Community Based Participatory Research:
Principles and Practices in the North

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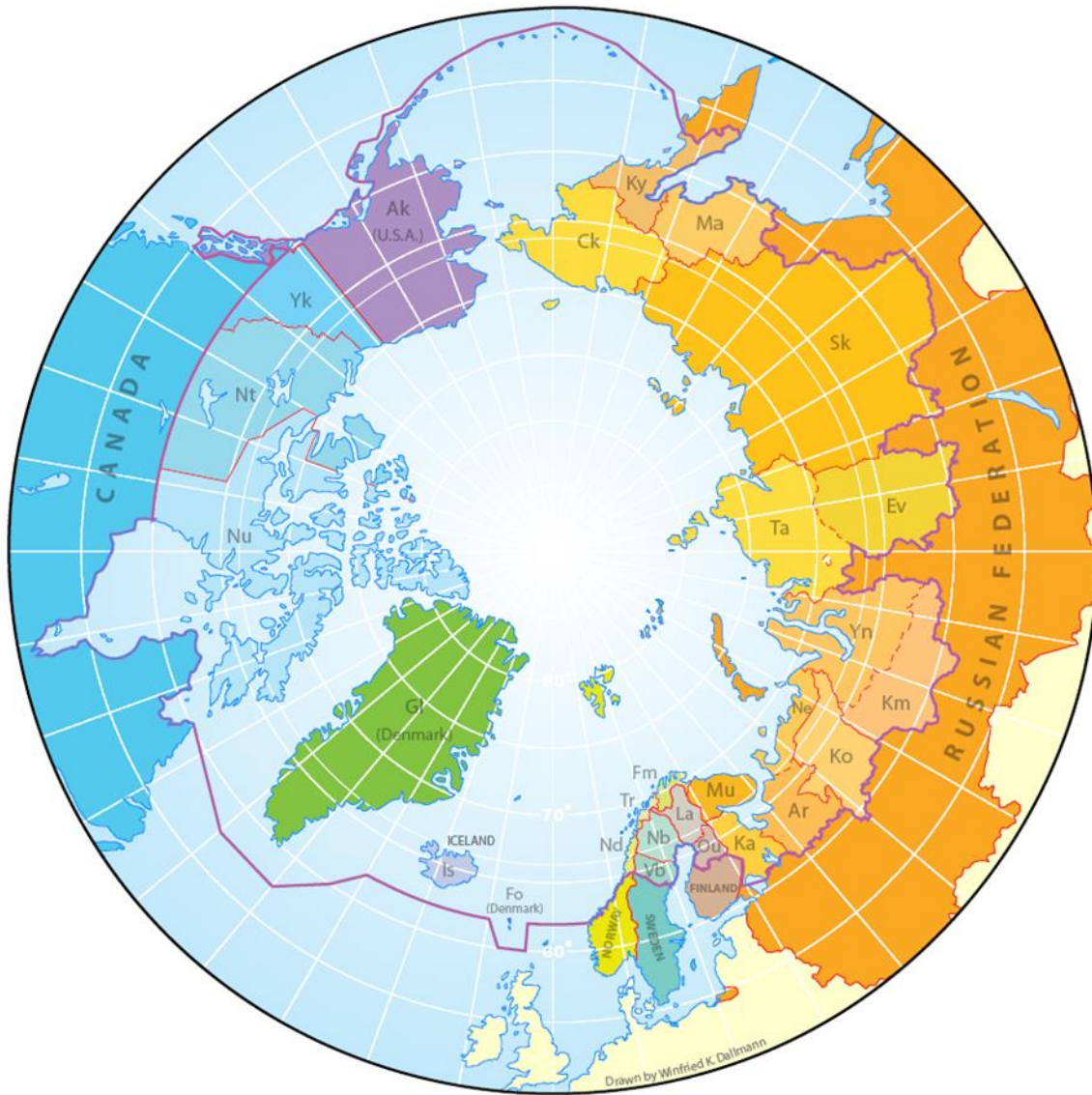University of Alaska Anchorage

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Drawn by Winfried K. Dallmann

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Introductions

(who is here and

what do we *already* know...)

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Workshop Overview

- Principles and Ethics of CBPR

- Partnerships

- Importance of trust and effective communication/dialogue

- Some Participatory Methods

- Greenland CBPR case study

- Reflections and Evaluations

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Learning Objectives

- Describe general components of CBPR approach for the North
- Discuss principles of 'best' CBPR practice and effective partnership
- Assess current or planned CBPR project for adherence to these best practices of partnership
- Describe the critical elements involved in trust and the importance of effective communication and dialogue
- Provide at least two examples of current or future CBPR projects and/or principles applied in the circumpolar context
- Identify at least two ethical challenges within CBPR and propose strategies to address them

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Questions for Reflections

1. What was the most interesting to you today?

2. What was most useful to you personally?

3. Name one thing that you will change in your research or practice.

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CBPR: Principles and Ethical Dilemmas

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Exercise
#1

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Individual Reflection:

- What kind of approach are you using in your own work?

- What kind do you want to use?

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One way to have more impact and learn more…

one useful approach

Community
Based
Participatory
Research

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CBPR:

- "An approach that incorporates formalized structures to ensure community participation."

  - Agency for Healthcare Research and Quality (2004)

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CBPR:

- An intersection between science and practice

- "inquiry with the participation of those affected by an issue for the purpose of education and action for effecting change"

  - Green et al (2000)

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CBPR:

- "…equitably involves all partners…with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities."

  - Kellogg Foundation Community Health Scholars (2008)

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Origins of CBPR

- **Northern: Action Research**: Lewin: 1940s
  - Cycle of action, reflection, problem-solving and decision-making for new actions
  - Organizational rational change

- **Southern: Participatory Research:** Freire: 1970s
  - Radical critiques by social scientists from Asia, Africa, Latin America
  - Critiques of structural underdevelopment and challenge to redistribute inequitable structures
  - Challenge academic distance from communities and new academic discourse of feminism, post-colonialism, post structuralism

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Other Concepts

Community Based Participatory Research (CBPR)

vs

Participatory Action Research (PAR)

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Principles of CBPR

Recognizes community as a unit of identity

Builds on strengths and resources

Facilitates partnership in all research phases

Promotes co-learning and capacity building

Seeks balance between research and action

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Principles of CBPR

Emphasizes local relevance and ecological perspective that recognizes multiple determinants

Involves system development through cyclical and iterative process

Disseminates findings and knowledge to all

Involves long-term process and commitment

Israel, Schulz, Parker, Becker, Allen, Guzman, "Critical Issues in developing and following CBPR principles," Community–Based Participatory Research in Health, Minkler and Wallerstein, Jossey Bass, 2000

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Participation in CBPR

Builds capacity and reduces dependency on "professional outsiders"

Ensures cultural and local competence

Facilitate sustainability

Enhances fit and productivity of programs

Addressed concerns of manipulation

Jewkes & Murcott, 1998, Rifkin, Muller & Bichmann, 1988, Cooke & Kothari, 2001

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Partnerships with Indigenous Peoples

- Western worldview is that the 'truth' is simply 'out there'
  - Western methods and theories are not always conducive to Indigenous peoples.
- Indigenous worldview is that the 'truth' is a 'process of relationships' developed with the individual
  - Reality, including knowledge, therefore exists because of the relationship it forms with the individual   Wilson (2008)

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Indigenous Research Methodology (IRM) – The 'Three R's'

1. **Respect**
   – cultural humility, particularly as "outside" researchers engaging with a community

2. **Reciprocity**
   – the responsibility individuals have for one another, the earth, and the self

3. **Relationality**
   – the relationships we form and for which we become responsible

Weber-Pillwax (2001)

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Principles to Consider in IRM

1. interconnectedness of all living things
2. impact of motives and intentions on person and community
3. foundation of research as lived indigenous experience
4. theories grounded in indigenous epistemology
5. transformative nature of research
6. sacredness and responsibility of maintaining personal and community integrity
7. recognition of languages and cultures as living process

Weber-Pillwax (1999)

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Ethical Dilemmas?

Possible Ethical Issues

- Role Confusion
- Who represents 'the community'?
- Data ownership?
- Use of biologic samples?
- Dissemination of results
  - Accessible and meaningful?
  - Scientifically sound?
  - How is data re-presented?
  - Whose 'voice' matters?

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Havasupai 'Genetic Piracy' Case

Rex Tilousi...approached an Arizona State researcher in 1989 regarding the diabetes cases. "I asked him, 'How can we prevent this from spreading?' " Mr. Tilousi now feels that the trust he placed in the researcher was abused.

- New York Times April 22, 2010

Nuu-chah-nulth People

"I gave my blood, and gave permission to take my children's blood because they said this study would help us out. To use it for something else without our permission is very wrong."

"…an unpleasant chapter in the Nuu-chah-nulth people's experience with Ward, who betrayed their trust and disappointed their expectation of a cure, or at least effective treatment of their suffering."

- Ha-Shilth-Sa (July 17, 2008)

Qanuqtuurniq
(Finding the Balance):
A Participatory Project-Evaluation

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Communication for Social Change

• Sustainability of social change more likely if individuals/communities affected own the process and content

• Empowering, horizontal relationships, with bias toward local content and ownership, and giving 'voice' to unheard

• Communities should be agents of own change

• Emphasis from persuasion and transmission of outside technical expertise to dialogue, debate and negotiation of issues that resonate with the community

• Emphasis on outcomes beyond individual behaviors to social norms, policies, culture and supporting environment

– Gumucio, 2001

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Background - Qanuqtuurniq*— Finding the Balance

- International Polar Year (IPY) outreach and communications project on **Inuit wellness** in Alaska, Canada and Greenland

- Broadcast on Aboriginal Peoples' Television Network – North (and 360-North in Alaska) in May 2009 and simultaneous Web cast

- Delivered in the Inuit language with English open captions / subtitles

- Focused on health issues of shared concern and community-based solutions and 'promising practices'

- Linked to ongoing IPY research (*Qanuippitali*? Inuit Health Survey)

- Used a 'communication for social change' model and multiple channels of delivery, some still continuing today

* In the Inuit language, *Qanuqtuurniq* implies working together to find innovative solutions.

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Inuit Youth Resilience in the Circumpolar North: Lessons Learned from an Innovative pan-Arctic TV Series on Inuit Wellness

**Canadian Conference on Global Health
Ottawa, 2010**

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Inuit Tuttarvingat

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QANUQTUURNIQ
FINDING THE BALANCE

Uqaalaqattalaaqpusi pingasuirluta takuksaulaaratta
A 3-part call-in series on Inuit wellness

National Aboriginal Health Organization (NAHO)
Organisation nationale de la santé autochtone (ONSA)
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Three 2-hour live TV phone-in shows broadcast May 11-13, 2009:

1. Inuit men's health
2. Inuit maternity care
3. **Inuit youth resilience**

Youth program panelists from Inuit regions with host.

Photo © Ed Maruyama

Engagement Opportunities - Pre-Broadcast

• **Working groups** developed the content script guides

• Video vignettes of selected **community programs**

• **Music/vocal recordings** contributed

• **Researchers and physicians** gave input

• **Facebook** page with over 600 subscribers

Vignette filmmaker and her daughter from Iqaluit, Nunavut .

Photo © Ed Maruyama

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Community Youth Video Vignettes

Inuusivut Project - Inuit Youth Media: Through art, videos, music,
• photography and other multimedia, Inuit youth are finding new ways to express themselves..

Project Life (Maniilaq, Alaska): Project Life is a youth wellness and suicide prevention program for the Maniilaq area of Alaska. It uses digital story-telling.

Inuvik Youth Centre (Inuvik, NWT):The reality for many Inuit living in remote communities is the necessity to move to larger communities to continue their education.

Artcirq (Igloolik, Nunavut): You will see how Artcirq helps youth to express themselves physically and spiritually through traditional Inuit themes and circus acts.

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Engagement Opportunities - During Broadcast

- Panelists
- Studio audience + physician
- Community focus groups
- Virtual youth focus group
- Skype for pre-arranged input
- Public phone-ins
- E-mail

Men's program panelists from Inuit regions.

Photo © Ed Maruyama

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Evaluation findings related to engagement

• "The … TV series was an innovative, multi-dimensional, collaborative health communication project …"
— Evaluation Report 2009

• Project perceived as successful by many participants: project team; panelists; community focus groups; viewers; others

• Project generated a lot of interest: new informal/formal networks; increased motivation for action; increased tools for action

Youth program studio audience.

Photo © Ed Maruyama

"It [sic] did a lot of networking within the community. … I had so many people come up to me and say they enjoyed the show, that they watched the show." — Community focus group facilitator

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Evaluation findings related to engagement Cont'd

- "[The TV series] raised both **interest** and awareness about complex health conditions in the North. …

- "[It] **stimulated community dialogue** and potential for both local and regional collaborative action to address those conditions.

- "Local capacity and new regional **networks were strengthened**.

- "'High-quality lessons' from the **participatory** evaluation of this 'communication for social change' project may be used to build on a **strong foundation of community-professional-academic partnerships**."

– Evaluation Report 2009

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Sample quotes from audience surveys responding to:

The most important thing I learned today from the…
youth show was …

- *"About various initiatives across the North – elders' point of view"*

- *"Wide range of innovative projects and programs that are underway"*

- *"Noted how many elders phoned in – indicates that they watch APTN and are very motivated by youth issues"*

- *"The emphasis on the positive and being realistic about the challenges"*

- *"Youth care and want to engage"*

– *From audience surveys and key informant interviews.*

Youth program panelist from Kugluktuk, Nunavut.

Photo © Ed Maruyama

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Evaluation findings - actions planned

How will Key Messages be Used?

- *"I want to try and facilitate programs in my region to help Inuit."*
  — Men's wellness audience member.

- *"I'm going to share these videos with research partners and community partners."*
  — Midwifery audience member.

- ***"I feel more empowered to create and to do good things for my community."***
  — **Youth program audience member.**

- *"Bring this knowledge to my home community Nain and consider Inuit maternity care myself."* — Midwifery audience member.
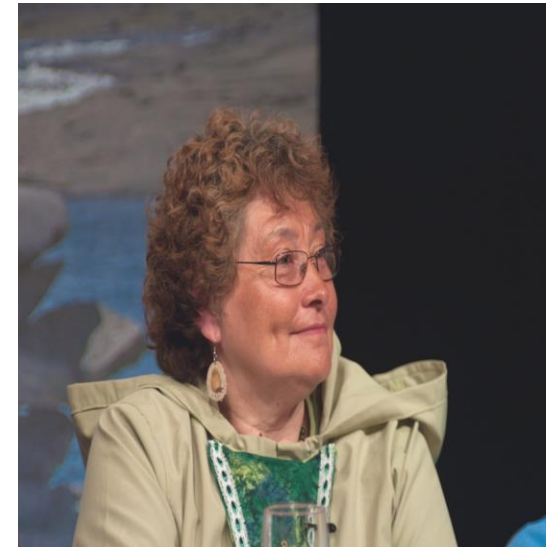
Maternity panelist and men's program audience member from Kuujjuaq , Nunavik (Northern Quebec).

Photo © Ed Maruyama

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Partnerships: Worth the time and effort? What does everyone get out of it?

Community-Based Participatory Research (CBPR)

" CBPR refers to a *partnership* approach to research that equitably involves community members, organization representatives, and researchers in all aspects of the research process."*

Israel BA, Eng E, Schulz AJ, et al., eds. Methods in Community-Based Participatory Research for Health. San Francisco, Calif: Jossey-Bass; 2005

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Rationale

Research ~~Controlled~~

History is written by people in power

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Challenge of Research/ Community Relationships

Shared University/ Community Control

⟵————————————⟶

University Control

Community Control

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What is a partnership?

'Someone' = individuals or organizations

- Someone who gains value/benefit from the process

- Someone who can offer value/benefit to the process

- Someone who provides a unique set of expertise and knowledge

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What makes for an effective partnership?

- Willingness and commitment
- Alignment of values and priorities
- Have staff/volunteer capacity to participate
- Hold leadership/authority positions in organization
- Have connections to, and are knowledgeable about, the community
- Having clear agreements in place about everyone's roles and responsibilities

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Community-Placed vs. Participatory

- Who choses the problem to be studied?

- How is the budget divided?

- Is there an intervention or service component?

- Where are the results disseminated?

- Who designed the intervention?

- Who made the research policy decisions? (e.g. is there a control group?)

- Who writes papers/makes presentations? Who owns the data?

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CBPR Assessment

Guidelines for Participatory Research in Health Handout

Community-Placed vs. Participatory

- Who chose the problem to be studied?

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- Who writes papers/makes presentations? Who owns the data?

Source: Adapted in part, from Reyes et al.
www.med.umich.edu/.../Fall%202005/Lichtenstein_Community-Based%20Participatory%20Research%20Workshop.ppt
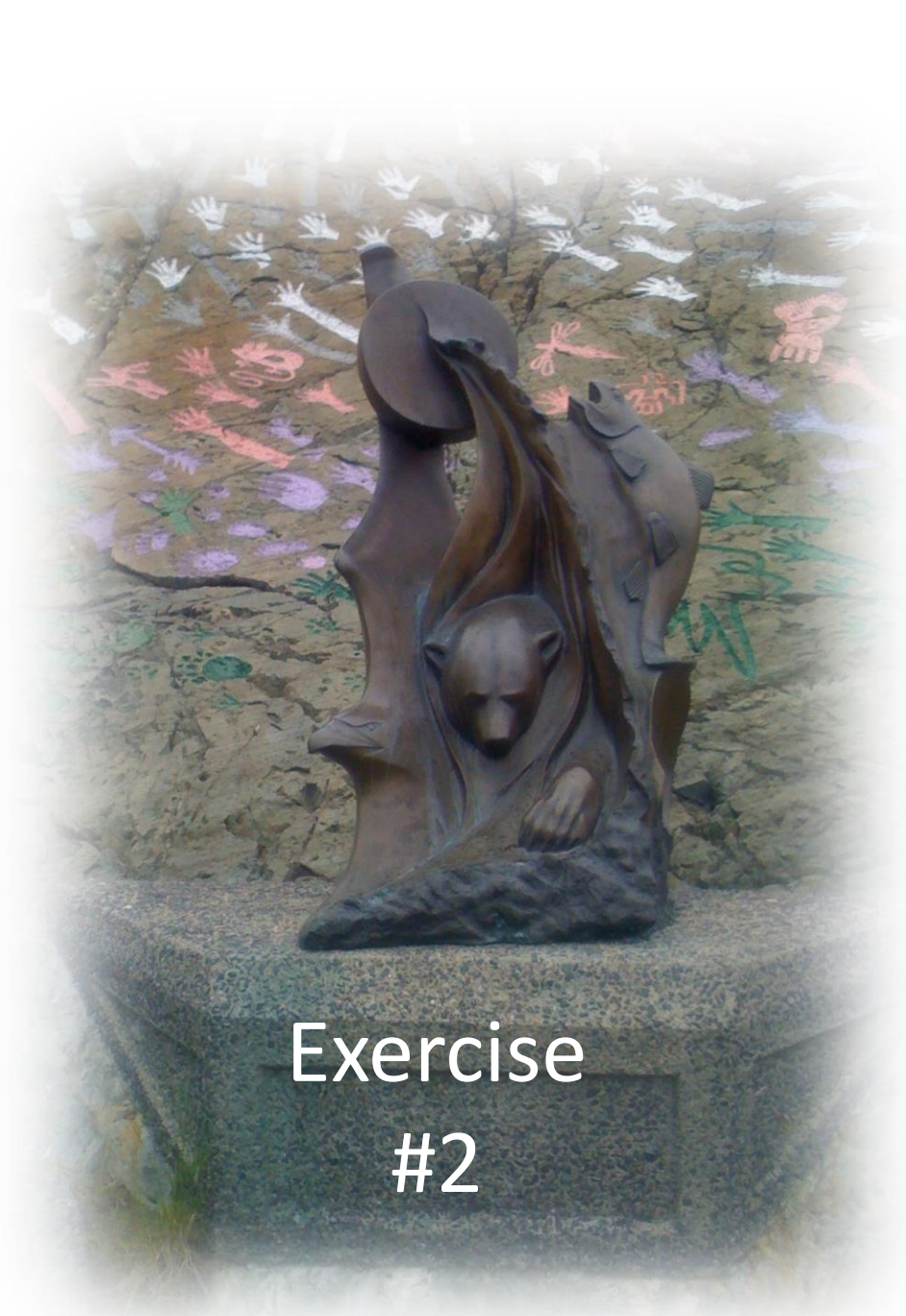
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Exercise
#2

The Inuit Health Study

- Developed to meet Inuit desire to have baseline information to inform policy
- Partnerships/Agreements established – including an extensive steering committee
- Various staff hired
- Adult/child survey reports shared publicly

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Inuit Health Survey

- http://www.isuma.tv/en/naasautit/qanuippitali-inuit-health-survey-vignette

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Group Exercise

- Using the CBPR Assessment tool, score the Inuit health study on whichever aspects you are able to given available information (i.e. Inuit health study handout).

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Reflective Group Exercise:

- How can this CBPR Assessment tool be useful in evaluating practice?

  - Gp #1: Participants and nature of involvement
  - Gp #2: Shaping the purpose and scope of the research
  - Gp #3: Research implementation and context
  - Gp #4: Nature of the research outcomes

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Inuulluataarneq (Having the Good Life): A Community Based Participatory Research Project in Greenland

Elizabeth Rink

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Sexually Transmitted Infections in Greenland

- 3 to 5 times higher than other indigenous populations in North America
- May lead to infertility in men and women
- Combination of low birth rate and high STI rate creates concern for the longevity of the Greenlandic population

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Inuulluataarneq

- Develop, implement, evaluate an STI educational program
- 15 to 19 year old adolescents and their parents
- Uummannaq, Paamiut, and Ittoqqortoormiit

Two Components

- Build capacity within Greenland to conduct *community based participatory research (CBPR)*
- Develop a socially and culturally relevant sexual health and social educational program

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Research Design

• **Quasi-Experimental, pre-post design**

Youth Component
1. Base Line Data Collection
2. Seven Session Educational Program
3. One Month and Six Month Follow Up
4. STI Testing

Parent Component
1. Base Line Data Collection
2. Focus Groups

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Project Structure

- **Boards**
  - External Advisory Board, Internal Advisory Board, and Community Advisory Board

- **Project Staff**
  - Outreach Worker, Research Assistants, Project Director, Statisticians, Research Investigators

- **Educational Content**
  - Self Confidence/Self Worth, What Does Your Future Look Like?, Feeling Ready for Sex, Trusting Your Partner, What Does It Mean to Have a Partner?, The Use of Condoms
  - Digital Story Telling (Voice Stories), Group Discussion, Information Sharing

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Data Collection

- Purposive Sampling Techniques by age and gender
  - 67 youth at baseline, 46 youth at 1 month follow up and 40 youth at 6 month follow up (Uummannaq and Paamiut)
  - 48% male and 52% female

- Recruitment through word of mouth, flyers, community meetings, meetings with community leaders, community presentations

- Questionnaires with youth and parents

- Focus groups with parents

- STI status was determined with self collected urine sample

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Data Management

- Youth and parent questionnaires and focus group tapes were sent to *Ilisimatusarfik* for data entry, transcription and management

- STI samples were sent to SSI in Copenhagen for analysis

- In the case of a positive test participants were notified and provided treatment

- IRB approval from Montana State University, Greenlandic Medical Research Council, and the Statens Serum Institute (SSI)

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Youth Attitudes and Communication

- Attitudes about sex did not change significantly over time
  - Ambivalent attitudes towards sex
  - Perceived low risk for STIs

- Increases in communication with a parent/guardian about sex were observed over time
  - What qualities are important in choosing close friends
  - What qualities to look for in a boyfriend/girlfriend/life partner
  - Symptoms of sexually transmitted infections
  - How to say no if someone wants to have sex and you don't want to
  - The importance of not pressuring other people to have sex
  - How to make decision about whether or not to have sex
  - How to use a condom
  - Reasons why not to have sex
  - What to do if a partner doesn't want to use a condom
  - How people can prevent getting sexually transmitted infections
  - How to know if you are in love

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Youth Sexual Risk Behaviors and Chlamydia Infection

- Individuals who reported talking with a parent/guardian about how to make decisions about whether or not to have sex were 0.2 times less likely to report engaging in sex (aOR=0.20, 95% CI 0.03-1.3, p=.098)

- Individuals who spoke with a parent/guardian about how to choose a method of birth control were also less likely to report engaging in sex (aOR=0.29, 95% CI .05-1.6, p=0.159)

- The odds of chlamydia infection were lower in individuals who reported talking with a parent/guardian about how well condoms can prevent STIs (aOR=.03, 95% CI .001-1.9, p=0.10), and talking with a parent/guardian about how people can prevent getting STIs (aOR=.03, 95% CI .00-1.2, p=.06)

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Parent Communication

- 5-point likert scale, with responses ranging from difficult (1) to easy (5) parent's ability to speak with youth in general as well as specifically about sex

- Parents were asked whether they had ever spoken with their teenager about 25 topics relevant to sex (coded 0 = no, 1 = yes)

- Overall parents reported it being somewhat easy to speak with youth in general and about sex

- Most difficult to speak with youth about the physiology of sex

- Majority would like to speak with youth more about sex

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Parent Focus Groups

- Four focus groups
- Themes
  - *Pregnancy*
    - Avoid pregnancy and pursue education before pregnancy
  - *Sexual health education*
    - Increase collaboration between agencies in communities
  - *Knowledge about STIs*
    - Parents unsure of their own knowledge
    - In some families it is taboo to talk about sex
  - *Talking openly about sex*
    - Small groups for parents to talk amongst themselves

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Community Based Participatory Research Findings

- **Ethical Review Process verses Community Process**
- **Data Collection**
  - Individual verses Group, Confidentiality
  - Quantitative verses qualitative questions
- **Timing**
  - Pace, Community Seasonal Patterns, Length of Time of Intervention
- **Language**
  - Use of Silence, Indirect Communication, Descriptive and Sharing of Experiences, Collective Decision Making
- **Self Refection**
  - Differences between insider/outsider perceptives
  - Cultural humility and positions of power

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Interaction of Place with CBPR

- The "where" of research methodologies impacts the research outcomes

- The concept of the "proximity paradox"

- Issues of Sample Size
  - Use of mixed methods
  - Descriptive statistics verses inferential statistics

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Sustainability or closure

Deciding if / when to end existing (successful) partnerships

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What does sustainability mean to your partnership?

- Does it mean a continuing relationship and discussion among CBPR partners and organizations?

- Does it mean continuing a program or intervention from a CBPR partnership or project?

- Does it mean changes in a policy or system that addresses a root cause of the issue examined by a CBPR partnership or project?

- Does it mean an increase in community capacity to conduct their own research?

- Does it mean the sustaining of outcomes achieved by a CBPR project or intervention?

- Does it mean sustained funding over a specified period?

Source: http://depts.washington.edu/ccph/cbpr/u7/u72.php

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When is it appropriate to dissolve a CBPR partnership?

- When there has been dishonesty, misuse or abuse within the partnership

- When all of the targeted goals have been achieved

- When there has been a gross violation of the partnership's principles

- When there is inadequate resources to support the partnership

Source: https://depts.washington.edu/ccph/cbpr/u7/u75.php

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Student Small Group Activity

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Integration of CBPR into Your Research Practice

In small groups address the following questions:

- How does your research project include community participation?
  - Discuss your experience with engaging community members in research?
- How could you increase community participation in your research?
- What are some strengths and challenges to including community participation in your research?
  - How could you address these challenges?

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Conclusions, Wrap up, Evaluations

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What have we learned?

- Build on what we (and others) know
- Work as a team
- Engage community in as many aspects as possible
- Reflect on our practice
- Other?

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Additional Resources

- http://www.lgreen.net/guidelines.html
- Isreal, BA, Eng, E, Schulz, AJ, and Parker, EA. 2012. Methods for Community-Based Participatory Research for Health. Jossey-Bass. ISBN: 978-1-118-28588-6
- Developing and Sustaining Community-Based Participator Research Partnerships: A Skill Building Curriculum. Online course freely available at: https://depts.washington.edu/ccph/cbpr/index.php
- Community-Based Participatory Research: A Partnership Approach for Public Health. Online course freely available from Michigan Public Health Training Centre at: http://miphtcdev.web.itd.umich.edu/trainings/courses/community-based-participatory-research-partnership-approach-public-health-downloadable

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Feedback and Evaluations

Thank you!!

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