

# Integrating Knowledge Translation Through Participatory Research

Participatory Research at McGill University (PRAM)

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Member of the Anisnabe Kekendazone-NEAHR  
Network Environment for Aboriginal Health Research

**Participatory Research at McGill**

<http://pram.mcgill.ca>



# Conventional Research

(nicknamed 'helicopter research')

...is when researchers make all the decisions

“outside research teams swooped down from the skies, swarmed all over town, asked nosey questions that were none of their business and then disappeared - never to be heard of again”

*Montour LT, et al. Diabetes Mellitus and Arteriosclerosis: Returning research results to the Mohawk Community. Canadian Medical Association Journal 1988;34:1591-93*

# Participatory Research (PR)

*“The systematic enquiry, with the **collaboration of those affected** by the issue being studied, for the purpose of education and **taking action** or effecting social change.” \**

# Integrated Knowledge Translation (IKT)

*A **collaborative way of doing research**. The **action-oriented** co-production of knowledge engaging researchers and stakeholders (knowledge users) of the research results. Involves integrating stakeholders into the entire research process study. \*\**

*\* Definition used by Centers of Disease Control, Atlanta GA, Institute of Medicine, USA, and The Royal Society of Canada Study of Participatory Research in Health Promotion 1995. - Green LW, George MA, Daniel M, Frankish CJ, Herbert CP, Bowie WR, O'Neill M.*

*\*\* Adapted from <http://www.cihr-irsc.gc.ca/e/33747.html>; Knowledge Translation at CIHR - Dr. Ian D Graham; February 28, 2007*

# Relationship between PR and Integrated KT

## What are the roles of the Research Partners ?

### PR

- Terms of partnership agreement
- Research goals and objectives
- Methods and duration of projects
- Strategy and content of evaluation
- Data collection
- Interpretation of data
- Joint dissemination of results in community language and scientific terms to communities, clinicians, administrators, scientists, and funding agencies

### IKT

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

*Based on: Macaulay AC, Gibson N., Freeman W, et al. Participatory Research Maximizes Community and Lay Involvement. BMJ 1999;319:774 -778*

*from <http://www.cihr-irsc.gc.ca/e/33747.html>; Knowledge Translation at CIHR - Dr. Ian D Graham; February 28, 2007;*

# Different Terminology...

- Action Research
- Participatory Action Research
- Community-Based Participatory Research (CBPR)
- Participative research
- Collaborative inquiry
- Peoples' Own Research
- Dialectic research
- Conscientising research
- Emancipatory research
- Social reconnaissance
- Participatory learning empowerment
- Democratic inquiry
- Participatory rural appraisal

However...

Differing emphasis on Action ↔ Research

Depending on the philosophical or motivational perspective

# History of participatory approach

## Northern Tradition

Kurt Lewin's action research 1940's; emancipatory and feminist research U.S.A.

## Southern Tradition

Alternative self-determination research paradigms from 3<sup>rd</sup> world, 1970's (Paulo Freire and others)

*Lewin, K. Action Research and Minority Problems.  
Journal of Social Issues 1946;2(4): 34-46*

# History of participatory approach

Evolved through...

Health Promotion (1980's - )

Lawrence W Green, Merideth Minkler, Nina Wallerstein,  
Barbara Israel, Ann C Macaulay...

# A ladder of citizen participation

## A continuum:

1. Manipulation
2. Therapy
3. Information
4. Consultation
5. Placation (concessions)

**Non-participation**

- 
6. Partnership
  7. Delegated power
  8. Citizen control

**Participation:  
3 degrees of citizen power**



# Participatory Research Goals

The equally important goals of participatory research are to

- undertake quality research with a high level of scientific rigour
- provide benefit to the knowledge users
- develop knowledge that is applicable to other settings.

**Scientific rigour should never be sacrificed!**

- strongest PR projects are the most scientifically rigorous (Viswanathan 2004).

Participatory research is an *approach* to research – as opposed to a methodology

- and therefore uses qualitative, quantitative or mixed methods as appropriate

Participatory Research



Integrated KT

# Is all Integrated KT PR?

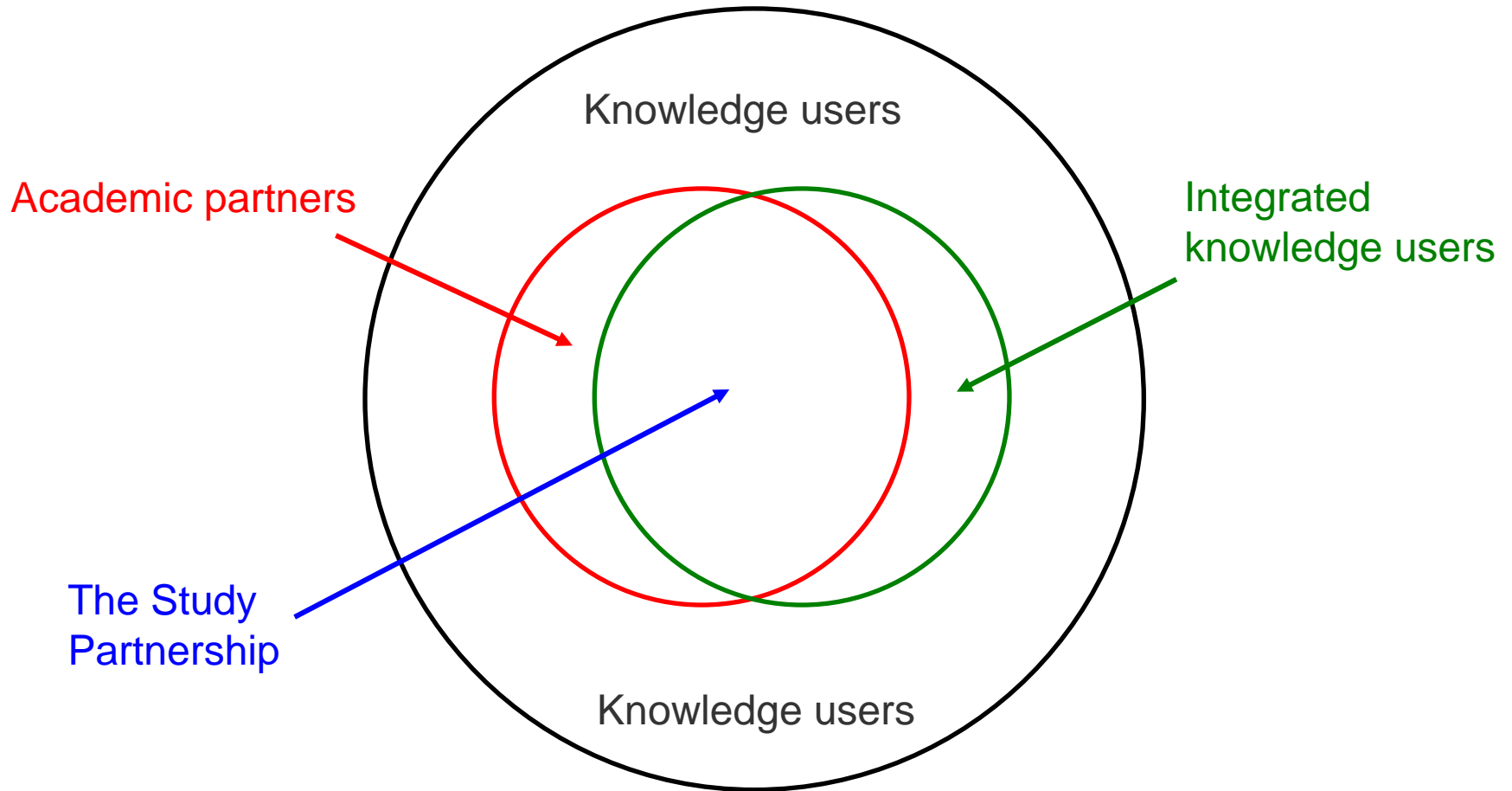
# Is all PR Integrated KT?

- Integrated KT (and PR) studies incorporate end users of the knowledge produced within the research project
  - Its motivation is effective and efficient knowledge to action
- PR often incorporates partners for other reasons
  - Those affected or impacted by the research, even though they may not directly use the knowledge
  - Those who control access to data; again, even though they may not directly use the knowledge
    - E.g., genetic research within an Aboriginal community
- Also Action vs. Research focus

# Integrated KT

- Integrated KT funding opportunities
  - *“KT Platforms”*
  - By definition, they bring researchers and knowledge users together in a structured and institutionalized way

# The Partnership



# Some IKT Principles

- All partners are experts with different experiences
- Power differentials among partners are acknowledged and sensitively addressed  
(political, gender, age, formal education, cultural)
- All stakeholders discuss potential harm as well as potential benefits of research
- Process is capacity building for everyone
  - Necessarily?

*Macaulay AC, Commanda LE, Freeman WL, Gibson N, McCabe ML, Robbins CM, Twohig PL North American Primary Care Research Group (NAPCRG) Policy Statement on Participatory Research; <http://www.napcrg.org/exec.html>*

# IKT Considerations

- Who owns the data? Where are data stored? What are your project's "OCAP issues?"
  - Future control and use of all data and samples
  - Secondary analysis
- Degree and types of protections for individuals and the whole community or group
- Process for resolving disagreements
- Incorporation of new collaborators into the team
- Degree and types of confidentiality
- Written agreement

*Participatory Research Maximizes Community and Lay Involvement. Macaulay AC, Commanda LE, Freeman WL, Gibson N, McCabe ML, Robbins CM, Twohig PL, for the Northern American Primary Care Research Group BMJ 1999; 319:774-8*

# Benefits of IKT

IKT and PR involve all stakeholders – those who will use, or be affected by, the results of the research – in the research process from formulation of the research question through interpretation and dissemination of results.

## And thus...

- By including all stakeholders, **KT is built into the research process** because the intended users of the results are involved in creating the knowledge
- Greatly increases the likelihood that results and recommendations will be acted upon (**Knowledge-to-Action**)
- Greatly **increases the relevance of the research** to intended users
- **Eliminates end-of-grant 'surprises'**. All stakeholders are aware of ongoing developments.



# Benefits of IKT

## Capacity Building

- Creates capacity among various stakeholders (communities and community members, patients, organisations, practitioners, policy makers, etc.) to address current and future issues.
  - Builds skills
  - Increases knowledge
  - Creates infrastructures
  - Enhances empowerment among groups who have historically been subjects of research, or merely passive consumers of its outcomes (especially in community-based projects)

# IKT Challenges

- Time, time, time, and more time ...
  - Any process takes much more time when all partners need to understand and agree on the issues.
  - Implications for academic tenure and promotion
  - Implications for time needed to address the issue under study
- Changing community and academic personnel
  - People come and go in a lengthy relationship – how will you accommodate this?
- Conflicting expectations
  - Not all partners will have the same needs or outlook
- Miscommunication
  - Misunderstandings will frequently arise. Building a solid basis of trust between all partners (a lengthy and evolving process) can help overcome.

# Some First Steps

- Imagine the range of possible knowledge users
- How can you incorporate knowledge users in some systematic way?
  - Use ecological model:
    - HP-IND-INT-ORG-POL-COM-NAT-INTERNAT
  - Identify *sectors*
  - Identify representatives of each sector
- Not all studies need be this inclusive
  - consider what end you are trying to accomplish
  - consider the scale of your study

# Is the Research Beneficial?

From the perspective of all stakeholders, should the research be pursued?

## Community:

- Can participants learn to take greater control over their lives?
- Does the project support and enable collaboration among all partners and existing resources?
- Does the project recognize and attempt to address important health, political, social and economic factors?

Problem-based orientation

# Is the Research Beneficial?

From the perspective of all stakeholders, should the research be pursued?

## Organisations (public/private/commercial/government...):

- Can knowledge users use process and results to take greater control over managing identified issues?
- Does the project support and enable collaboration among all partners and existing resources?
- Does the project recognize and attempt to address important health, political, social and economic factors?

Problem-based orientation

# Is IKT Appropriate for Me?

**Some other questions researchers should ask themselves before engaging in a PR process include** (adapted from Alvarez 2001):

- Are your personal goals (e.g. professional, tenure), perspective and interpersonal style (e.g. team player, good listener) compatible with a PR approach?
- Are you open to a problem-oriented approach, as opposed to purely curiosity-based research? I.e., are you most interested in affecting change with regard to a concrete, real world problem?
- Are you willing to put the effort into developing partnerships with knowledge users and sustaining a PR process?
- Are you prepared to be flexible in your project objectives and potentially have your proposed project turned down by knowledge users?

# Is IKT Appropriate for Me?

## *More...*

- Are you prepared to engage in shared decision-making at all the important stages in the research process and enter into joint governance of the project?
- Are you aware that a PR process can often be time consuming and administratively burdensome?
- Are you willing to learn from and maximize the expertise of the knowledge users, even if that expertise is non-scientific?
- Are you willing to openly acknowledge power differentials between researchers and knowledge users, especially with regards to community-based research?
- Would your institution and/or department head value and support a PR approach?

# Is IKT Appropriate for Me?

**Knowledge users considering partnering with researchers may ask themselves:**

- Is the area of research important to your context and in line with the needs of the community or organization you represent?
- Are you and your organisation or community willing to accept research results that may be other than you imagined?
- Does your job description include building linkages with researchers and, if not, is there openness to expanding it as such?
- Are you aware of the realities of research, including funding timelines and limitations, the need to produce scientifically rigorous results and publish in academic journals?



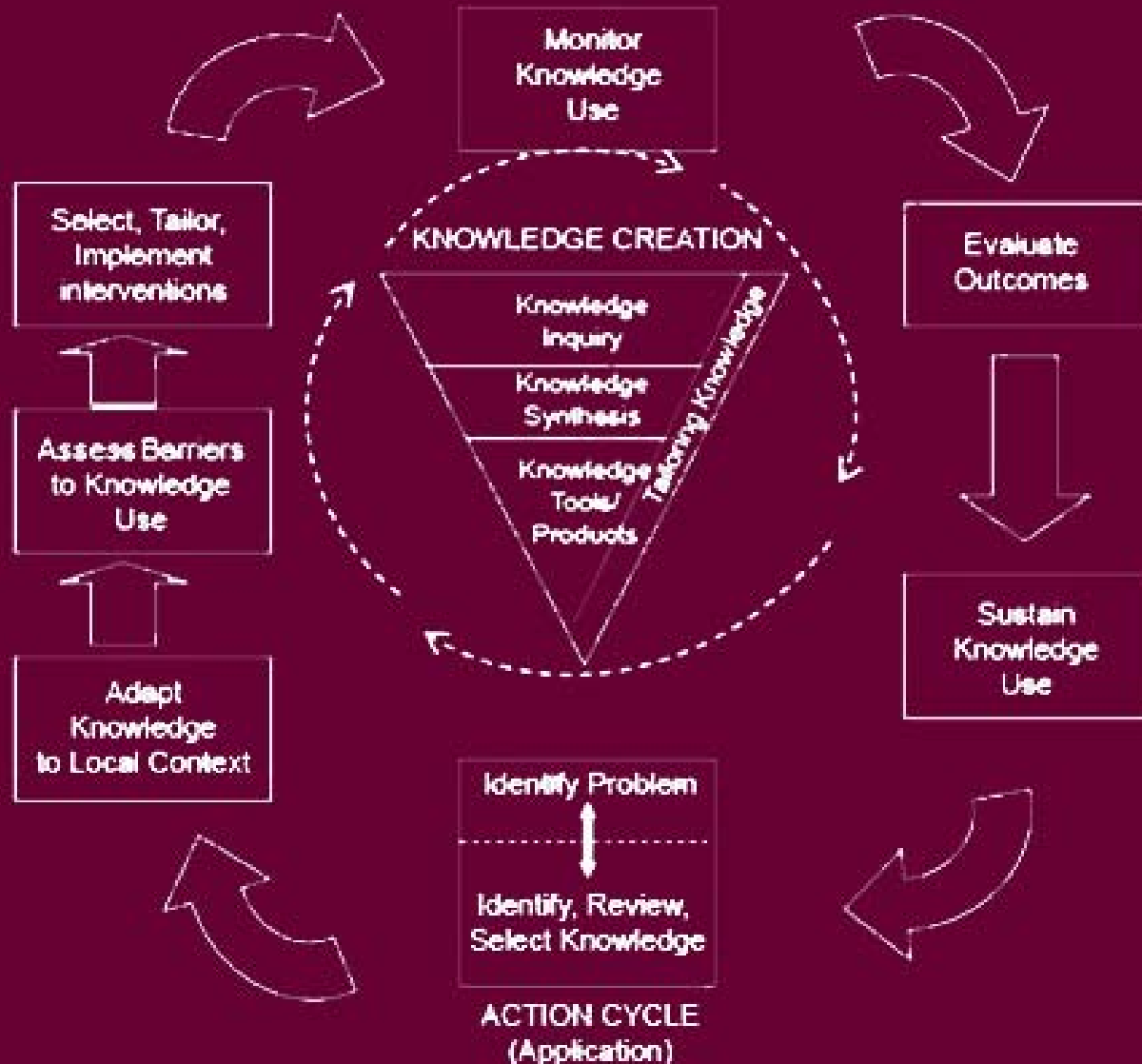
# Is IKT Appropriate for Me?

## *More...*

- Are you willing to put the effort into developing partnerships with researchers and sustaining a PR process?
- Are you prepared to be flexible in your project objectives and potentially have your proposed project adjusted by researchers?
- Are you prepared to engage in shared decision-making at all the important stages in the research process and enter into joint governance of the project?
- Are you aware that a PR process can often be time consuming and administratively burdensome?

# Knowledge to Action Process

*ID Graham*



# Example

## Integrated Knowledge Translation

*PR* → *IKT*

- **KSDPP returning results...**

Macaulay AC, Ing A, Salsberg J, McGregor A, Saad-Haddad C, Rice J, Montour L, Gray-Donald K. Community-based participatory research: lessons from *sharing results with the community*. *Kahnawake Schools Diabetes Prevention Project*. 2007. *Progress in Community Health Partnerships: Research, Education and Action* 1(2), p.143-152

- **IKT approach** (i.e. including community in, among other steps, the dissemination planning) **leads to strong end-of-study dissemination strategy**
  - community investment in the problem (i.e. lifting the burden of diabetes from future generations)
  - motivated them to take the results around in a series of targeted presentations at all the key identified organisations in the community - MCK, KMHC, KEC, etc.

## Case study: Paediatric palliative care

This research team undertook a study to document implementation of a new home based paediatric palliative care program and to describe the living conditions of families in the program; and to analyse the program's action process and the development of the participants who had participated in the program - terminally ill children, parents, siblings and volunteers. The **research team included researchers together with the palliative care team** – director and coordinator of the home care program and later also the volunteer coordinator and her assistant. Parents and volunteers were interviewed to voice their concerns, and to propose solutions. **Due to their time pressures from caring for their terminally ill children parents were not fully involved in all the decision making, but one parent helped in developing the questionnaire and many parents participated in interpreting the results and making recommendations for future care.**

## Case Study: Engaging in collaborative research design

*Aligning projects with realities of funding* There is a research funding opportunity in colon cancer requiring that the researchers partner with patients or communities. A family medicine research group has a high level of the necessary expertise, but the Community Advisory Committee (CAC) from a practice-based research network has identified their priority to be research into illicit drug use. One researcher drives in trepidation out to the CAC meeting and informs the group of the funds and available expertise, while acknowledging that he knows that this subject is not one of their interests. However during the CAC meeting, one member needs to leave to visit her father terminally ill with colon cancer, and another expresses great frustration that her husband will not go for colonoscopy after his father had been diagnosed with the illness. What was the end decision? The CAC voted to partner with the researchers and apply for funding (it was successful), and the researchers promised to try to find expertise and funding for a future project in illicit drug use.

# Taking an Integrated Partnership Approach to Examining the Benefits of an Integrated Partnership Approach

We are interested in understanding the benefits of participatory research, decided to undertake a systematic review of the evidence in its favour. We were determined that the study, appropriately, **would be carried out in a participatory manner**, integrating knowledge-users into the entire research process right from the beginning with

- **formulating the research question** and
- **preparing the grant application.**

first steps in this process were

- **imagine the various sectors that would benefit from the results** of this research,
- **identify individuals and organisations who could represent these interests**, and
- **solicit their participation.**

Identified 4 key action sectors: public health policy makers; research funders; community-partnering health research organisations; and university or hospital IRBs/REBs.

# Taking an Integrated Partnership Approach to Examining the Benefits of an Integrated Partnership Approach

-2-

It was understood that the size of the study's team should not be so large as to hinder progress, especially as this was for a one-year synthesis grant. Therefore the **list of partners should not be exhaustive, but representative** of the different sectors. Invitations were therefore extended, and key decision makers enlisted from

- **1 federal and 1 provincial public health agency** (Public Health Agency of Canada and Peel Region Public Health, Ontario);
- **1 federal and 1 provincial research funder** (CHSRF and FRSQ [CIHR was interested but could not be involved because of conflict of interest - they were the funder]); as well as
- **1 community-university health research organisation** (Community-Campus Partnerships For Health); and
- **1 institutional review board** (McGill University Faculty of Medicine IRB).

# Taking an Integrated Partnership Approach to Examining the Benefits of an Integrated Partnership Approach

-3-

All partners declared their full commitment to the study and to acting on its findings within their organisations and beyond to their respective service bases. All partners were involved in the iterative process of drafting the research proposal and dissemination plans. And all partners outlined their commitment to how they would contribute over the course of the year of research, reviewing and interpreting findings at regular intervals, and ultimately crafting and disseminating results within their respective jurisdictions. This plan predefines a commitment to policy change at the governmental and various organisational levels.

## Potential Impact

- Degree to which the question responds to a knowledge gap identified by decision-makers
- Commitment and capacity of the decision-maker partners to use the synthesis in their decision-making
- Likelihood that the project will have a positive and substantive impact on health outcomes, practice or policy
- Overall quality and feasibility of the end-of-grant knowledge translation plan
- Relevance of the proposal to themes identified in this funding opportunity



# Participatory Research at McGill (PRAM)

*PRAM* opened in September 2006 with a mission to create new scholarship in the field of participatory research, and advance its use and understanding within the Faculty of Medicine and allied units at McGill

- Consultation
- Needs Assessment
- Faculty Development Workshops (for CME credit)
- Partnering on Grants
- Seminar Series
- Training and Seed Funding

# Participatory Research at McGill (PRAM)

The image shows a screenshot of the PRAM website with several annotations. The website header includes the PRAM logo and navigation links: Home, NEAHR, Scholarships, Events, Seminars, Resources, Members, Archives, and a [Français] link. The main content area is divided into several sections:

- News:** Includes links for 'Assessing your Needs: Take the Survey', 'NEW PR Toolkit', 'NEAHR Network', 'PRAM in the McGill Reporter', and 'Fellowships & Scholarships'.
- What's new in PubMed:** A link to an RSS feed of the latest 31 days of Participatory Research items indexed in NCBI PubMed.
- Past Presentations available!** Lists speakers like Ian Graham and Lawrence W. Green.
- Participatory Research @ Lunch:** A section for monthly seminars with guest speakers.
- Second Friday of each month:** A section for guest speakers discussing topics of interest.
- Next one will be on Friday, February 5 @ 12:00PM:** Details for an upcoming seminar by Dr. Christophe Bedos.
- Goals:** A list of objectives including furthering scholarship, developing a network, offering seminars, assessing needs, offering expertise, supervising students, developing workshops, consulting with community organizations, and working with ethics boards.
- Postgraduate scholarships available 2006-2008:** Details about graduate student stipends and competition status.



Annotations with arrows point to the following elements:

- Needs Assessment:** Points to the 'Assessing your Needs: Take the Survey' link.
- Seed Grants:** Points to the 'NEW PR Toolkit' link.
- RSS Feed of Latest PR Lit in PubMed:** Points to the 'What's new in PubMed' link.
- Training Grants:** Points to the 'Fellowships & Scholarships' link.
- Archive of past guest presentations:** Points to the 'Past Presentations available!' section.
- Upcoming Seminars:** Points to the 'Next one will be on Friday...' section.
- Resource Literature:** Points to the 'Resources' navigation link.
- Other Web Resources:** Points to the 'Members' navigation link.
- Members (find a PR expert):** Points to the 'Members' navigation link.
- Other Scholarships:** Points to the 'Postgraduate scholarships available 2006-2008' section.

At the bottom left, there is a text box: 'Resources @ <http://pram.mcgill.ca>'.

# Participatory Research at McGill (PRAM)

## Understanding the needs of the McGill community

- Limited qualitative study of faculty members and staff already using PR
- 
- Use results to design faculty-wide needs assessment
- 
- Use results to design faculty development workshops in conjunction with the Office of Faculty Development / CME

# Qualitative Study

- Prospective semi-structured interviews with 7 academic team members
- Focus group with 9 participants
  - from 8 departments across 3 faculties (Medicine, Arts, Education).
- Participants were selected for their range of pre-existing knowledge and experiences with participatory research
  - with the goal of eliciting a broad set of thematic categories.
- Interviews and focus group were conducted in the winter and spring of 2007 and analysed in August 2007.

# What we found...

Qualitative study revealed these themes as important to McGill faculty and staff using PR...

Table 1

<b>Major Theme</b>	<b>Sub-Categories</b>
<b>Conceptual Framework</b>	<i>Action vs. Research; Key aspects of PR; General need for PR</i>
<b>Institutional issues</b>	<i>Institutional needs for PR; Institutional support for PR; Barriers to PR</i>
<b>Partnerships</b>	<i>Ethics; Agreements PR process</i>
<b>Academic Development</b>	<i>Need for academic PR expertise; Personal PR goals</i>
<b>New developments</b>	<i>PR developments; PR Impact on policy; Interest in PR from other areas</i>

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# Needs Assessment

Emergent themes from the qualitative analysis were then used to form categories for the needs assessment survey.

Categories:

- *PR Background*
- *Partnerships*
- *Funding*
- *Research & Evaluation*
- *Disseminating Results & Influencing Policy*
- *Professional & Academic Skills/Leadership*
- *Ethics.*

# Needs Assessment

The questionnaire was piloted at the end of October 2007 and administered in two waves

## *Results:*

- 126 responses
- 14 of the 21 departments in the Faculty of Medicine (including some bench science...)
- 2 Schools (Nursing and Physical & Occupational Therapy)
- 4 Centres, 3 clinical units, 7 divisions, and 1 department outside the Faculty of Medicine

# Needs Assessment

## Results:

Table 2: Responses to “It is important to me to improve my knowledge of... 1 (most) - 5 (least)”

Question	N	Mean	SD
grantsmanship skills specific to PR	124	<b>1.88</b>	0.976
evaluation methods and models used in PR	125	<b>2.03</b>	1.047
research partnership agreements, encompassing partner responsibilities, data ownership, protection, etc.	124	<b>2.03</b>	1.012
Identifying and overcoming challenges	125	<b>2.07</b>	1.108
integrated Knowledge Translation throughout the PR process	125	<b>2.10</b>	1.098
major challenges to conducting PR and how these challenges may be overcome	124	<b>2.12</b>	1.130
PR issues with IRBs	119	<b>2.13</b>	1.008
using evaluation results to manage, plan, strategize and improve partnership	123	<b>2.14</b>	1.058
how to influence policy	124	<b>2.16</b>	1.136
how to develop and maintaining partnerships	124	<b>2.20</b>	1.189
process evaluation for a PR partnership using a model-based approach	125	<b>2.20</b>	1.054
scholarly and community dissemination of PR studies	125	<b>2.30</b>	1.158
how to identify PR partners	125	<b>2.33</b>	1.243
how to balance personal, community, academic values in PR	121	<b>2.45</b>	1.118
key terms and principles used in PR	125	<b>2.51</b>	1.175
tenure and promotion in relation to PR	120	<b>2.93</b>	1.385



# Needs Assessment

Table 3: Preferred Learning Format (lower mean=higher rank; multiple responses allowed)

Learning Format	N	Mean	SD
Half-day workshop	119	<b>1.80</b>	1.078
E-learning tools	111	<b>2.73</b>	1.279
Individual/group consultations	112	<b>2.88</b>	1.224
One-day workshop	113	<b>2.94</b>	1.159
Other	28	<b>4.50</b>	1.139

# Needs Assessment

Table 4: Participatory Research Experience

Exp	N	%
none	23	19.3
some	78	65.5
significant	18	15.1

Table 5: Years involved in research

Years	N	%
0	2	1.6
1-5	30	24.0
6-10	25	20.0
11-15	16	12.8
16>	52	41.6

Table 6: Partners

Partner	N
Professionals	103
Patients	81
Organisations	78
Community members	57
Policy makers	44
Others	10

# Needs Assessment

## *Workshop Development*

- Needs assessment results informed workshop content by prioritising learning
  - how much time was allotted to each topic

# Needs Assessment

## *Workshop Development*

- 1 in 3 questions showed a significant difference between groups by “*Rate your Level of PR Experience*” (1-way ANOVA)
  - Therefore a second, more advanced workshop should be planned as a later follow-up.

# Needs Assessment

## *Workshop Development*

- Comparing means among those with "significant" PR experience...
  - highest responses were for:
    - *how to influence policy*
    - *PR issues with IRBs*
    - *integrating KT throughout the PR process*
    - *grantsmanship skills specific to PR*
    - *research partnership agreement*

# Delivered Workshop

## *Content:*

- Introduction to participatory research (PR)
- Identifying and recruiting partners
- Engaging in collaborative research design
- Taking stock of facilitators and barriers
- Maintaining partnerships over time
  
- Ethics and governance
- Joint dissemination of results
- Identify PR funding opportunities
- Knowledge translation
- Resources

# Delivered Workshop

## *Pilot Workshop:*

- Piloted in the Department of Family Medicine
  - for CME credit for physicians

## *Participants:*

- 15 Participants
- 10 family physicians
- 1 anthropologist
- 1 community advisory board member
  - from an ongoing PR project
- 3 FM research staff members

# Delivered Workshop

## *Feedback:*

- All Participants said they would recommend the workshop to a colleague
- Most felt that there should have been more time for concrete examples
  - less didactic slides



# Good resources

- PRAM – Participatory Research at McGill (<http://pram.mcgill.ca>)
- CIHR Knowledge Translation Portfolio  
(<http://www.cihr-irsc.gc.ca/e/29418.html>)
- CIHR Guidelines For Health Research Involving Aboriginal People  
([http://www.cihr.ca/e/documents/ethics\\_aboriginal\\_guidelines\\_e.pdf](http://www.cihr.ca/e/documents/ethics_aboriginal_guidelines_e.pdf))
- Guidelines for Participatory Research (<http://lgreen.net/guidelines.html>)
- Community Campus Partnerships for Health (<http://www.ccph.info>)  
Includes examples of research agreements  
(<http://depts.washington.edu/ccph/commbas.html#Principles>)
- NAPCRG Policy Statement on Participatory Research  
(<http://www.napcrg.org/exec.html>)  
Short version of this document published as  
Participatory Research Maximizes Community and Lay Involvement Macaulay AC et al, BMJ 1999;  
319;774-8
- KSDPP – The Kahnawake Schools Diabetes Prevention Project  
(<http://www.ksdpp.org>)