Who are we?
High Plains Research Network

- Practice-based Research Network
- 16 counties: 30,000 sq. miles and 150,000 people
- 16 hospitals and 58 primary care practices
- 150 providers (MDs, PAs, NPs)
- Community Advisory Council (C.A.C.)
- Community Liaisons
- Academic Researchers
HPRN: Who We Are

Medical Mistakes Survey

The High Plains Research Network (HPRN) of the University of Colorado Department of Family Medicine is collaborating with the HPRN Community Advisory Council in conducting a research study that aims to better understand and improve patient care. Medical errors can occur in various settings (such as a hospital, outpatient clinic, or in the home) and can be caused by factors such as negligence or errors in judgment. We hope those who have experienced a medical mistake would take the time to fill out this form and send it back to us.

If you fill out this form, please do not include any personal or medical identifiers that have been individually identified. We are not a reporting agency, and any personal information will be kept confidential. We will keep any information you provide in confidence and will not disclose what people are experiencing. If you have any questions about this survey or how the information will be used, you can contact the principal investigator, Dr. Jack Wintjell, at 303-724-9712. This study has been reviewed by the Colorado Multiple Institutional Review Board (094-0901).

1. Have you or a family member experienced a medical mistake?
   - No
   - Yes — if you, who?
     - Self
     - Family Member

   Please describe what happened.

2. Do you feel that you or the family member was harmed by this medical mistake? (Please check one answer)
   - No
   - Yes —

   If yes, how were you harmed?

3. Who have you or your family member talked to about this? (Please check all that apply)
   - Me
   - Hospital investigator
   - Patient representative
   - Doctor
   - Pharmacist
   - Other — please specify

4. Who was involved in this event?

   - Patient
   - Family/Friends
   - Healthcare providers
   - Medical facility
   - Other — please specify

   Additional comments:

   - Date:
   - Location:

Perry: Colorectal cancer testing a must

Colorado Springs

Springfield
“Poisons in the Water”: Walpole Island First Nation and The University of Western Ontario Research Partnership

Carol Herbert and Judy Peters
Pre-conference
NAPCRG Annual Meeting
Montreal, November 2009
Collaborative Research Team Members

WIFN
- Current: Dean Jacobs; Rosemary Williams; Naomi C. Williams
- First project: Lucy Harrison; Judy Peters; David White

UWO
- Jack Bend; Jorge Burneo; Bradley Corbett; Regna Darnell; Carol Herbert; Julie Hill; Gideon Koren; Noel Kowal; Michael Rieder; Katie Schoeman; Kathy Speechley; Christianne Stephens; Charlie Trick; and Dana Winterburn
Columbia, Missouri

“Go Ward One”

Community-Academic collaborative

NAPCRG 2009

CBPR Pre-conference

Kahnewake, Quebec
Who are we?

Community: 100,000 people (20% minorities)
- Strong, long-term, active, committed community-based organizations (CBOs) & churches.
- But “Splintered” efforts & competition
- Geographical separation (race & income)
- Poor history of cooperation between university and minority community
- Strong new leadership/readiness to change

University:
- Recent history of inter-disciplinary and community collaborations (PHD,CBOs)
Partnership

May 2008: Community Round-tables
July 2008: Community strategic planning
   - Appreciative Inquiry
   - “Give children a healthy start”
   - “Go Ward One” CAB starts to meet

Dec 2008: RWJF Health Kids/Healthy Communities grant proposal

March 2009: Community Engagement surveys (mini-grants)/work-groups

Sept 2009: New CBPR projects starting
   - “Playgrounds without Borders”
   - “Comedar Popular”
HERZL TODAY, TOMORROW & THE FUTURE
Using participatory research to study patient satisfaction at a family medicine teaching centre

Vinita d’Souza, Marie Claude Gatineau, Vera Granikov, Albert Herscovitch, Kenneth Hung, Janique Johnson-Lafleur, Dr. Michael Malus

NAPCRG 2009 Pre-conference November 14, 2009
Who we are

- **7 Patients** and **7 staff representatives** of the Herzl Family Practice Centre (HFPC) came together with **6 researchers** in Family Medicine to work together on this project.

- External experts were invited to collaborate when needed.
Project goal

- to understand, measure and improve patient satisfaction with healthcare services received at the HFPC through a process that maximizes HFPC community involvement in accordance with accepted guidelines for participatory research.
HYPE: Healthy Youth Peer Education

Jenna Azar
Dr. Abby Letcher, MD
Mark Mckenna
Yesenia Rodriguez
Clarice Shackleford
Dr. Lora Taub-Pervizpour, Ph. D
HYPE: Who Are We?

• We are a community of youth and adults working together to build a welcoming, healthy community in Allentown.

• Youth team currently has 10 teens, 10th-12th grades, that have been with the program for at least 2 years.

• Partnership of Lehigh Valley Health Network, Muhlenberg College, and Touchstone Theater.

Here at HYPE everyone has an important voice.
It’s all about friendship, trust, understanding, unity, and having a choice.
The HYPE Leadership Program

Youth trained as researchers and advocates using public health, community media, and creative arts

High School youth, diverse backgrounds
Four week intensive summer program
Yearlong leadership and community organizing initiatives

HYPE youth explore determinants of a welcoming community and root causes of power and disempowerment among youth to create positive community change

Healthy relationships
Stereotyping
Violence

School inequality
Environmental degradation
Kahnawake Schools Diabetes Prevention Project (KSDPP)
1994 – present
www.ksdpp.org

KAHNAWAKE
Community Advisory Board
Intervention staff
Research staff

UNIVERSITIES
Researchers & students

CREATING KNOWLEDGE

Ethical space

Funded by: CIHR, NHRDP, CDA, SSHRC, Aboriginal Diabetes Initiative (Health Canada), Kateri Memorial Hospital Centre Kahnawake, Kahnawake community, and Private Foundations
KSDPP 1994 to the present

Objectives
- Short term: increase physical activity, healthy eating habits and positive attitudes
- Long term: reduce prevalence of Type 2 diabetes capacity building and sustainability

Intervention
- Originally elementary schools, now extended to pre-schools and high school
- Numerous community wide events to encourage healthy lifestyles
- New recreation path, only healthy foods at schools, youth centre and arena

Evaluation
- Elementary school children Grades 1-6
- Toddlers eating environments
- Process evaluations of developing interventions, teachers’ experiences, community ownership

Training
- Includes 2 Masters students and one PhD candidate from Kahnawake
Partners in Research: Maximizing Immigrant and Refugee Health through CBPAR

Activated Community

Trusted Community-Based Organizations

Successful and Sustainable CBPAR Partnerships

Prepared Researchers

Supportive - Flexible Infrastructure

Goal: Develop & Evaluate a Process to Support CBPAR Partnerships

Funded by NIH Partners in Research R03
Who we are and what we’re doing

Project Management Team: Michele Allen, Kathie Culhane-Pera, Kathleen Call, Shannon Pergament, Efren Maldonado, Saeed Fahia, Hli Xiong
Trained 10 Hmong, Latino and Somali scholars in research basics and CBPAR principles.
  • Rosaura de la Torre and Mikow Hang represent the group
  • Community Scholars defined an area of health interest.
Trained 22 faculty in CBPAR principles.
Matched community scholars with faculty working in their area of interest.
Are supporting and evaluating the partnerships.
SLEEP FOR SUCCESS
PREVENTING THE CONSEQUENCES OF SLEEP DEPRIVATION IN CANADIAN YOUTH!

• Partners:

Riverside School Board
Gail Somerville
Chake Berberian
Enzo Diloia
Elizabeth Gilles-Poitras
Jennifer McNeil

McGill University
Dr. Reut Gruber
Eva Monson
Nikki Amirlatifi
Dan Brouillette
Erika Kleiderman
Zoe Schwartz

• Special Thanks to Ann Macaulay and Jonathan Salsberg for all their support with the Sleep for Success Program.
Sleep For Success

**Goal:** To improve sleep habits and increase sleep duration, with the long-term goal of combating the health adverse consequences of sleep deprivation, particularly improving academic success.

**Approach:** Community-based interventions aimed at improving children’s sleep by changing lifestyles.

**Reasons:** Increased levels of sleep deprivation in Canadian society in general, in children and adolescents in particular.
Healthy Children, Strong Families, and Supportive Communities

Project Partners
Supportive Communities

- Use community advisory boards (CAB’s) to document environmental barriers and supports to healthy nutrition and physical activity, and design environmental interventions in three AI communities.
Taking Neighborhood Health to Heart (TNH2H) Community-Academic Partnership

• Began in 2006 as a National Institutes of Health funded research project studying neighborhood health & health disparities.

• Includes people from 5 diverse neighborhoods in & around the former Stapleton airport site (East Montclair, NW Aurora, NE Park Hill, Park Hill, Stapleton), the University of Colorado Denver and the Stapleton Foundation.

• Community involved in all phases of research.
Specific Aims of Partnership:

- Formalize a community-based participatory research (CBPR) process and engage the community in an ongoing partnership.
- Collect data to describe the health of people and neighborhoods.
- Make sense of data with the community and identify ways to improve health.

Primary Research Question:

- What is the impact of built and social environments on health and health disparities?

Status of Project and Partnership:

- Completed NIH research project July 2009, received additional funding for data dissemination and data collection of hard-to-reach populations.
- Now setting our new vision and direction in response to project information and participation.
- Community leads data dissemination process and direction-setting.
“The empowerment of women inside and outside of prison in their emotional, mental, physical, and spiritual healing through the participatory research process”
In September 2007 the research project was shut down inside the prison. The prison health research team moved to B.C. Women’s Hospital and changed our name to **Women in2 Healing**

Our team includes collaborations with community researchers, academics, service providers and health care professionals.
Primary Health Care: Engaging the Métis Nation - Saskatchewan in the Development of Evidence Informed Programs to Enhance Health and Well-being

VR Ramsden, K Patrick, J Crowe, C Bourassa & S McKay

Presented at the NAPCRG Pre-Conference on November 14, 2009
Who are we?

The vision of the Métis Nation – Saskatchewan was to be able to identify ways to enhance the health and well-being of the citizens.

The research question being answered was “What is the health of the Métis in Saskatchewan?”

This is the first *provincial* health survey of the Métis Nation – Saskatchewan.

The community in this research endeavour is comprised of representation from: the Métis Nation of Saskatchewan; a Métis community; First Nations University of Canada; and, the University of Saskatchewan.
Who are we?

The Team

YMCA and McGill Department of Kinesiology and Physical Education (DKPE) (in alphabetical order)

- Paula Bush (PhD Student, DKPE), Enrique García Bengoechea (PhD, DKPE), Sharon Parry (YMCA director), Roger Redman (YMCA teen programs coordinator)

General objective

- To increase the number of teens who participate regularly in the various the YMCA teen program activities
Who are we?

- Specific objective
  - In what ways can the YMCA
    - Adapt principles of social marketing to meet their programming needs
  - Integrate these principles into their programme planning, implementation, and evaluation in order to increase the number of teens who participate regularly in the various the YMCA teen program activities
Finding Partners
KSDPP

Community invited academic researchers
Kahnawake Rates of Disease
Aged 45 to 64 years

1981
12% Type 2 diabetes (2x national average, reconfirmed in 2007)

1985
50% with retinopathy after 10 years of disease
Macrovascular complications 6x higher for those with diabetes (matched for age and sex)

Forming the partnership

• Original Kahnawake working group was two family physicians, and the Directors of Kahnawake hospital, education centre and social services centre (all under community control)

• Working group invited two academic researchers from two universities for their expertise in health promotion and evaluation

• Expanded team agreed to use participatory research and together wrote the grant proposals

• Took seven years to get funding!!

• Hired staff from community

• Formed the Community Advisory Board (CAB)

• Team developed Vision and Mission and KSDPP Code of Research Ethics
Finding Partners

Reut Gruber, McGill University
Gail Somerville, Riverside School Board
WIFN and UWO Ecosystem Health Partnership

NIN DA WAAB JIG HERITAGE CENTRE

UWO ECOSYSTEM HEALTH RESEARCH TEAM, SCHULICH SCHOOL OF MEDICINE & DENTISTRY

WALPOLE ISLAND HEALTH CENTRE

COLLABORATIVE COMMUNITY HEALTH PROJECT:
DETERMINING THE HEALTH RISK OF THE WIFN COMMUNITY FROM EXPOSURE TO ENVIRONMENTAL CONTAMINANTS

Health Feasibility Study (2004/2005)

Fish Consumption Study (2005/2006)

Baseline Biomonitoring Project (2007/2008)
Finding Community

Partnership formed because of a mutual interest of members of the WIFN and members of the UWO Ecosystem Health Group in the relationships between exposures to environmental pollutants and potential for damage to human/ecosystem health.
Finding Community

- WIFN Heritage Centre Director approached UWO to do feasibility study
- UWO team led by toxicologist, includes anthropologist with long-standing relationship with community, medical experts, participatory-research expert, graduate student already working in WIFN
“Seeking patients to join the Herzl Family Practice Centre Patient Perspective Research Advisory Committee.”
Finding community - Staff

A volunteer representative came forward from each group:
- Administrative staff
- Physician
- Psychologist
- Nurse
- Resident
Finding community - Challenges

- Project buy-in not from all physicians, as a result most patient representatives come from only a few physicians.
- Different motives to participate.
Finding Community

- Friends
- Community Partners
- Youth Outreach
Youth Involvement Strategies

- **WORD OF MOUTH!**
  - HYPE youth spread awareness about the HYPE program and encourage involvement.
  - ~20% participants come through word of mouth through partner organizations including
    - Allentown School District
    - Youth programs
    - Lehigh County Juvenile Probation
    - Lehigh County Children and Youth

- Stipend for youth
- **Relationships** are the key
- 26 teens have participated, some for all 4 years
Finding Community - Background

- Partnership was been visible within the community
  - Always have delivered on agreements
  - HCSF & Wisconsin Nutrition and Growth Study (WINGS)
  - Listen to the tribe’s unique perspective
  - Attended and assisted in local events

- CAB brainstorms and prioritizes its own unique issues and interventions
The Birth and Life of a CAB

Meet and greet
Leave information behind

Invite lots of people
Ask for referrals. Invite them, too.

Get the word out
Provide a meal. Vary the times of the meetings.
Finding Community - Growth

- Grow a network
  - Agencies
  - University
  - Community
    - known and unknown voices
    - cross-generational
  - Experts
  - Non-traditional partners

- At each meeting prioritize who is not at the table that needs to be, and get them there
HPRN: Finding Community

- Community Partners: ASK
  - Recommendations from practices and other community organizations
  - Cold calls to potential community leaders
  - Friend of a friend of a friend

- Academic Partners through HPRN staff

- Funders
When finding community, we need to consider:

- Why participate?
- Representative vs. community expert
- How long do I serve?
- When do we add new members?
HPRN: Finding Community
Finding Our Community Through Conversation

- People who live in five partner neighborhoods are diverse in terms of SES, race/ethnicity, and their social contexts.
- We wanted to learn more about important health issues for people in different neighborhoods to understand diverse perspectives and identify common ground.
- Stapleton Foundation, through their existing connections, helped the University identify people living in communities to participate in focus groups.
Finding Our Community Through Conversation

• Conducted five focus group discussions within each neighborhood, each group lasted from 1 to 2 hours.

• Asked people to talk about health issues they care about and about health resources within their communities.

• Generated lively discussions about range of issues.
Community Conversations About Health

- Invited focus group participants and others to attend a community gathering on focus group findings and TNH2H.
- Over 40 people attended, generating wide ranging discussion about health – and of disparities in health and health resources within and across five neighborhoods.
- Described community-based participatory research, which was met with both interest and skepticism.
- Invited people to become part of TNH2H and to invite others – have had over 80 people involved throughout project (including monolingual Spanish speakers).
Building Trust
Building Trust
We build trust in our partnerships by:

• Women In2 Healing Newsletter
• Weekly WebEx meetings
• Once a month face to face team meeting
• Publications in the media with a focus on the activities of Wi2H
• Closed facebook group
• Presentations in the community about our research
• Women’s rec. program
• Establishing and Educational Bursary for women
• Online blog
• Website
"The ideas, opinions, and experiences of all members of the Research Advisory Committee are of equal value."
Trust

- casual and non-judgmental atmosphere
- ensuring that everyone has a chance to and feels comfortable to speak
- transparency, researchers bring everything to the table

Creative Commons Attribution.
sicampnz.ning.com
Trust

Trust between Paula and the YMCA

- The YMCA’s willingness and commitment to work together
  - Share and merge ideas and expertise to build new and better ideas (e.g., hosting an outdoor Roller Boogie)
  - The YMCA’s full participation (e.g., attendance, ideas, and feedback for presentations)

- Everyone gives credit to and is supportive of the other

- Each finds value in the collaboration

- “You see your role as a guide rather than some one who imposes a point of view”
Trust

- Trust between Paula and the teens
  - The challenge of getting consent
- Trust between student and advisor
  - A dissertation about process
Taking Neighborhood Health To Heart: From Community Involvement to Ownership

- University of Colorado Denver and the Stapleton Foundation convened community residents to examine factors affecting heart health in five metro Denver neighborhoods.
- Early focus was largely driven by the requirements of the funding grant.
- Early community response: “How can we help you complete YOUR project?”
- Discussions about historical research abuses and methods for ensuring that study findings were shared with community led to the formation of the Data Review and Dissemination committee (DRAD).
Committed Engagement
KSDPP Code of Research Ethics

1994: researchers and community jointly developed KSDPP Code of Research Ethics
• outlines obligations of all partners
• protects individuals and community

2007: revised
• includes Mohawk philosophy and principles of participatory research
• outlines how principles are put into practice

Code adopted and adapted by other organisations, recognised by CIHR Guidelines for Research Involving Aboriginal Peoples

Process and outcomes both important
2007 KSDPP Code of Research Ethics
http://www.ksdpp.org/elder/code_ethics.html

- Principles
- Obligations of Community & Academic Researchers
- Rights of the Community and Participants
- Review and Approval Process for Ethically Responsible Research (CAB issues certificate of approval)
- The Consent Process
- Ombudsperson
- Data Collection and Data Management, Access to Data
- Dissemination and Publication of Research Results
- Knowledge Translation (all results go first to community)
- KSDPP Authorship Guidelines
- Multi-site Research and Multi-site Research Agreement
- Researcher Check- list Principles
Committed Engagement

• Meetings to inform partners prior to planned activities
• Meetings involve all partners: Heritage Centre, Health Centre, and UWO
• Dissemination at public meetings
• Approval prior to presentations or publications
Committed Engagement

• Data sharing agreements for each project
• Four Band Council resolutions (2005-2009)
• Formal Memo of Understanding between UWO and WIFN - June 1, 2009
Resolution passed by Walpole Island First Nation Chief and Council at the meeting of May 16, 2005.

“The Walpole Island First Nation Chief and Council grants permission to the Medical Doctors on the UWO Ecosystem Health Research Team to access the health records of WIFN band members who agree, to determine if there is sufficient information available for the purpose of conducting an epidemiological study to assess the health risk of the Walpole Island First Nation Community from exposure to environmental contaminants.”
Resolution passed by Walpole Island First Nation Chief and Council at their Council meeting of Sept. 19, 2005.

“The Walpole Island First Nation Chief and Council grants permission to members of the UWO Ecosystem Health Research Team to begin conversion of health records of WIFN band members who agree for the purpose of conducting an epidemiological study to assess the health risk of the Walpole Island First Nation Community from exposure to environmental contaminants. These health records are to be made anonymous by members of the Walpole Island Health Centre before transfer of any copies to the UWO Ecosystem Health Research Team.”
Communication
Communication

**1st - 2nd meeting:** Introductions, history, mission, goals. Discuss and Brainstorm environmental ‘supports’ and ‘barriers’ to healthy diet and physical activity.

**2nd – 3rd meeting:** Look at the top 4-5 “supports” and “barriers” to healthy lifestyles.
Communication

- University Experts partner with Local Experts
- CAB Surveys to understand engagement
- Keep the membership fluid
- Encourage subgroups
- Email, letters and phone calls to CAB members regularly
- Strong relationship with local Media
  - Keeps community informed
Balancing modes of communication

- Informal discussions
  - Paula drops by

- Formal meetings
  - Each requests meetings when he or she feels the need

- Email
  - Allows us to clarify things on paper, share ideas and resources, ask questions, and make decisions collectively
  - Email discussions have allowed us to get to know one another better and to develop our working relationship
Balancing modes of communication

- Balanced, open, two-way communication style
  - Allows us to continually ensure we understand what we are each willing to invest, as well as our respective expectations and limits
  - Allows us to work towards our goals continuously and incrementally, focusing the bulk of our energies on turning our ideas into action
Monthly Potluck

Community Advisory Board meeting 2nd Tuesday of each month:

‘set’dinner ➔ potluck

Why important?

- Encourages ownership
- Builds a sense of community and trust
- Encourages celebration of diversity
- Universal principal: everyone needs to eat
Monthly Potluck: why important?

Building ownership
- Brainstorming
- Presenting results
- CBOs predominantly trying new things together
- Family atmosphere
- New role of public affairs students
Q & A and Discussion

Facilitator:
Dr. Carol Herbert