

Bringing the Perspectives of Older People into Research on Aging: Ways of Community Engagement

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Overview of Presentation

- Knowledge Translation and Mobilization
- Forms of Citizen Engagement
 - Representation
 - Leadership
- National Consultations with Older People:
 - Informing a Canadian health services research agenda
- Shaping research:
 - As participants
 - As reviewers
 - As researchers
- From Advocacy to Partnership

Knowledge Translation (KT) is the bridge between discovery and impact



What is Knowledge Mobilization or KT?

- “the exchange, *synthesis* and ethically-sound application of knowledge –
- within a complex system of *interactions* among researchers and users –
- to accelerate the capture of the *benefits of research* for Canadians through improved health, more effective services and products, and a strengthened health care system”
 - (<http://www.cihr-irsc.gc.ca/e/29418.html>)

Knowledge translation and mobilization involves

- Making users aware of knowledge and facilitating their use of it
- Closing the gap between what we know and what we do
- Moving knowledge into action

- Ideally, it begins with partnership, with including the ‘end – users’ and stakeholders of research in defining the issues and the questions

The Gap between Research and Policy and Practice

- Consistent evidence of failure to translate research findings into clinical practice:
 - 30-40% patients do not get treatments of proven effectiveness
 - 20–25% patients get care that is not needed or potentially harmful (*Schuster, McGlynn, Brook, 1998; Grol R, 2001; Graham et al, 2006*)
- Cancer outcomes could be improved by 30% with optimum application of what is currently known
- 10% reduction in cancer mortality with widespread use of available therapies

The research - practice/policy gap

- Costs to health of Canadians:
 - Unnecessary research done
 - Important research not done
 - Duplication of effort
 - Inability to generalize to real world
- Consistent evidence of failure to translate research findings into practice that would improve the health of Canadians
- Engaging stakeholders from the beginning is seen as a way to reduce this gap.

Outcomes of engagement between older people and researchers

Together, researchers and older people, as stakeholders, can be involved in:

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

CIHR Institute of Aging's Citizen Engagement Activities

- Regional Seniors' Workshops on Research
- Older people as judges for IA's student poster competition: evaluating knowledge translation merit of presentations
- One or more older citizens as lay representatives on Institute Advisory Board
- Annual updates to the National Seniors' Council, which reports to three federal Cabinet Ministers
- Seniors' organizations across Canada invited to host *Café Scientifique* discussions with researchers, policy makers and community representatives



CIHR CAFÉ SCIENTIFIQUE
PRESENTS

Science on tap

Quench your interest

Tuesday, November 2, 2010 (10:00am-2:00pm)
Qualicum Beach Civic Centre

Address: 747 Jones Street, Qualicum Beach
Meeting Room: Lions' Room (Ground Floor)
Map: http://www.qualicumbeach.com/civic_map.asp

Join us on:

facebook

Take Back Your Sidewalks: Creating Pedestrian-Friendly Communities for Seniors Café

Are you interested in learning more about pedestrian-friendly downtown design for seniors in your community?

You are invited to join an open-dialogue with a panel of experts in fall/injury prevention and municipal design for healthy aging.

Come help us work together to create safe spaces for seniors in Qualicum Beach and Parksville.

Complimentary Lunch Provided
Attendance by Registration Only

Contact: Lynne MacFadgen
Email: ccs@viu.ca; Tel: (250) 740-6160

Panelists:

Vicky Scott, PhD, RN
Senior Advisor on Fall and Injury Prevention,
BC Injury Research & Prevention Unit

Anne Martin-Matthews, PhD
Scientific Director of the National Institute of
Aging, Canadian Institutes of Health
Research, and UBC Sociology Professor

Bob Weir, P.Eng
Director of Engineering and Utilities, Town of
Qualicum Beach



2000-2010
CIHR IRSC
www.cihr-irsc.gc.ca

Moderator: Matt Herman, Director of Injury Prevention
and Healthy Built Environment, BC Ministry of Healthy Living and Sport



VANCOUVER ISLAND
UNIVERSITY

Café Scientifique - Halifax 2009 Seniors' Mental Health



CIHR - Regional Seniors' Workshops on Research

Regional Seniors' Workshop on Research Prairie Region



June 24 – 25, 2004
Regina, Saskatchewan

- **Prairies – Regina (June 2004)**
- **Atlantic – Halifax (November 2004)**
- **British Columbia & North Regions – Vancouver (March 2005)**
- **Ontario – Toronto (November 2005)**
- **Quebec – Montreal (May 2006)**
- **Summary Report - 2007**

Seniors' Research Workshop Results

Top priorities for research on aging, identified by seniors and advocates across the country were:

- Health care and health services
- The housing-care continuum
- Health promotion



Follow-up with Engaged Citizens: We acted on what we heard

- Priority research topic identified by older people:
‘Health Services and Systems for an Aging Population’ as strategic research priority for Institute of Aging
- Maintaining contact with participants: newsletters, local meetings, seeking consultation
- Showing that recommendations have been ‘heard’

Getting the Perspectives of Older People in Research on Aging

❖ Shaping Research Questions and Outcomes:

1) As Participants in Research

- Informing research findings and outcomes
- Defining and shaping the research agenda

2) As Reviewers and Appraisers of Research

3) As Research Collaborators

- Older people as participants in research:

- Design of products (eg., assistive devices)
- Evaluation of policies (e.g., ‘Age-Friendly Cities’)
- Assessing appropriateness of services



Participants in Research

- AMM's study of home care workers, elderly clients, carers in three Canadian provinces:
- **Agencies** value: 'Care plan' completed in the most efficient time
- **Workers** value: Consistent, reliable work schedule, completing the 'care plan' without mishap and on time
- **Elderly clients** value: a "focus on the person," "preservation of autonomy," and interactions characterized by recognition, validation, collaboration, and negotiation.

"Valuing the Older Person in the Context of Delivery and Receipt of Home Support: Client Perspectives", K. Byrne, K. Frazee, J. Sims-Gould, and A. Martin-Matthews, *Journal of Applied Gerontology*, 2010,.

Older People Inform and Shape the Research: identify unanticipated issues

- In Home Care study pilot phase:
 - Ethno-cultural diversity issues (food preparation, footwear, language)
 - Issues of time: “50” minute hour
 - New terminology for interview team
- Pilot interviews analyzed on on-going basis: added questions to later full study interviews
- Elderly client safety issues: diversity of perspectives (not only ‘worker’/medical as literature emphasizes).

Other Research Roles: Assessing Research Proposals and Outputs



- Also: Lay Reviewers on CIHR peer review panels:
 - Reading Lay Summaries
 - Assessing the utility and value of research proposals

Older People as Researcher Collaborators



GREY MATTERS

A GUIDE TO COLLABORATIVE RESEARCH WITH SENIORS

Nancy Marlett and Claudia Emes

Older People as Research Collaborators

- Initial project ('high risk') funded by Institute of Aging Pilot Grant: tested methods of engaging older people as researchers.
- Outcome: 2010 publication, *'Grey Matters: A Guide for Collaborative Research with Seniors'*.
- Nancy Marlett and Claudia Emes, U of Calgary (in collaboration with the Kerby Centre)
- Open access on U Calgary Press website
- Tool has two purposes:
 - for older people wanting to conduct research
 - for those aiming to involve older people in research collaborations

“Being involved after the research has been designed is like being invited to comment on the menu after the meal has been prepared”. *Grey Matters*, 2010, p. 4

“You might be invited to take part in this type of research by:

- working to define problems and needs
- providing input into:
 - where to study the issues
 - who to contact
 - how to do the research
- collecting information
- helping with analysis and interpretation”.

Partnerships in Research and also in Policy and Practice

- Moving beyond advocacy for older people to partnerships with older people

BC: Integrated Primary and Community Care Patient and Public Engagement Framework

- “Patients are partners in care when they are supported and encouraged to participate: in their own care; in decision making about that care; at the level they choose; and in redesign and quality improvement in ongoing and sustainable ways.” *BC Ministry of Health – Integrated Primary and Community Care Policy Paper*
- “Public engagement: processes by which individuals, groups and organizations have an opportunity to participate in decision-making that affects their lives.” *Public Health Agency of Canada (PHAC)*

Three Care Domains: Individual; Program and Service Design; and System and Community

- In the **individual care domain**, patient engagement enables patient and family to be active, involved in own care decisions and in day-to-day management of health and well-being
- In the **program and service design domain**, patients, families, communities and/or strategic partners are engaged in design, delivery and evaluation of programs.
 - *BC Ministry of Health – Integrated Primary and Community Care Policy Paper*

The Third Domain in BC's model

- In the **system and community domain**, patients, families, communities and/or strategic partners are engaged:
 - strategic planning or policy making activities
 - setting priorities
 - informing resource- allocation decisions
 - playing a role in governance
 - *BC Ministry of Health – Integrated Primary and Community Care Policy Paper*

Engagement in research

- In 2010, Canadian Health Services Research Foundation (CHSRF) allocated \$2.6 million to projects:
 - engaging stakeholders (patients) in design, delivery and evaluation of health services
 - researching the outcomes and promising practices emerging from projects.
- In 2011, \$650,000 for research stream: “Your Voice Counts”
- Other initiatives specific to research centres (“Friends of the Centre on Aging, University of Victoria)

Value of Citizen Engagement

- Now supported by a rich body of evidence:

Many quality, safety and business outcome measures:

- improved health outcomes for patients
- superior patient and provider experience
- better financial performance
- fewer errors
- more diligent decision-making
- better risk management
- a more knowledgeable, cohesive citizenry

Advocacy to Partnership: Sweden Example

- Ryhov Hospital in Jönköping, Sweden :
 - Traditional hemodialysis and peritoneal dialysis center
 - In 2005: a patient, Christian, asked about doing it himself
 - Christian taught a 73-yr-old woman how to do it...
 - Together, they taught others how to do it.
 - Oldest person now on self-dialysis: 83 years old
 - Aim: 75% of patients on self-dialysis (currently have 60% of patients)

Source: Maureen Bisognano,
Institute for Healthcare Improvement
USA (Vancouver: CHSPR conference 2012)

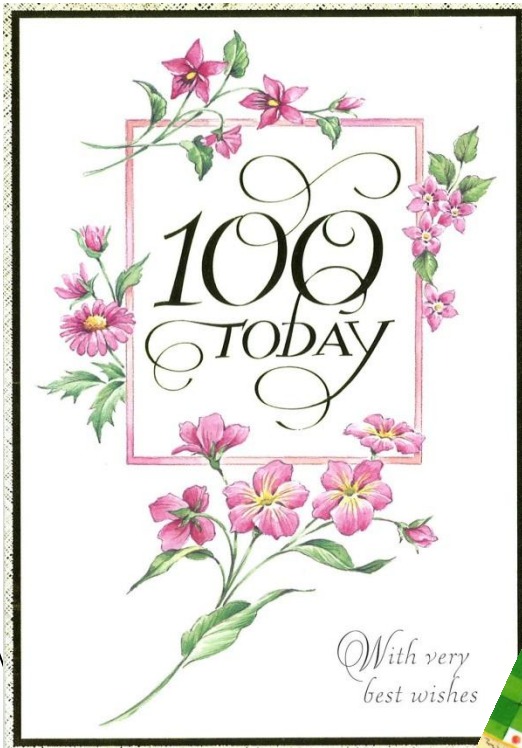
Challenges and Opportunities:

- Ingrid (nurse): “I got the courage to change (after 40 years) because I saw the patients ‘lift up.’ I moved from being a technical expert to a coach.”
- Britt Mari (nurse): “The patients are our partners in designing the unit, buying equipment, teaching, and planning.”
- Elderly ‘patients’:
 - “I have a new definition of health.”
 - “I want to live a full life. I have more energy and am complete.”
 - “I learned and I taught the person next to me, and next to her. Of course the care is safer in my hands.”



Multiple realities of old age





Summary: What I hope you heard

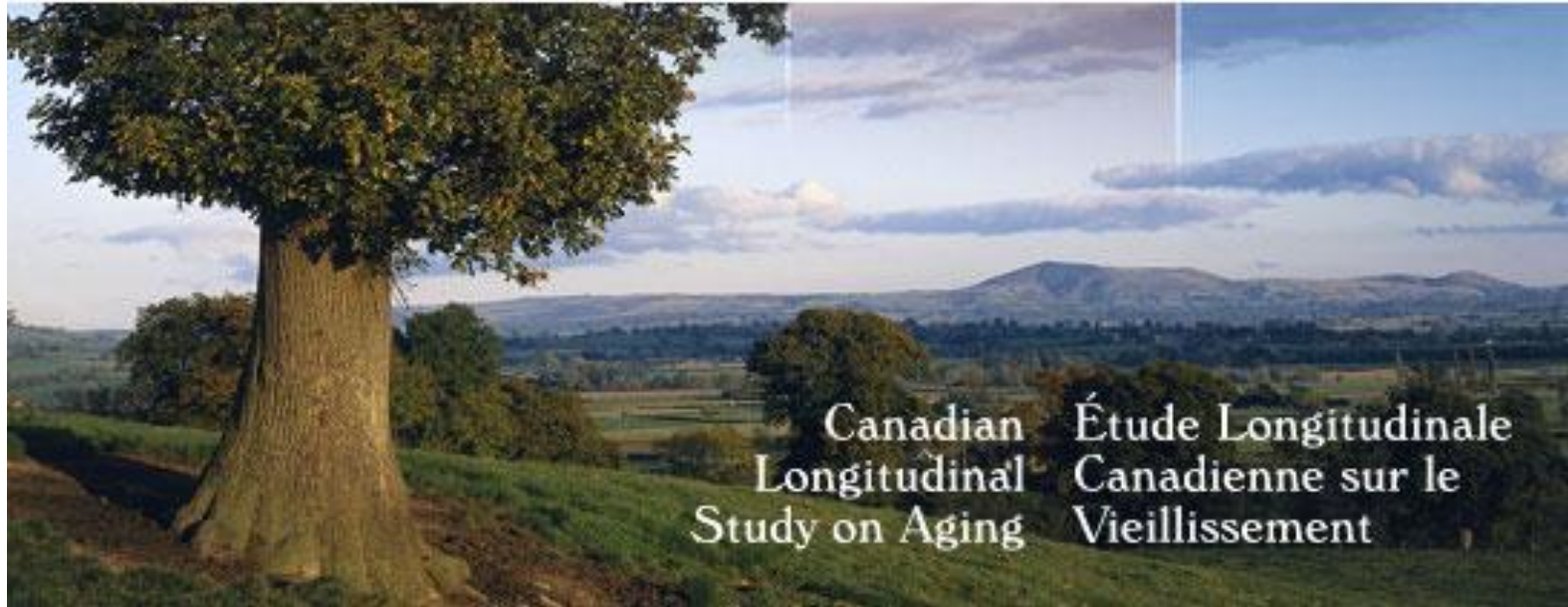
- What Knowledge Translation/ Mobilization is
- Examples of Citizen Engagement in research
 - representation
 - leadership (Café's and topics)
- National Consultations
 - How older people shape health services research agendas
- Examples of shaping research:
 - As participants
 - As reviewers
 - As researcher collaborators
- Overall theme: From Advocacy to Partnership

The Future is Aging!



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***3 Principal Investigators; 80+ Co-investigators; 60+ Collaborators
Parminder Raina (NPI); Christina Wolfson; Susan Kirkland***

Duration 20 years: 50,000 Canadians aged 45 years and over