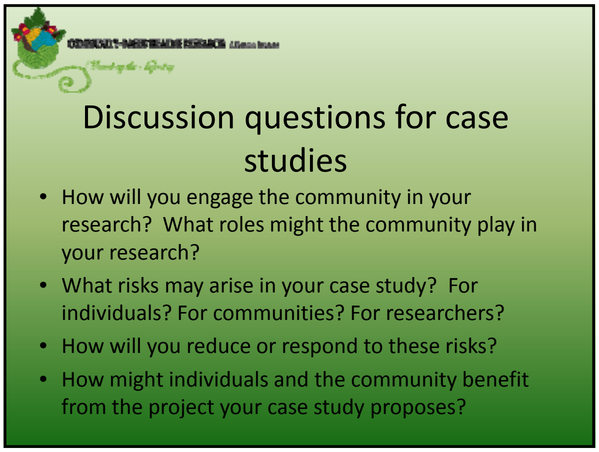
Some Parting Thoughts

Some Métis scholars (Evans, Anderson, Dietrich, Logan) assert that, though well intentioned, the TCPS 2 may have the unintended effect of marginalizing health research in Métis communities.

Specifically: 'community' as presented in the guidelines possesses two key flaws which effectively marginalize the access of Métis communities to such an important bulwark of funding:



1. it assumes a certain level of infrastructure simply not present in most Métis communities and as such, requires application and reporting criteria unlikely to exist in Métis communities in the ways it (apparently) does in those of First Nations; and
2. it assumes a 'landedness' to community (like specific First Nations or Métis Settlements) which, though conceptually convenient, fails to account for the formation and survival of communities not so easily recognized according to such criteria



Discussion questions for case studies

- How will you engage the community in your research? What roles might the community play in your research?
- What risks may arise in your case study? For individuals? For communities? For researchers?
- How will you reduce or respond to these risks?
- How might individuals and the community benefit from the project your case study proposes?

References

Bartlett, J., Iwasaki, Y., Gottlieb, B., Hall, D., Mannell, R. (2007) "*Framework for Aboriginal-guided decolonizing research involving Métis and First Nations persons with diabetes"* in *Social Science and Medicine,* pg. 1-12.

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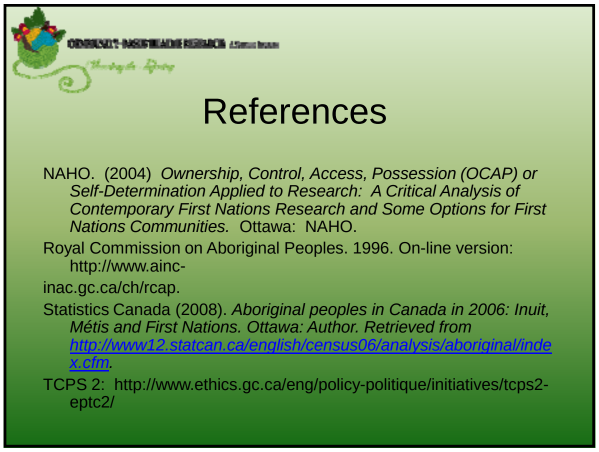
http://www.naho.ca/firstnations/english/documents/toolkits/FNC_OCAPInformationResource.pdf



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NAHO. (2004) *Ownership, Control, Access, Possession (OCAP) or Self-Determination Applied to Research: A Critical Analysis of Contemporary First Nations Research and Some Options for First Nations Communities.* Ottawa: NAHO.

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inac.gc.ca/ch/rcap.

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TCPS 2: http://www.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/

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Qualitative Research: A Brief Overview

June 2011

Table 1. Comparison of quantitative and qualitative research approaches

	Quantitative	Qualitative
General framework	Seek to confirm hypotheses about phenomena	Seek to explore phenomena
	Instruments use more rigid style of eliciting and categorizing responses to questions	Instruments use more flexible, iterative style of eliciting and categorizing responses to questions
	Use highly structured methods such as questionnaires, surveys, and structured observation	Use semi-structured methods such as in-depth interviews, focus groups, and participant observation
Analytical objectives	To quantify variation	To describe variation
	To predict causal relationships	To describe and explain relationships
	To describe characteristics of a population	To describe individual experiences
		To describe group norms
Question format	Closed-ended	Open-ended
Data format	Numerical (obtained by assigning numerical values to responses)	Textual (obtained from audiotapes, videotapes, and field notes)
Flexibility in study design	Study design is stable from beginning to end	Some aspects of the study are flexible (for example, the addition, exclusion, or wording of particular interview questions)
	Participant responses do not influence or determine how and which questions researchers ask next	Participant responses affect how and which questions researchers ask next
	Study design is subject to statistical assumptions and conditions	Study design is iterative, that is, data collection and research questions are adjusted according to what is learned

From: Mack, N., C. Woodsong, K.M. McQueen, G. Guest, E. Namey (2005). Qualitative Research Methods: A Data Collector's Field Guide Module 1: Qualitative Research Methods Overview. (p1-12). Family Health International. http://www.fhi.org/en/RH/Pubs/booksReports/QRM_datacoll.htm

- Qualitative evidence in Action… some examples
- http://www.videovolunteers.org/impact
- http://www.youtube.com/watch?v=X8lSw5Cdi8k&NR=1
- http://www.youtube.com/watch?v=eVYb_NYlW44

MODULE OVERVIEW

THINKING about
Qualitative Research

DOING
Qualitative Research

MANAGING
Qualitative Research

THINKING

WHAT TYPES OF QUALITATIVE INFORMATION ARE:

A) AVAILABLE?

B) OBTAINABLE?

C) DESIRABLE?

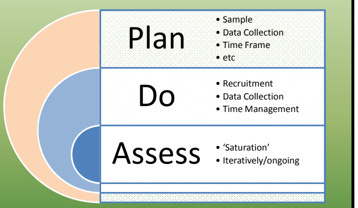
ETHICAL ISSUES & QUALITATIVE APPROACHES

Consider:

- Personal/Individual
- In depth
- Nature of Topic
- Cultural Aspects

Minkler, M. (2004). Ethical challenges for the “outside” researcher in community-based participatory research. *Health Education and Behaviour. 31*, 684-697

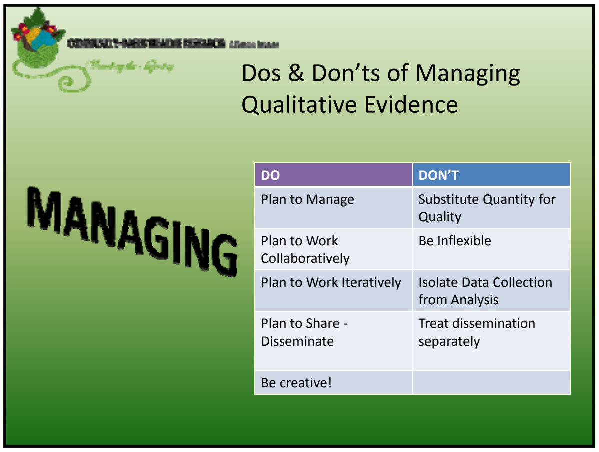
DOING



Plan
- Sample
- Data Collection
- Time Frame
- etc

Do
- Recruitment
- Data Collection
- Time Management

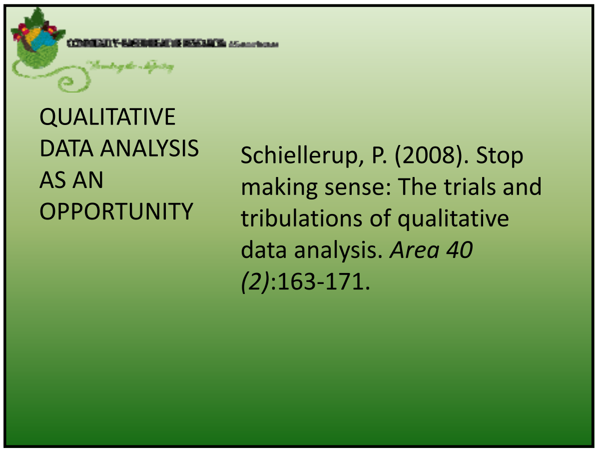
Assess
- ‘Saturation’
- Iteratively/ongoing



Dos & Don'ts of Managing Qualitative Evidence

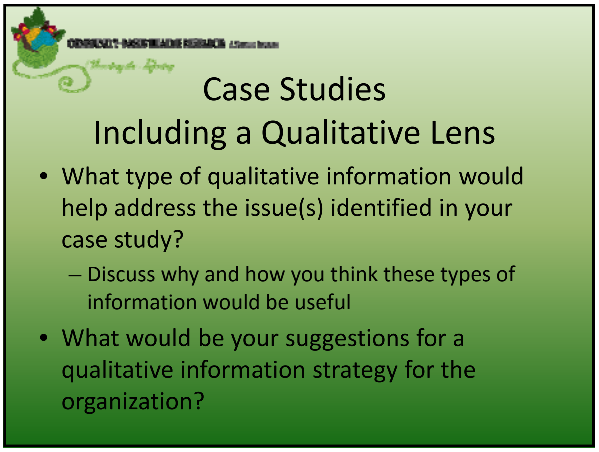
MANAGING

DO	DON'T
Plan to Manage	Substitute Quantity for Quality
Plan to Work Collaboratively	Be Inflexible
Plan to Work Iteratively	Isolate Data Collection from Analysis
Plan to Share - Disseminate	Treat dissemination separately
Be creative!	



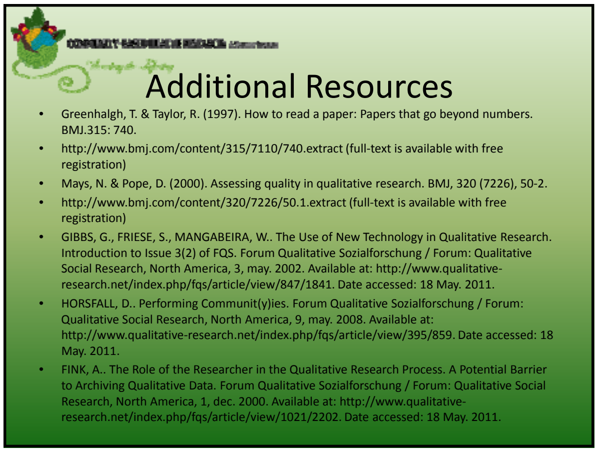
QUALITATIVE DATA ANALYSIS AS AN OPPORTUNITY

Schiellerup, P. (2008). Stop making sense: The trials and tribulations of qualitative data analysis. *Area 40 (2)*:163-171.



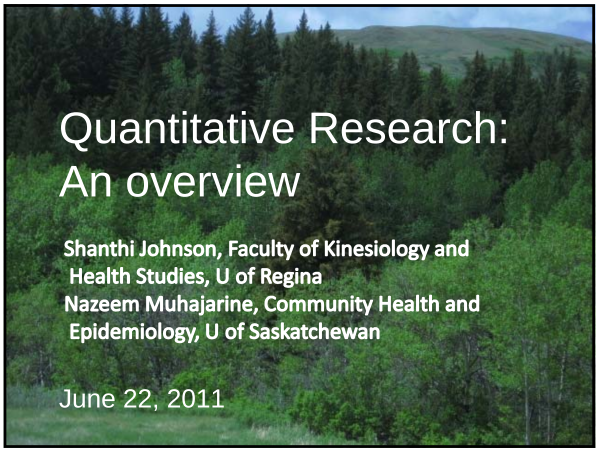
Case Studies
Including a Qualitative Lens

- What type of qualitative information would help address the issue(s) identified in your case study?
  - Discuss why and how you think these types of information would be useful
- What would be your suggestions for a qualitative information strategy for the organization?



Additional Resources

- Greenhalgh, T. & Taylor, R. (1997). How to read a paper: Papers that go beyond numbers. BMJ.315: 740.
- http://www.bmj.com/content/315/7110/740.extract (full-text is available with free registration)
- Mays, N. & Pope, D. (2000). Assessing quality in qualitative research. BMJ, 320 (7226), 50-2.
- http://www.bmj.com/content/320/7226/50.1.extract (full-text is available with free registration)
- GIBBS, G., FRIESE, S., MANGABEIRA, W.. The Use of New Technology in Qualitative Research. Introduction to Issue 3(2) of FQS. Forum Qualitative Sozialforschung / Forum: Qualitative Social Research, North America, 3, may. 2002. Available at: http://www.qualitative-research.net/index.php/fqs/article/view/847/1841. Date accessed: 18 May. 2011.
- HORSFALL, D.. Performing Communit(y)ies. Forum Qualitative Sozialforschung / Forum: Qualitative Social Research, North America, 9, may. 2008. Available at: http://www.qualitative-research.net/index.php/fqs/article/view/395/859. Date accessed: 18 May. 2011.
- FINK, A.. The Role of the Researcher in the Qualitative Research Process. A Potential Barrier to Archiving Qualitative Data. Forum Qualitative Sozialforschung / Forum: Qualitative Social Research, North America, 1, dec. 2000. Available at: http://www.qualitative-research.net/index.php/fqs/article/view/1021/2202. Date accessed: 18 May. 2011.



Quantitative Research: An overview

Shanthi Johnson, Faculty of Kinesiology and Health Studies, U of Regina
Nazeem Muhajarine, Community Health and Epidemiology, U of Saskatchewan

June 22, 2011

Overview

- What is quantitative research? - Nazeem
- Questions, design and measurement issues - Nazeem
- Sources of data - Shanthi
- Two case studies - Shanthi, Nazeem
- Main lessons from the session – Nazeem, Shanthi

What is quantitative research?

- A branch of research where the design is typically controlled by the researcher, data are represented by numerical values, which are manipulated statistically to obtain a result that represent a universal true value.

Typical research questions

- What is the prevalence of falls (in 2011) leading to treatment in community dwelling elderly in Regina?
- What is the pattern of depression during pregnancy in first time mothers in Saskatoon, and is this pattern likely to chance during post-partum period?
- What factors of the family, and that of the neighbourhood in which children reside are associated with school readiness at kindergarten?

Typical Research questions (2)

- Are elderly living in unsupported care settings experience more severe consequences due to falls than those who live in supported care units?
- Are children in full-day kindergarten programs show better developmental achievements than children in ‘regular’ (part-day) kindergarten programs?

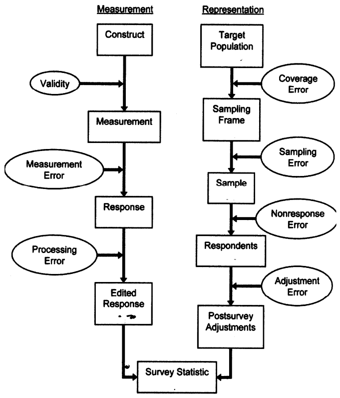
Research designs

- Experimental:
  - Treatment, stimulus, manipulation
  - Control/comparison
  - Time-limited
  - Structured, pre-defined
- Types of experimental designs
  - Varies from classical experiment, quasi-experiment, etc.

Design and measurement issues

- Representation
  - – Sample vs. population
- Design
  - – control/comparison (internal validity)
- Measurement
  - – Content, cognitive, usability
  - – Validity and reliability
- Analysis
  - – generalizability (external validity)

Design and measurement issues



Sources of quantitative data

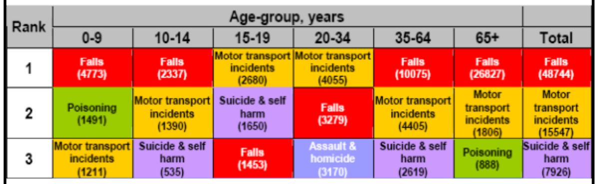
- Primary data – data we collect
- Secondary data – use of existing data
  - – Historical in nature (e.g., SPHERU history project)
    - http://historymatters.gmu.edu/mse/numbers/online.html
  - – Community level data (e.g., community counts)
    - http://www.gov.ns.ca/finance/communitycounts/default.asp
    - Saskatchewan – indicators project (e.g., Jeffery et al.)
  - – Population level data (Statistics Canada, Canadian Institute for Health Information)
    - http://www5.statcan.gc.ca/subject-sujet/theme-theme.action?pid=2966&lang=eng&more=0
    - http://uregina.ca/datalibrary/
  - – Administrative data (e.g., hospital discharge data)
    - http://www.health.gov.sk.ca/health-databases-info-doc

Fall/related Injuries in Saskatchewan

■ *Common & Costly* -- Numbers speak

Public Health Agency of Canada, 2005; Sask - Ministry of Health, 2008; …

Ranking of major categories of external causes of injury hospitalizations by age-group, SK, 1995/96-2004/05.



Rank	Age-group, years						
	0-9	10-14	15-19	20-34	35-64	65+	Total
1	Falls (4773)	Falls (2337)	Motor transport incidents (2680)	Motor transport incidents (4055)	Falls (10075)	Falls (26827)	Falls (48744)
2	Poisoning (1491)	Motor transport incidents (1390)	Suicide & self harm (1650)	Falls (3279)	Motor transport incidents (4405)	Motor transport incidents (1806)	Motor transport incidents (15547)
3	Motor transport incidents (1211)	Suicide & self harm (535)	Falls (1453)	Assault & homicide (3170)	Suicide & self harm (2619)	Poisoning (888)	Suicide & self harm (7926)

Source: Saskatchewan Comprehensive Injury Surveillance Report, 1995/96-2004/05.

Two examples

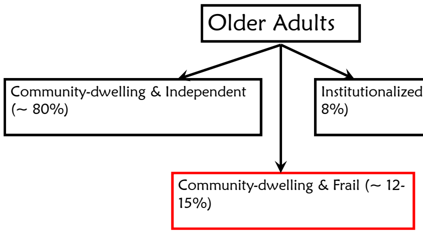
- Home Support Exercise Program – Shanthi
- Quality of Life Study - Nazeem

Community-based Exercise Intervention Study

article available at
http://thehealthline.ca/pdfs/HSEPEvaluationPaper.pdf

Shanthi Johnson

Continuum of Older Adults



Older Adults

Community-dwelling & Independent (~ 80%)

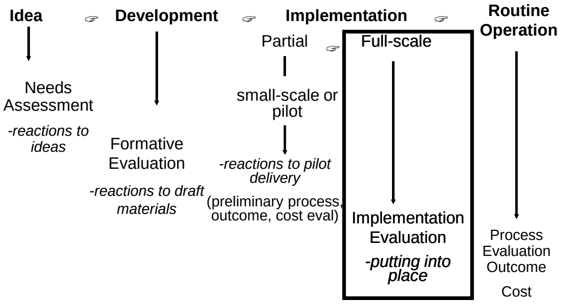
Institutionalized & Frail (~ 5-8%)

Community-dwelling & Frail (~ 12-15%)

Why focus on frail older adults?

- at risk for poor health outcomes
- often homebound
- difficult to reach
- need formal or informal support
- multiple functional deficits
- nutritional risk
- falling common
  - Incidence, Consequences
  - Exercise -- effective Intervention

Stages of Planning & Development



Idea ☞ **Development** ☞ **Implementation** ☞ **Routine Operation**

Needs Assessment
-reactions to ideas

Formative Evaluation
-reactions to draft materials

Partial ☞ Full-scale

small-scale or pilot
-reactions to pilot delivery
(preliminary process, outcome, cost eval)

Implementation Evaluation
-putting into place

Process Evaluation Outcome

Cost

Prior Models

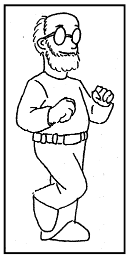
- Recruitment
- Delivery (PT or OT)
- Equipment
- Transport
- Strength training
- No mechanism for sustainability

Exercise Intervention –
Home Support Exercise Program

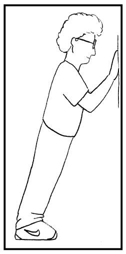
- Simple, functional
- No equipment, transport or extra visits
- Uses existing infrastructure for client recruitment, motivation
- Built-in mechanisms for monitoring & support

10 Simple Exercises

Walking



Wall push-ups



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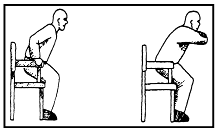
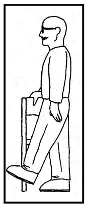
10 Simple Exercises

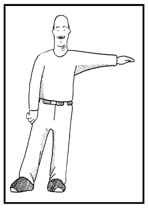
Get up from a chair



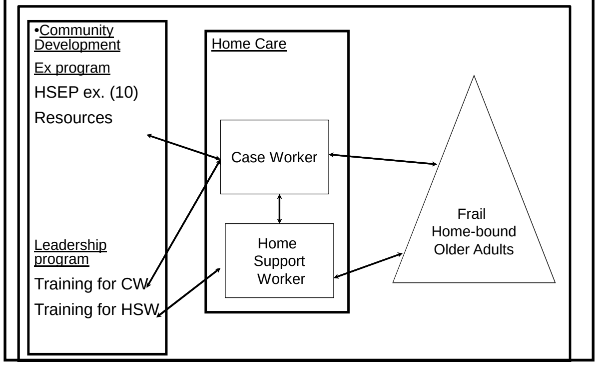


Leg lifts

Reaching



Community-based Research – Home Support Exercise Program (HSEP)



Streamlined Process for Sustainability

Case Workers:
- Brief intro (10-15min)
- Leave package
- Hotline/verbal consent
- Authorize HSW
- Follow-up

HSW's:
- Encourage client
- Monitor, review
- Monthly reports

Community-based Intervention Research

Purposes:
- Reach the group of interest - feasible?
- Will they do the exercises – compliance?
- Will it help - effective?

Methods

Sample:
- Recruitment through home care
  - Pre established inclusion/exclusion criteria
  - Wait listed comparison group
  - List of clients not available to researchers

Measures:
- Background info (existing info vs. data collection)
- Functional status
  - Timed up and go, Sit to Stand (1 and 5 repetitions)
- Psychosocial measures
  - Vitality Plus, Falls efficacy scale & Activity-specific balance confidence

Methods

Intervention:

- Taught in the home by trained researcher (when HSW was there)

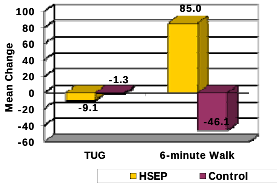
Data Collection:

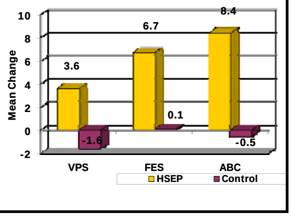
- – By community based researchers with support from CW/HSW
- – Importance of proper information management
  - files, data,
  - Need to establish prior to study actually takes places

Findings:

- Reaching intended target group
  - – Average age 80+; 50% living alone; multiple health problems; ~80% used needed walking aids & assistance to go out; received home care on average 2.5 days/week
- Compliance
  - – Only 20% program dropout; over 90% reportedly did at least one of the exercises three or more times a week
- Effectiveness

Home Support Exercise Program





Community-based intervention

- Engage partners early on & Keep them involved throughout
- Design – don't have complete control
- Measurements – simple, practical
- Information management
- In-built knowledge translation

Quality of Life Studies http://www.usask.ca/cuisr/about/modules-quality.html

Nazeem Muhajarine

Case study: Saskatoon Quality of Life Studies, 2001 to 2011
Paper--http://www.springerlink.com/content/qp87750861277160/fulltext.pdf

COMMUNITY-UNIVERSITY INSTITUTE FOR
SOCIAL RESEARCH

Quality of Life Module: Quality of Life in Saskatoon, SK: Achieving a Healthy, Sustainable Community

Summary of Research

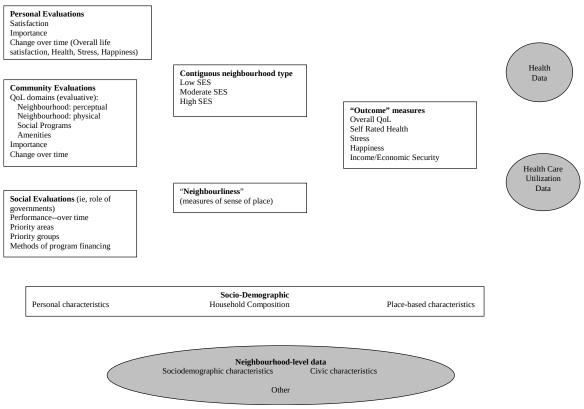
2004 Iteration

Prepared By: Allison Williams and Peter Kitchen

Researchers (in alphabetical order)
Peter Krebs, Community Liaison, Quality of Life Module
Bill Holden, Planning Department, City of Saskatoon
Nazeem Muhajarine, Community Health & Epidemiology
CUISR, SPHERU
Allison Williams, School of Geography & Earth Sciences,
McMaster University, Hamilton, ONT

Building Healthy Sustainable Communities

Analytical Scheme—Saskatoon Quality of Life Quantitative Data



Personal Evaluations
Satisfaction
Importance
Change over time (Overall life satisfaction, Health, Stress, Happiness)

Community Evaluations
QoL domains (evaluative):
  Neighbourhood: perceptual
  Neighbourhood: physical
  Social Programs
  Amenities
Importance
Change over time

Social Evaluations (ie, role of governments)
Performance--over time
Priority areas
Priority groups
Methods of program financing

Contiguous neighbourhood type
Low SES
Moderate SES
High SES

"Neighbourliness"
(measures of sense of place)

"Outcome" measures
Overall QoL
Self Rated Health
Stress
Happiness
Income/Economic Security

Health Data

Health Care Utilization Data

Socio-Demographic
Personal characteristics
Household Composition
Place-based characteristics

Neighbourhood-level data
Sociodemographic characteristics
Civic characteristics
Other

Operationalizing Concepts

- Community

Postal Code Length of time in neighborhood Number of homes lived in	Saskatoon Quality of Life questionnaire
Community quality	5 items from Saskatoon Quality of Life questionnaire 3 items from Questions SAF-Q5A, Q5B, and Q5C from the National Longitudinal Study of Children
Neighborhood as a place to raise children	Question SAF-Q2 from the National Longitudinal Study of Children

Community quality questions

Please tell me whether you strongly disagree (1), disagree (2), agree (3), or strongly agree (4) about each of the following statements about your community.

1. This is a close-knit neighbourhood.
2. People in this neighbourhood can be trusted.
3. People around here are willing to help their neighbours.
4. People in this neighbourhood do not share the same values.
5. People in this neighbourhood generally do not get along with each other.
6. It is safe to walk alone in this neighbourhood after dark.
7. It is safe for children to play outside during the day.
8. There are good parks, playgrounds and play spaces in this neighbourhood.

Mental and Physical Health

Self-rated health	NPHS 2000 survey
Chronic conditions	NPHS 1998 survey (with some items omitted from NPHS list)
Psychological Distress	Kessler. Short screening scales to monitor population prevalences and trends in non-specific population distress. Psychological Medicine 2002; 32: 959-976.
Functional Limitations	CCHS Cycle 1.1 September 2000-01
Injury	NPHS 2000 survey
Workplace injury	NPHS 2000 survey
Absence from work (and reason)	NPHS 2000 survey

Data collection procedure

- Questionnaire developed using various sources of measures
- Focus group of about 20 individuals from target population to explore clarity of questions, respondent reactions to potentially sensitive questions, and obtain estimate of length of time needed
- Questionnaire revised, then field-tested with random sample of about 40 individuals using CATI, to obtain time estimates, potential response rates, ensure question clarity, ensure adequacy of interviewer preparation and "debug" computer program.
- Data collected through telephone survey by trained interviewers using CATI

So Far. . . Original research

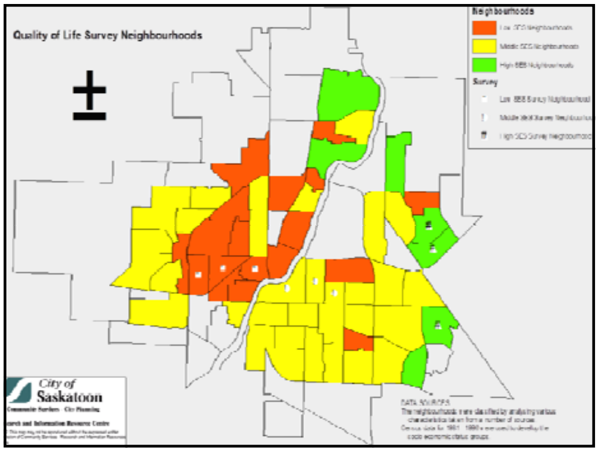
- Existing knowledge of QofL in Saskatoon
- For 2001, 2004, 2007, 2010
  - Telephone survey
  - Interviews and focus groups
  - A review of existing policies

Sample Frame Methodology

- 58 Saskatoon neighbourhoods grouped according to SES (from 2001, 2006 Census)
  Median hshld. Income ($)
  Percentage Employed (%)
- K-means cluster routine used (3-cluster solution)
  1. High SES cluster (n= 7) (high SES)
  2. Medium SES cluster (n=33) (middle SES)
  3. Low SES cluster (n= 18) (low SES)

2001 Summary Statistics (Means) for Three Neighbourhood Clusters

COMPONENT VARIABLE	HIGH SES (N=7)	MIDDLE SES (N=33)	LOW SES (N=18)
Median Income ($)	79,493	43,815	25,192
% Employed	80.2	71.3	50.1



Main lessons from the session

1. Questions amenable to quantitative research are specific, and need to be stated up-front. Typically, these are of the form of ‘what’ and ‘how’ rather than ‘why’ questions.
2. Design is under researcher’s control—stronger the design (less bias, very little alternate explanations possible) the more valid the results.

Main lessons from the session (2)

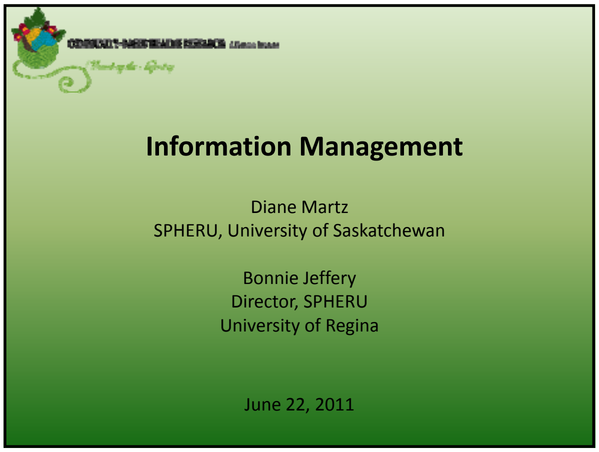
3. Many designs are possible; but, generally involve comparisons between groups of people, across place, and over time.
4. Many different types of biases are possible (‘threats to validity’); minimizing biases (at: design stage, collection of data, and analyzing of data) is the critical challenge.
5. Results typically reported at group level.
6. Larger the sample the more precise the results.

Main lessons from the session (3)

7. Consider the use of data we collect vs. use of existing data
8. Interpretation need to be consistent and bounded within the results obtained.
9. Common misconception: Quantitative research better than qualitative or any other type of research.
10. Consider: quantitative research used in complement with other types of research for greater depth and breadth.

Case studies

- What type of question(s) related to your cases are amenable to a quantitative study?
  - Write out the questions (hypothesis) and discuss why and how these type of information would be useful for your case
- What would be the data sources for the question(s) that you want to answer using quantitative approach?
- Discuss a) how the quantitative information may complement (or not) any other type of information you may have, and b) strategies for presenting these information.

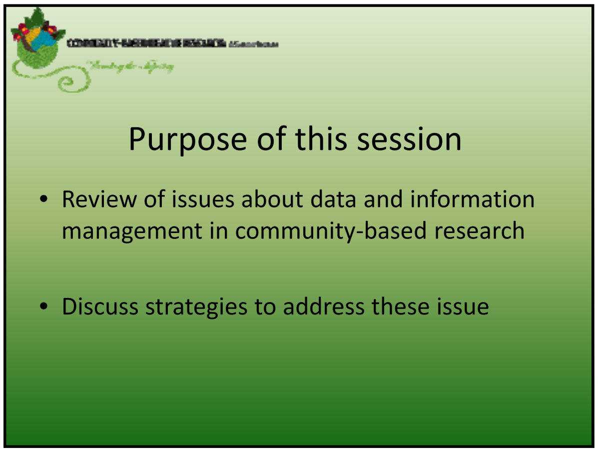


Information Management

Diane Martz
SPHERU, University of Saskatchewan

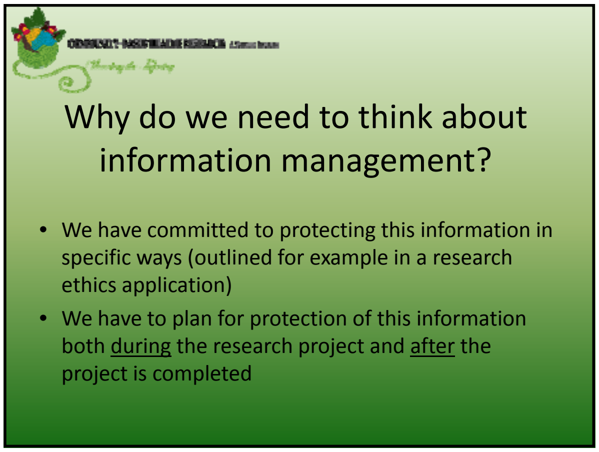
Bonnie Jeffery
Director, SPHERU
University of Regina

June 22, 2011



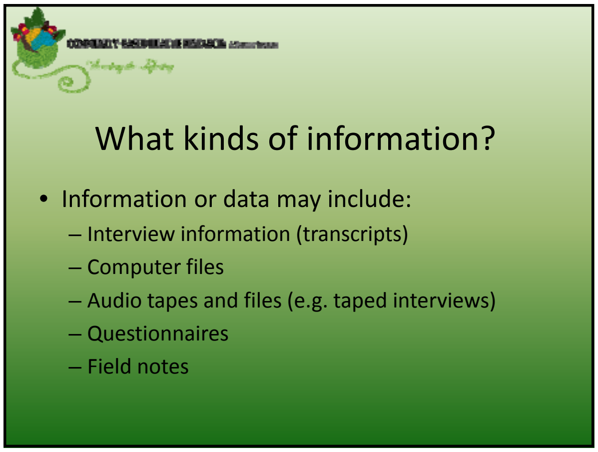
Purpose of this session

- Review of issues about data and information management in community-based research
- Discuss strategies to address these issue



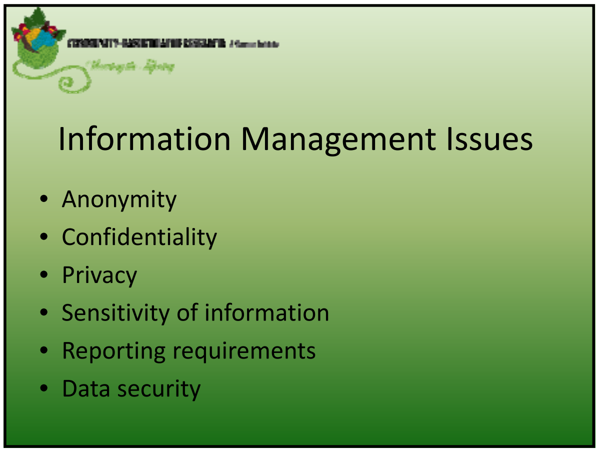
Why do we need to think about information management?

- We have committed to protecting this information in specific ways (outlined for example in a research ethics application)
- We have to plan for protection of this information both <u>during</u> the research project and <u>after</u> the project is completed



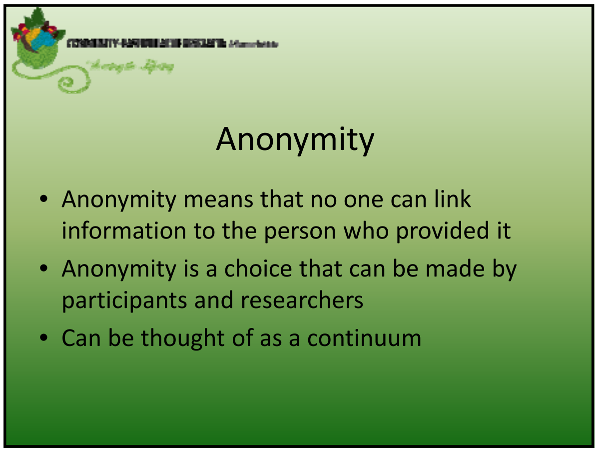
What kinds of information?

- Information or data may include:
  - Interview information (transcripts)
  - Computer files
  - Audio tapes and files (e.g. taped interviews)
  - Questionnaires
  - Field notes



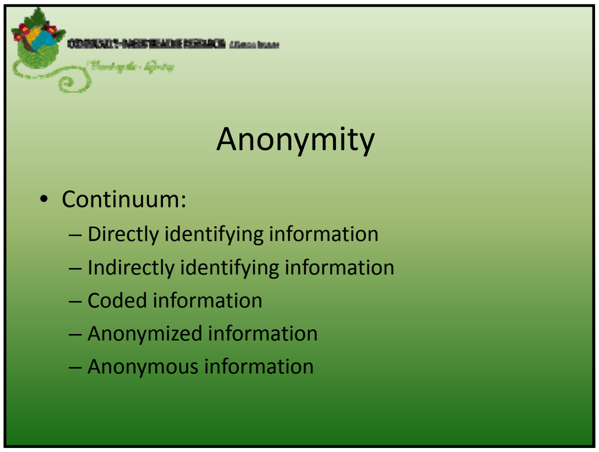
Information Management Issues

- Anonymity
- Confidentiality
- Privacy
- Sensitivity of information
- Reporting requirements
- Data security



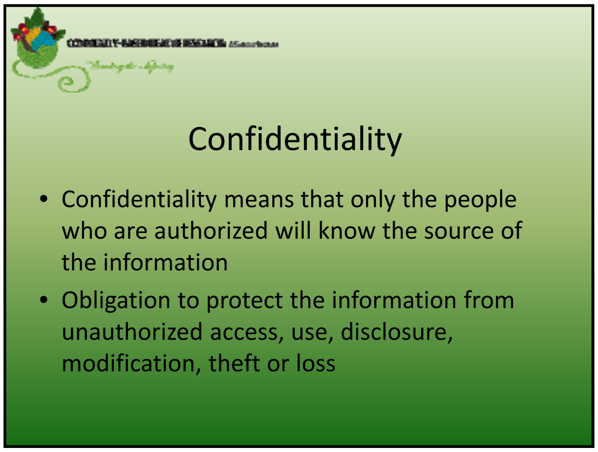
Anonymity

- Anonymity means that no one can link information to the person who provided it
- Anonymity is a choice that can be made by participants and researchers
- Can be thought of as a continuum



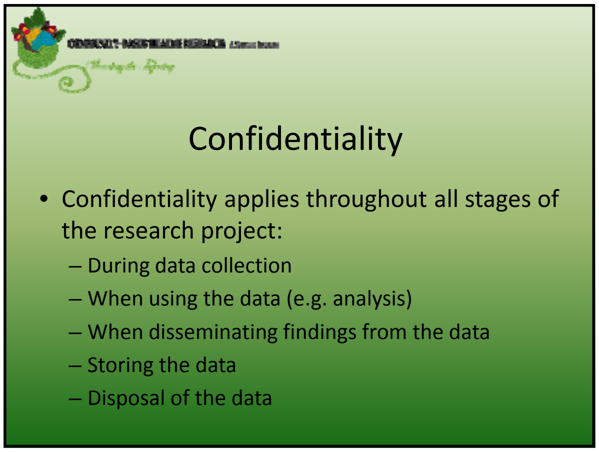
Anonymity

- Continuum:
  - Directly identifying information
  - Indirectly identifying information
  - Coded information
  - Anonymized information
  - Anonymous information



Confidentiality

- Confidentiality means that only the people who are authorized will know the source of the information
- Obligation to protect the information from unauthorized access, use, disclosure, modification, theft or loss

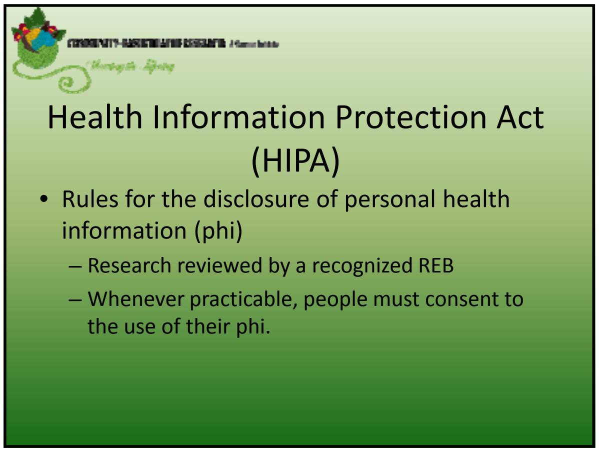


Confidentiality

- Confidentiality applies throughout all stages of the research project:
  - During data collection
  - When using the data (e.g. analysis)
  - When disseminating findings from the data
  - Storing the data
  - Disposal of the data

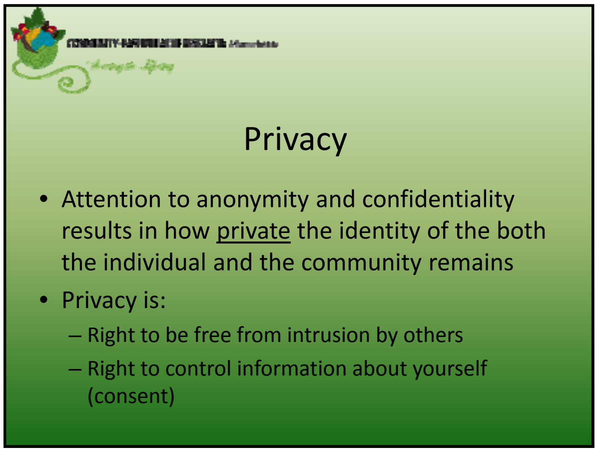
Confidentiality

- Confidentiality (and anonymity) issues in community-based research:
  - Role of community partners in the research
  - Research with small communities
  - Qualitative research methods



Health Information Protection Act (HIPA)

- Rules for the disclosure of personal health information (phi)
  - Research reviewed by a recognized REB
  - Whenever practicable, people must consent to the use of their phi.

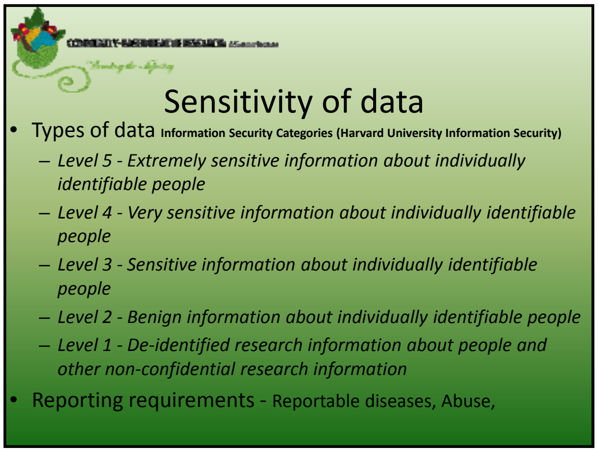


Privacy

- Attention to anonymity and confidentiality results in how private the identity of the both the individual and the community remains
- Privacy is:
  - Right to be free from intrusion by others
  - Right to control information about yourself (consent)

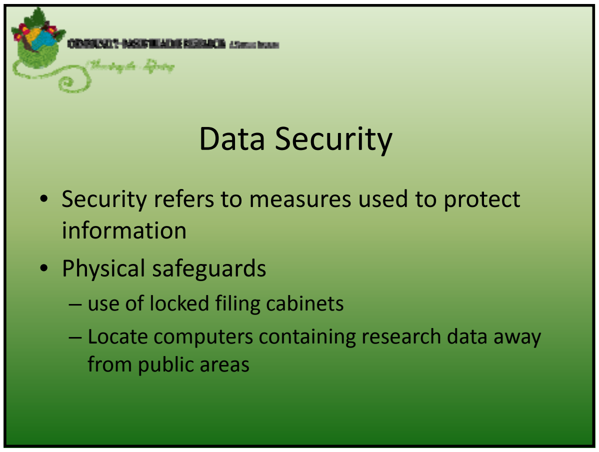
Privacy

- Consent
  - Individual
  - Community
- Online privacy tool – how many variables do you need to be able to re-identify someone?
- http://www.ehealthinformation.ca/rebwizard/ca



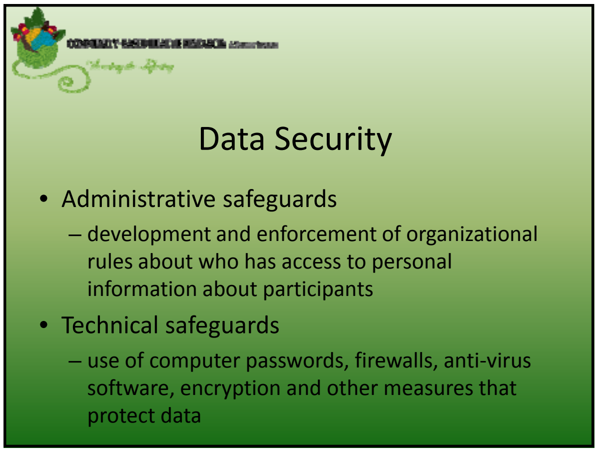
Sensitivity of data

- Types of data Information Security Categories (Harvard University Information Security)
  - *Level 5 - Extremely sensitive information about individually identifiable people*
  - *Level 4 - Very sensitive information about individually identifiable people*
  - *Level 3 - Sensitive information about individually identifiable people*
  - *Level 2 - Benign information about individually identifiable people*
  - *Level 1 - De-identified research information about people and other non-confidential research information*
- Reporting requirements - Reportable diseases, Abuse,



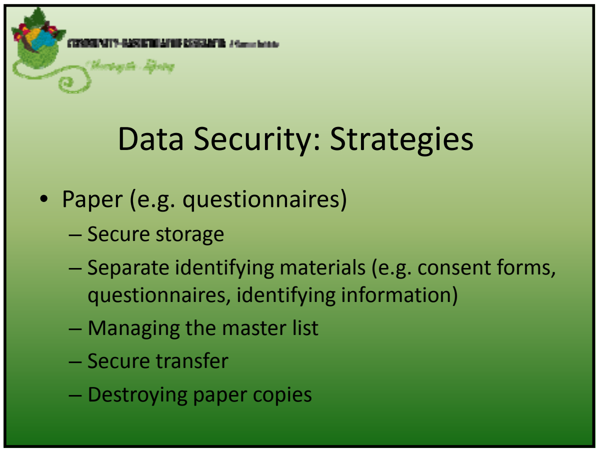
Data Security

- Security refers to measures used to protect information
- Physical safeguards
  - use of locked filing cabinets
  - Locate computers containing research data away from public areas



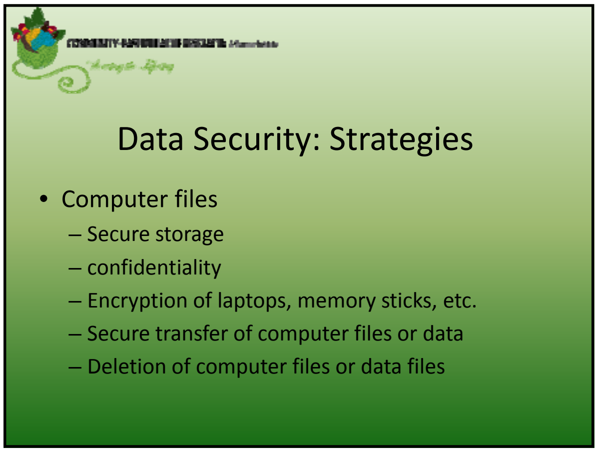
Data Security

- Administrative safeguards
  - development and enforcement of organizational rules about who has access to personal information about participants
- Technical safeguards
  - use of computer passwords, firewalls, anti-virus software, encryption and other measures that protect data



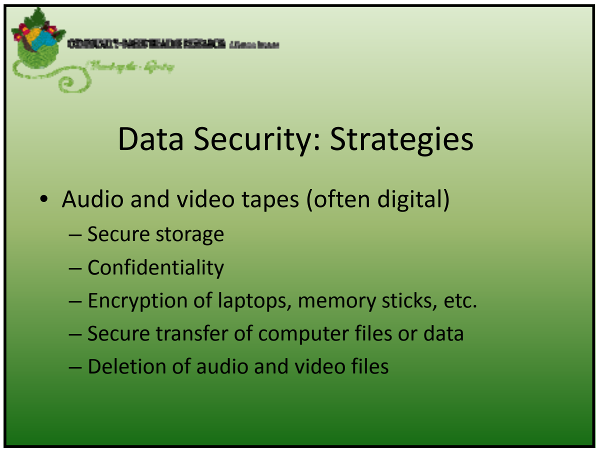
Data Security: Strategies

- Paper (e.g. questionnaires)
  - Secure storage
  - Separate identifying materials (e.g. consent forms, questionnaires, identifying information)
  - Managing the master list
  - Secure transfer
  - Destroying paper copies



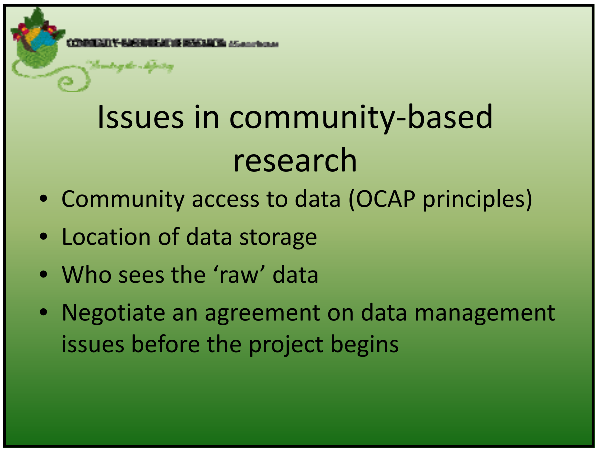
Data Security: Strategies

- Computer files
  - Secure storage
  - confidentiality
  - Encryption of laptops, memory sticks, etc.
  - Secure transfer of computer files or data
  - Deletion of computer files or data files



Data Security: Strategies

- Audio and video tapes (often digital)
  - – Secure storage
  - – Confidentiality
  - – Encryption of laptops, memory sticks, etc.
  - – Secure transfer of computer files or data
  - – Deletion of audio and video files



Issues in community-based research

- Community access to data (OCAP principles)
- Location of data storage
- Who sees the ‘raw’ data
- Negotiate an agreement on data management issues before the project begins

Discussion questions for case studies

1. What specific aspects of data management are most important for your case study?
2. Discuss strategies for addressing these.
3. Discuss how both individual and community consent might apply in your case study.

Engaging Policy Makers: Making Opportunities for Change

Tom McIntosh
Political Science & SPHERU
University of Regina

Outline

- Why engage with policy-makers?
- Who do you engage?
- How and when do you engage?
- Pitfalls and how to avoid them
- The importance of ideas for policy change

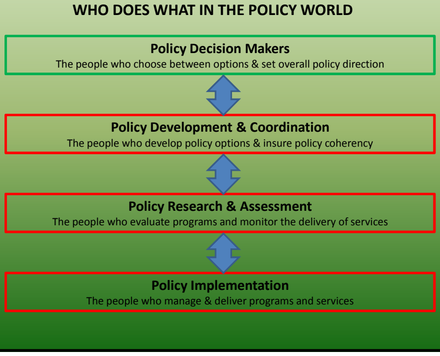
Why engage with policy makers?

- Community & CBO relationship to policy makers
  - BFFs? Enemies? Frenemies?
- How policy change happens
  - Problems, solutions (ideas) and politics
- Windows of opportunity for change
- Being ready when the window opens
  - Relationships, relationships, relationships

Who Do You Engage?

- Multiple factors go into this decision…
- What kind of change are you likely looking for?
  - Improve existing services? Wholesale change in direction?
- Who has the time/interest in the research issue?
- Who might have knowledge/resources you need?
- What is the political context your working in?
  - Open to new ideas? Hostile to your community/clients?

WHO DOES WHAT IN THE POLICY WORLD



Policy Decision Makers
The people who choose between options & set overall policy direction

Policy Development & Coordination
The people who develop policy options & insure policy coherency

Policy Research & Assessment
The people who evaluate programs and monitor the delivery of services

Policy Implementation
The people who manage & deliver programs and services

There are many policy worlds…

- Federal & provincial governments
- Local & regional governments (municipalities, RMs, regional health authorities)
- First Nations governments (bands & tribal councils)
- Metis political organizations (MNC, MNS)
- Your research can impact one or more policy world…
- Policy-makers & Decision-makers different in each

Choosing your allies carefully…

- Goal: To get your research into the hands of those who can use it best…
  - If not now, then in the future (when a window opens)
- Policy allies who have connection (buy-in) to your research ideas can identify opportunities
- Decision-makers come & go … policy-makers are forever

How to engage policy-makers

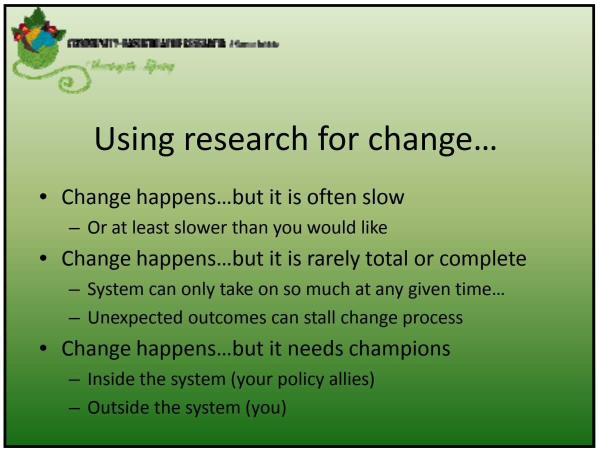
- Early is better than later
  - Esp. if they have knowledge/resources you need
- Early contact has many benefits
  - Can clarify research questions & approach
  - Can identify challenges you will face
  - Can identify potential 'champions' inside policy world
- Commitment has to run both ways…

How to make policy allies…

- Respect their reality (if you want respect for yours)
  - Understand the constraints on them
  - Look for common ground & mutual interests
- Take their input seriously
  - The art of the possible…
- Build the relationship over course of research
  - Regular mtgs, updates, feedback & assessment

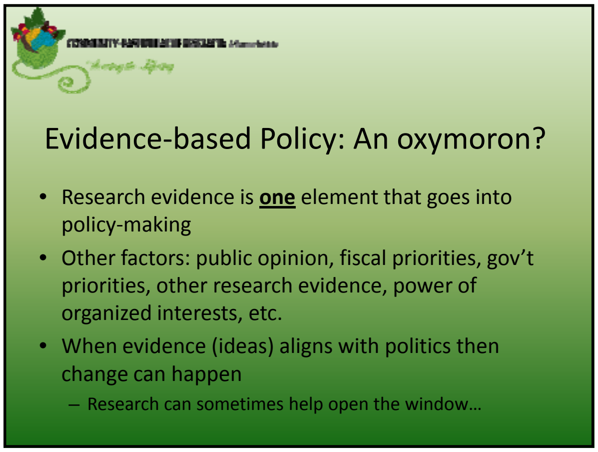
Pitfalls & How to Avoid Them

- Always be clear about roles & responsibilities
  - Ownership, control, access & possession of research
- Put your expectations on the table…
  - What you want to achieve, what you're willing to accept
- Avoiding 'capture' doesn't mean staying in hiding…
- Know when to fold 'em…
  - Not every relationship works out…



Using research for change…

- Change happens…but it is often slow
  - Or at least slower than you would like
- Change happens…but it is rarely total or complete
  - System can only take on so much at any given time…
  - Unexpected outcomes can stall change process
- Change happens…but it needs champions
  - Inside the system (your policy allies)
  - Outside the system (you)



Evidence-based Policy: An oxymoron?

- Research evidence is **one** element that goes into policy-making
- Other factors: public opinion, fiscal priorities, gov't priorities, other research evidence, power of organized interests, etc.
- When evidence (ideas) aligns with politics then change can happen
  - Research can sometimes help open the window…

Comments & Questions?

- Does any of this make sense?
- Points of clarification…
- Your own experiences with policy makers?

Your case studies…

- What are the policy implications of your research?
- Who would you engage with in the policy world(s)?
  - Which policy world(s) & why?
- What would their role be?
- What risks/rewards are possible?
- Sketch out a plan for engaging policy makers in your project

Knowledge Translation for Community-Based Health Research

Dr. Jo-Ann Episkenew
Director and Co-Principal Investigator
Indigenous Peoples' Health Research Centre

What Is Knowledge Translation?

Knowledge translation is 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.

It's All About Relationships!

This process takes place within a complex system of interactions between researchers and knowledge users that may vary in intensity, complexity and level of engagement depending on the nature of the research and the findings as well as the needs of the particular knowledge user.

End of Grant KT

This type of KT reports new knowledge and highlights the findings' potential impact of using the findings, the strength of the evidence, and includes:

- conference presentations
- publication in open access peer-reviewed journals
- non-peer reviewed publications and web postings
- DVDs

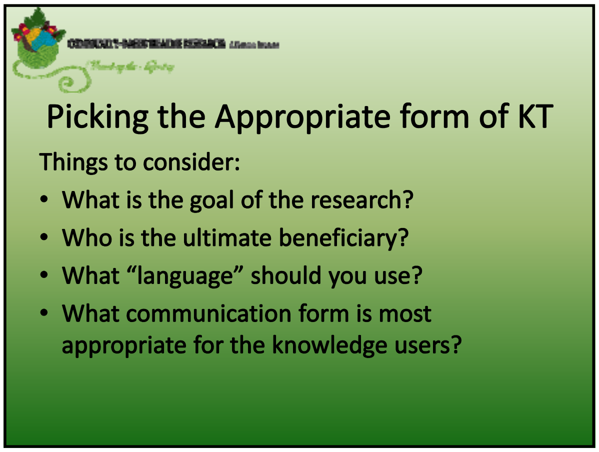
Integrated KT (IKT):

A way of doing research that is collaborative, action-oriented, and involves the co-production of knowledge with researchers engaging the stakeholders who are the end users.

It's really about involving stakeholders in the entire research process.

How are stakeholders involved?

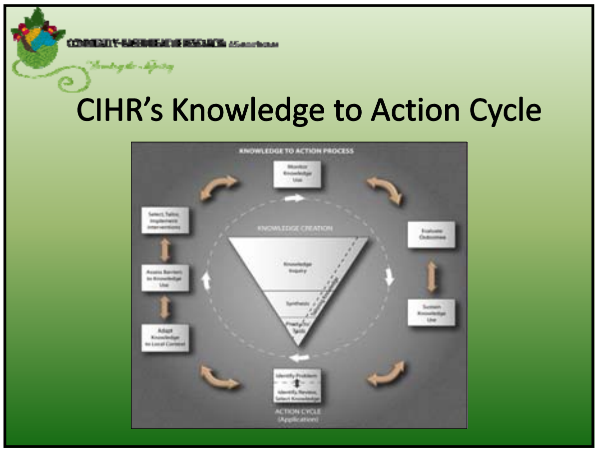
- Shaping the research questions;
- Deciding on the methodology;
- Helping with data collection and tools development;
- Interpreting study findings;
- Crafting the message and disseminating the research results; and/or
- Moving the results into practice.



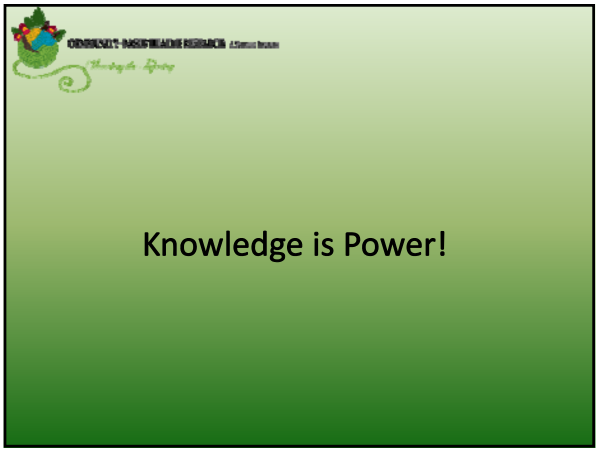
Picking the Appropriate form of KT

Things to consider:

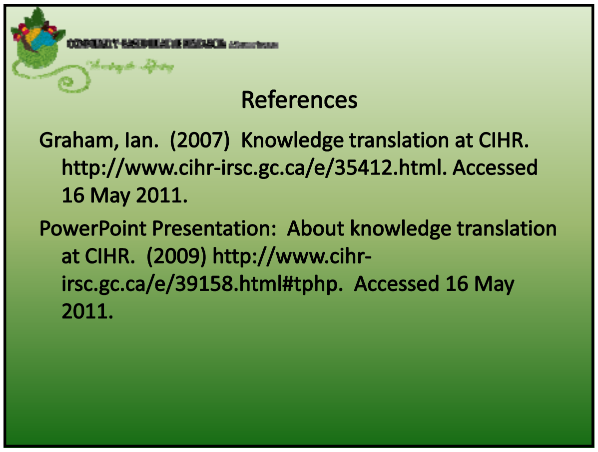
- What is the goal of the research?
- Who is the ultimate beneficiary?
- What "language" should you use?
- What communication form is most appropriate for the knowledge users?



CIHR's Knowledge to Action Cycle



Knowledge is Power!



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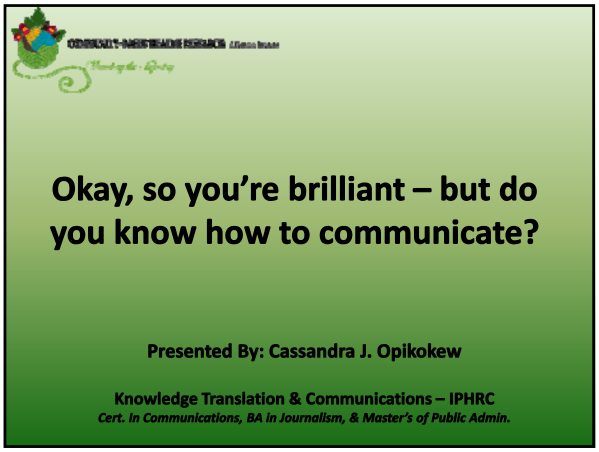
Graham, Ian. (2007) Knowledge translation at CIHR. http://www.cihr-irsc.gc.ca/e/35412.html. Accessed 16 May 2011.

PowerPoint Presentation: About knowledge translation at CIHR. (2009) http://www.cihr-irsc.gc.ca/e/39158.html#tphp. Accessed 16 May 2011.



Okay, so you're brilliant – but do you know how to communicate?

Presented By: Cassandra J. Opikokew

Knowledge Translation & Communications – IPHRC
Cert. In Communications, BA in Journalism, & Master's of Public Admin.

What is communications?

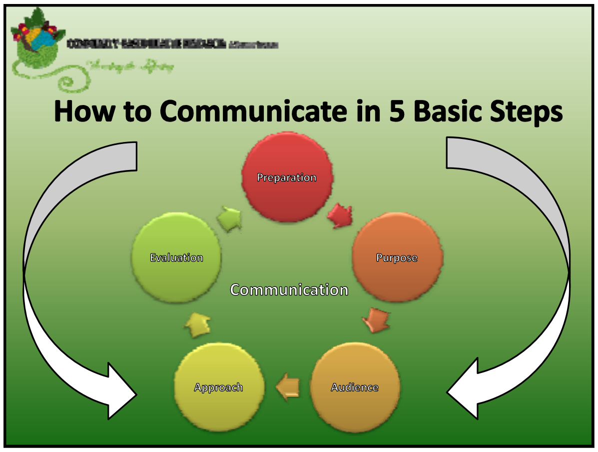
- **Exchange of information – but *strategic*.**
- **Systematic planning, implementing, monitoring and revision of communications within and with organizations.**

Why should it matter to you?

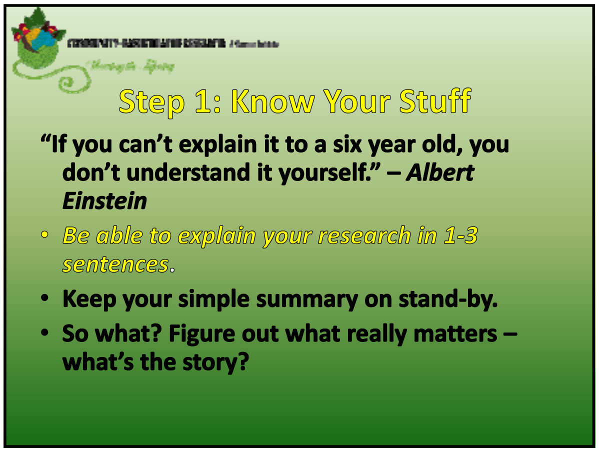
- Communications ←→ KT
- **Researcher profile**
- **Publicize results – you're doing work that matters, right?**
- **Keep funders and institutions happy**
- **It's free!**
- **"Everyone's doing it."**

Basic *FREE* Communication Tools

- Website, website, website!
- **Blog**
- **Media advisories and releases**
- **Social networking sites**
- **Targeted outreach**
- **Email**
- **List-servs**
- **Youtube**
- **PowerPoint**



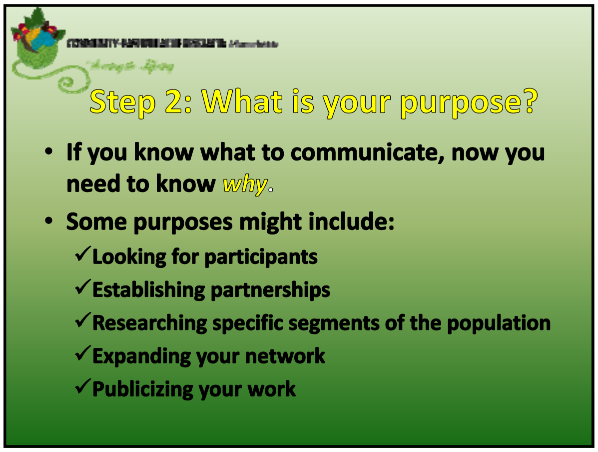
How to Communicate in 5 Basic Steps



Step 1: Know Your Stuff

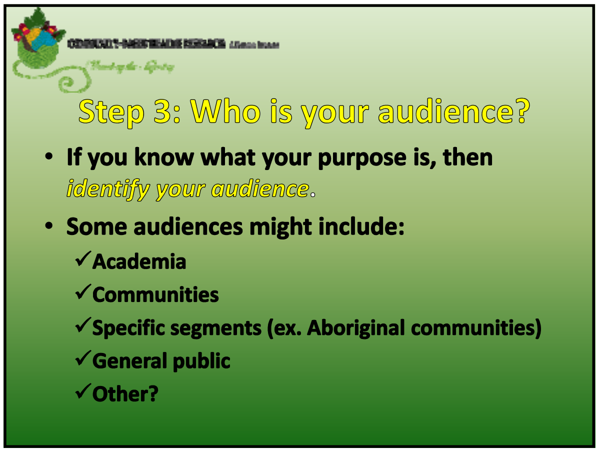
"If you can't explain it to a six year old, you don't understand it yourself." – *Albert Einstein*

- *Be able to explain your research in 1-3 sentences.*
- **Keep your simple summary on stand-by.**
- **So what? Figure out what really matters – what's the story?**



Step 2: What is your purpose?

- **If you know what to communicate, now you need to know *why*.**
- **Some purposes might include:**
  - ✓**Looking for participants**
  - ✓**Establishing partnerships**
  - ✓**Researching specific segments of the population**
  - ✓**Expanding your network**
  - ✓**Publicizing your work**

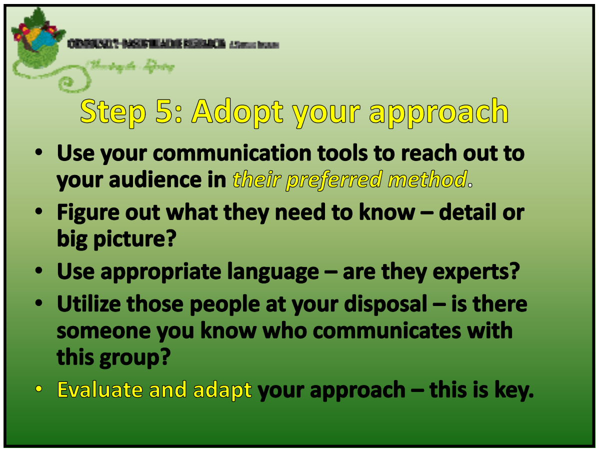


Step 3: Who is your audience?

- If you know what your purpose is, then *identify your audience.*
- Some audiences might include:
  - ✓Academia
  - ✓Communities
  - ✓Specific segments (ex. Aboriginal communities)
  - ✓General public
  - ✓Other?

Step 4: How do *they* communicate?

- Once you know your audience, figure out *how* they prefer to communicate.
- Some examples include:
  - ✓Academia – journals, list-servs, presentations, networking events, etc.
  - ✓Communities – local papers/events, high-traffic areas
  - ✓Specific segments (ex. Aboriginal communities) – community media, personal communications, etc.
  - ✓General public – mainstream media



Step 5: Adopt your approach

- Use your communication tools to reach out to your audience in *their preferred method.*
- Figure out what they need to know – detail or big picture?
- Use appropriate language – are they experts?
- Utilize those people at your disposal – is there someone you know who communicates with this group?
- Evaluate and adapt your approach – this is key.

So you need media, eh?

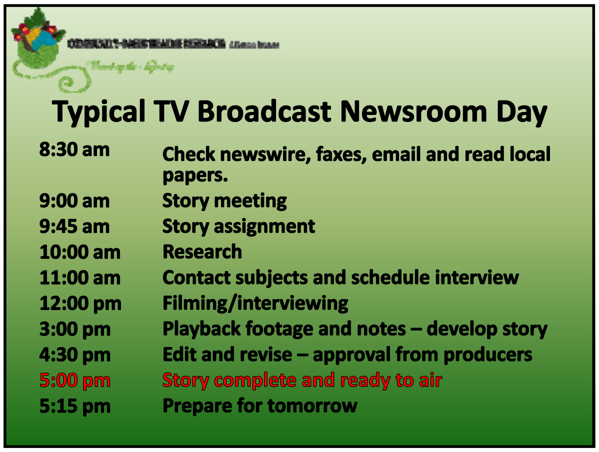
Utilizing media for reaching out to larger audiences

When to Use Media

- You have an exciting *story* or *"result"*
- You are an "expert" on a hot topic
- You have an event or something open to public
- You do something interesting or new
- You have something to show and people to talk about it
- Use media sparingly and strategically

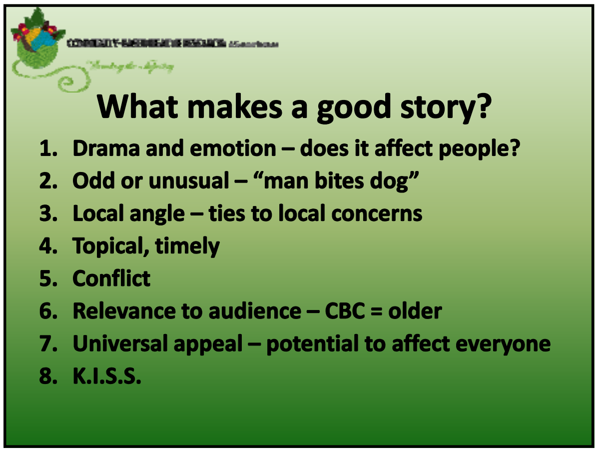
When NOT to Use Media

- You have ethical or legal restrictions
- You have no one they can talk to
- You are looking for participants
- You just want to share information
- You have nothing to "show"
- Weekends – tough sell, weak news
- You have no story



Typical TV Broadcast Newsroom Day

8:30 am	Check newswire, faxes, email and read local papers.
9:00 am	Story meeting
9:45 am	Story assignment
10:00 am	Research
11:00 am	Contact subjects and schedule interview
12:00 pm	Filming/interviewing
3:00 pm	Playback footage and notes – develop story
4:30 pm	Edit and revise – approval from producers
5:00 pm	Story complete and ready to air
5:15 pm	Prepare for tomorrow

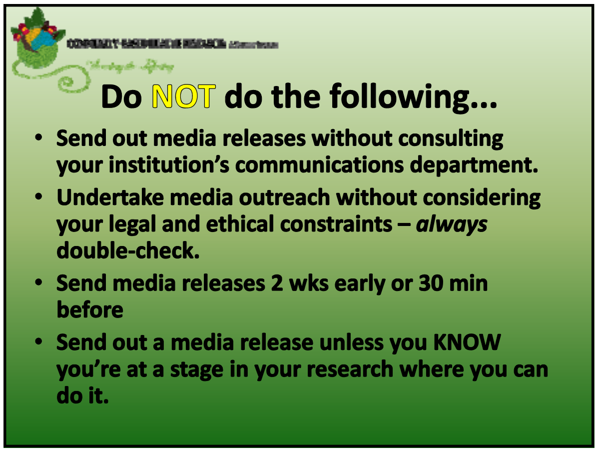


What makes a good story?

1. Drama and emotion – does it affect people?
2. Odd or unusual – "man bites dog"
3. Local angle – ties to local concerns
4. Topical, timely
5. Conflict
6. Relevance to audience – CBC = older
7. Universal appeal – potential to affect everyone
8. K.I.S.S.

Media with Knowledge Users

- Without them, there is no story
- Figure out key characters
- Pick "good talkers"
- Have them on stand-by and pre-arranged
- They answer your "so what?" question
- Include them in developing your communications plan
- Assign someone to "media duty"

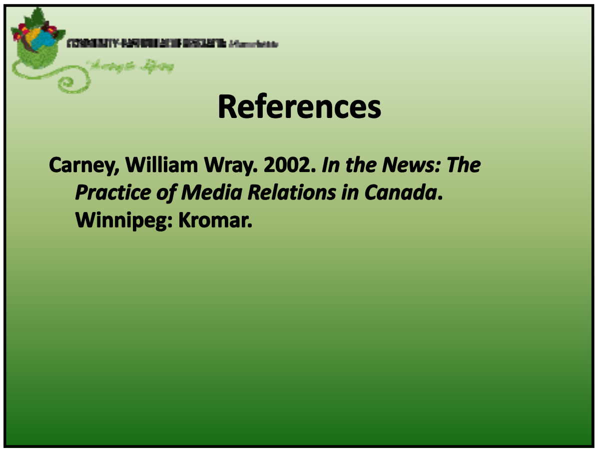


Do NOT do the following…

- Send out media releases without consulting your institution's communications department.
- Undertake media outreach without considering your legal and ethical constraints – *always* double-check.
- Send media releases 2 wks early or 30 min before
- Send out a media release unless you KNOW you're at a stage in your research where you can do it.

Events & Media Contact

- Have handouts ready.
- Have your talkers on stand-by with contact information.
- Assign someone to handle media if you expect a lot.
- Get their media contact information.
- *Make connections for next time.*
- Track your coverage.



References

Carney, William Wray. 2002. *In the News: The Practice of Media Relations in Canada*. Winnipeg: Kromar.

“This has been an amazing learning experience for me and will assist the CBO that I work for.”

“Well done, I would recommend the institute to my colleagues and senior leadership.”

Appendix A

Community-Based Health Research: A Summer Institute

Weaving the Tapestry

Program

COMMUNITY-BASED HEALTH RESEARCH: A Summer Institute

Weaving the Tapestry

SPHERU
SASKATCHEWAN POPULATION HEALTH AND EVALUATION RESEARCH UNIT

IPHRC

PRAIRIE COMMUNITY-BASED HIV RESEARCH PROGRAM

June 19 – 24, 2011 Regina, Saskatchewan

Sunday, June 19

Registration and Reception		
4:30 - 8:30	Registrations (Room #: ED 191)	
5:00 - 6:30	Grocery Shopping Trip	A Regina City Transit bus will be picking up and dropping participants off between the North and South Residences.
7:00 - 9:00	Welcome Reception	University Club (College West Building, Room 215)

Monday, June 20

Introductions and Guest Speaker		
8:00	Registrations (Room #: ED 191)	
8:15	***CONTINENTAL BREAKFAST (Room CK187)***	
9:00	Introductions	Bonnie Jeffery, Jo-Ann Episkenew and Paula Migliardi
9:15	Opening Prayer & Remarks	Elder Betty McKenna
9:30	Opening Address	Charlotte Reading, University of Victoria. *Community-Based Research: Walking the Path Together*
	BREAK (10:45-11:00)	
11:00	Building Community	Linda Goulet, First Nations University of Canada
12:00	***LUNCH PROVIDED (Room CK187)***	
Session I: Developing Relationships & Partnerships		
1:30	Part 1 - Collaboration	Linda Goulet, First Nations University of Canada
		Gloria DeSantis, SPHERU, University of Regina
	BREAK (2:45-3:15)	

Monday, June 20 (con't)

Case Study Introductions
(All case study work will take part in the same room as listed below.)

3:15 - 4:30	Case Study 1: Room CK184	*All Nations Hope AIDS Network: Community-Based Research and Capacity Development.*
	Case Study 2: Room CK185	*Lung Association of Saskatchewan: Effective and Culturally-Safe Knowledge Translation for First Nations and Métis Peoples' Respiratory Health.*
	Case Study 3: Room CK187	*Play It Safer Network: What's hot and what's not…? Ensuring the community input and investment of a community-based organization.*
	Case Study 4: Room CK188	*Paths to Living Well for Standing Buffalo Youth: Sharing the Learnings*
	Case Study 5: Room CK192	*The 595 Prevention Team: What Goes Around: How Peers Use their Social Networks to Share Safer Drug Use Resources.*
	Case Study 6: Room CK193	*Saskatoon Poverty Reduction Partnership: Community-Based Research Case Study*
4:45 - 5:30	Course-for-Credit Meeting: Room 185	Instructors meeting with graduate students taking the institute for course-credit.

Tuesday, June 21

Session I: Developing Relationships & Partnerships (continued)

8:15	***CONTINENTAL BREAKFAST (Room CK187)***	
9:00	Part 2 - Research Ethics	Diane Martz, SPHERU, University of Saskatchewan
		Carrie Bourassa, IPHRC, First Nations University of Canada
	BREAK (10:15-10:45)	
10:45	Case Study Work	
12:00	***LUNCH PROVIDED (Room CK187)***	

Session II: Research Methods for Community-Based Health Research

1:30	Part 1: Qualitative Methods	Sylvia Abonyi, SPHERU, University of Saskatchewan
		Pammla Petrucka, SPHERU, University of Saskatchewan
	BREAK (2:45-3:15)	
3:15 - 4:30	Case Study Work	

Wednesday, June 22

Session II: Research Methods for Community-Based Health Research (continued)

8:15	***CONTINENTAL BREAKFAST (Room CK187)***	
9:00	Part 2 - Quantitative Methods	Nazeem Muhajarine, SPHERU, University of Saskatchewan
		Shanthi Johnson, SPHERU, University of Regina
	BREAK (10:15-10:45)	
10:45	Case Study Work	
12:00	***LUNCH PROVIDED (Room CK187)***	

Session III: Information Management

1:30	Information Management	Bonnie Jeffery, SPHERU, University of Regina
		Diane Martz, SPHERU, University of Saskatchewan
	BREAK (2:45-3:15)	
3:15 - 4:30	Case Study Work	

Community Conversations at the Albert Scott Community Centre

6:00	Shuttle Bus Service	A Regina City Transit bus will pick up participants between the North and South Residences.
7:00	Keynote Presentation	Andrée Cazabon *3rd World Canada - Engaging Communities in Reconciliation*
9:15	Shuttle Bus Service	

Thursday June 23

Session IV: Knowledge Translation & Communications

8:15	***CONTINENTAL BREAKFAST (Room CK187)***	
9:00	Part 1 - Policy Makers	Tom McIntosh, SPHERU, University of Regina
	BREAK (10:15-10:45)	
10:45	Case Study Work	
12:00	***LUNCH PROVIDED (Room CK187)***	

Session IV: Knowledge Translation & Communications (continued)

1:30	Part 2 - Communities	Jo-Ann Episkenew, IPHRC, University of Regina
		Cassandra Opikokew IPHRC, University of Regina
	BREAK (2:45-3:15)	
3:15 - 4:30	Case Study Work	

Friday, June 24		
Panel Discussion		
8:15	***CONTINENTAL BREAKFAST (Room CK187)***	
9:00	Panel Discussion	A graduate student, faculty member and community member will reflect on their learnings from the institute.
BREAK (10:15-10:45)		
Case Study Presentations		
10:45	Case Study 1	
11:10	Case Study 2	
11:35	Case Study 3	
12:00	***LUNCH PROVIDED (Room CK187)***	
Case Study Presentations (continued)		
1:30	Case Study 4	
1:55	Case Study 5	
2:20	Case Study 6	
BREAK (2:45-3:00)		
3:00	Closing Remarks	Bonnie Jeffery and Jo-Ann Episkenew
3:15	Closing Prayer & Remarks	Elder Betty McKenna

IPHRC

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SASKATCHEWAN POPULATION HEALTH AND EVALUATION RESEARCH UNIT

PRAIRIE COMMUNITY-BASED
HIV RESEARCH PROGRAM

UNIVERSITY OF
SASKATCHEWAN

University
of Regina

CIHR IRSC
Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

Saskatchewan
Health Research
FOUNDATION