

# Table of Content

Executive Summary.....	3
Word from the Scientific Director .....	5
<b>Regional Seniors’ Workshop on Research</b> .....	<b>6</b>
Background.....	6
Participants .....	6
Objectives of the RSWR .....	6
Key Topics .....	6
Breakout Sessions.....	7
Seniors’ Panel: Sharing Research Experiences.....	7
<b>RSWR for the British Columbia Region: Day 1, March 30, 2005</b> .....	<b>8</b>
Introduction .....	8
Welcome Address.....	8
It’s Time for Research on Aging: An Overview of the Institute of Aging and the Canadian Institutes of Health Research .....	9
The Institute of Aging.....	10
Research Supported by IA: CanDRIVE .....	11
From Concept to Results in Chronic Disease Management.....	12
Questions and Comments .....	13
Breakout Session: British Columbia Research Priorities .....	14
Lower Mainland .....	14
BC Interior.....	15
Vancouver Island.....	15
North .....	16
Discussion on Research Priorities Reports.....	16
Seniors’ Panel: Seniors’ Engagement in Research for Healthier Communities	17
From Pain to Peace, Thanks to Research .....	17
Research for Change on Seniors’ Issues in the North .....	18
Guide to Care Facilities and Seniors’ Housing in Prince George .....	18
Community-based Research on the Relationship Between Abused Older Adults and the Criminal Justice System .....	19
Seniors’ Community-based Research and Prospects for Influencing Policy .....	19
Questions and Comments.....	20
Impressions of Day 1 .....	22
The Aging Brain .....	22
Questions and Comments.....	24

# Table of Content

<b>RSWR for the British Columbia Region: Day 2, March 31, 2005.</b>	25
Research Themes and Projects in BC	25
Questions and Comments	26
Breakout Session Reporting: Ongoing Engagement Strategy	27
Group #1	27
Group #2	27
Group #3	28
Group #4	28
The Knowledge Exchange Task Force	29
Questions and Comments	30
The Canadian Longitudinal Study on Aging	30
Questions and Comments	32
Closing Remarks	33
<b>Annexes</b>	35
Figure 1	35
Annex A: British Columbia Participants	36
Annex B: British Columbia Regional Implementation Committee Members	39
Annex C: National Organizing Committee Members	40
Annex D: Facilitators and Speakers	40
Annex E: Institute of Aging - Institute Advisory Board Members	41
Annex F: Institute of Aging - Staff and Contact Information	42



## Executive Summary ▶▶


**The** Institute of Aging of the Canadian Institutes of Health Research (CIHR) was honoured to present the Regional Seniors' Workshop on Research for British Columbia in Vancouver, on March 30th and 31st, 2005. This Regional Seniors' Workshop on Research was the third in a series to be hosted across Canada. Participants from across British Columbia and the Territories to its north were invited to this important two-day event. The workshops aim to formally initiate knowledge exchange and networking on the topic of research on aging among seniors, seniors' organizations, service providers and the Institute of Aging. More specifically, the Institute of Aging's has a number of goals:

- To increase participants' awareness about the CIHR, the Institute of Aging, and regional activities related to research on aging;
- To gather input on health issues that are priorities for research on aging in different Canadian regions;
- To increase participants' understanding of the research process and its benefits to their lives;
- To increase participants' understanding of established processes to protect individuals involved in research (ethics);
- To gain insight on guiding principles and expectations for an ongoing engagement strategy linking the Institute of Aging, seniors' organizations, service providers, and seniors in their communities;
- To increase participants' commitment to research on aging through planned engagements, participation and support of research on aging.

The Regional Seniors' Workshop on Research for British Columbia offered participants a range of presentations aiming to enlighten them on the research process and the various research initiatives on aging in the province and regions to the north. Other topics included turning research results into products or services and the Canadian Longitudinal Study on Aging.

Among the networking activities, participants of the Regional Seniors' Workshop on Research for the British Columbia Region took part in two breakout sessions. The first allowed participants to express their views on which health or social issues should be priorities in research on aging. These included the following:

- The need for translation of existing (research) knowledge into policy and practice;
- A better understanding of all aspects of the housing-care continuum, including an emphasis on rural and remote areas;

- 
- Investigations into the impact of policy changes related health and care services available to older adults;
  - A shift in the orientation of health professionals from drivers to partners in health care;
  - The need for more culturally-sensitive health research, services and programs.

In the second breakout session, the participants discussed essential elements and best practices for ongoing engagement between the Institute of Aging and communities of seniors, seniors' organizations, and service providers. Four principal strategies were brought forward:

- Build on existing networks and infrastructures.
- Engage older adults as knowledge brokers.
- Use multiple media to communicate.
- Try a pilot project in one sub-region, offering research funding to address key issues.

Through the hard work of all involved, the Regional Seniors' Workshop on Research for British Columbia succeeded in realizing its objectives. This two-day exchange shed new light on regional health research activities and needs, initiated discussion on processes for sharing research information, and offered participants unique opportunities for networking and dialogue.



## Word from the Scientific Director - May 2005 ▶▶

**I**n May 2003, the Institute of Aging of the Canadian Institutes of Health Research (CIHR) held a National Seniors' Forum for Research in Ottawa. The forum was designed to inform Canada's seniors about the Institute of Aging and its strategic directions, provide information on ways in which older people can be involved in research, and, most importantly, to engage forum participants in discussions of recent trends in research on aging and the identification of gaps in research. As the first step in an on-going consultative process, information on these gaps and concerns is to be brought to the scientific community to inform the future priorities of the Institute of Aging.

One of the principal outcomes of the National Forum was a recommendation that regional workshops be held across Canada to engage a broader community of seniors and governmental and voluntary organizations in these discussions. The first Regional Seniors' Workshop on Research focused on the Prairies, and was held in Regina in June 2004. The second workshop, gathered participants from the Atlantic region in November 2004 in Halifax.

This, the third Regional Seniors' Workshop on Research, brought together key representatives from British Columbian and northern Canadian

communities, in Vancouver on March 30 and 31, 2005. Over 60 seniors, members of seniors' organizations, advocates, and government personnel who work on seniors' issues, participated in this two-day event.

On behalf of the National Organizing Committee, the British Columbia Regional Implementation Committee and the Institute of Aging, I am pleased to present the Proceedings of the Regional Seniors' Workshop on Research for British Columbia. Committee members, Institute of Aging staff and volunteers are listed in the Annexes to this Report. I sincerely thank them, and the active and engaged workshop participants, for their contributions to this endeavour.



Anne Martin-Matthews  
Scientific Director,  
Institute of Aging



## Regional Seniors' Workshop on Research »

### Background

The Institute of Aging of the Canadian Institutes of Health Research (CIHR) held a National Seniors' Forum on Research in May 2003 to discuss national research priorities on aging and health with seniors and representatives of seniors' organizations across Canada. At the conclusion of the meeting, there was agreement on the need to hold similar regional workshops across the country. Hence, the Institute of Aging (IA) is introducing a series of Regional Seniors' Workshops on Research (RSWR) across Canada. The IA wants to hear seniors' views with respect to needs and priorities for research on aging in Canada. The IA also wants to connect with Canadian seniors, seniors' organizations and service providers, and find ways to stay connected. Regional workshops are to be active, interactive and relevant to older adults and those who work with them.

### Participants

Participants of the RSWR are mainly seniors, representatives from seniors' organizations and health, social and community services providers. The number of participants at a regional workshop is typically limited to 50.

### Objectives of the RSWR

The RSWR strive to offer participants several opportunities:

- To express which health or social issues should be priorities in research on aging;
- To become familiar with various research projects on aging in their region;
- To find out why taking part in research projects is important;
- To be informed of their rights as participants in research and researchers' responsibility;
- To help plan for a strategy to connect the Institute of Aging with seniors, seniors' organizations and service providers.

### Key Topics

- Turning research results into services, products or policies
- Privacy and informed consent in research
- The roles of seniors in research
- Research and ethics
- The Canadian Longitudinal Study on Aging



## Breakout Sessions

### Breakout Session #1: Regional Perspectives on Priorities in Research on Aging

The purpose of this session is to provide a forum for identification and discussion of regional health issues that should be priorities in research on aging.

### Breakout Session #2: Developing an Ongoing Engagement Strategy

The purpose of this session is to get input from participants about essential elements and best practices for ongoing interactive engagement and consultation processes between the Institute of Aging and seniors, seniors' organizations, and service providers.

## Seniors' Panel: Sharing Research Experiences

The purpose of the Seniors' Panel is to increase awareness of various roles seniors can play in the research process and to promote future engagement of seniors in such a process. Four seniors who have contributed in one role or another to research on aging present their individual experiences. The presentations are followed by a question and answer period. Panel members are selected based on having experience with one or more of

the following roles:

- Participants/human subjects
- Research staff
- Advisors on user perspective
- Members of research ethics boards
- Participants in selection panels for research grants/contracts
- Participants in identification of research needs or policy redirection
- Participants in application or transfer of research results
- Seniors who returned to school later in life to obtain graduate degrees and are now doing research





## RSWR for the British Columbia Region:

Day 1, March 30, 2005 ▶▶

### Introduction

The Regional Seniors' Workshop on Research for the British Columbia Region was held in Vancouver on March 30 and 31, 2005, at the Westin Bayshore Resort and Marina. Approximately 60 invited participants from the lower mainland, island, and interior of BC, as well as representatives from the northern parts of British Columbia and Canada, participated in this two-day event.

### Welcome Address

**Ms. Phyllis Bentley Co-Chair, BC Regional Implementation Committee**

Ms. Phyllis Bentley, Co-Chair of the BC Regional Implementation Committee, welcomed all the “young or wannabe-young” seniors who had come from across British Columbia. “You are the basis of aging research,” she told them. “It is your opinions and behaviours that are the source of all their speculation.” She extended regrets for the Scientific Director of the Institute of Aging, Dr. Anne Martin-Matthews, who was too ill to attend, and introduced Dr. Martin-Matthews' Assistant Directors, Drs. Susan Crawford and Linda Mealing.

**Dr. Susan Crawford, Assistant Director, Vancouver, Institute of Aging**

Dr. Susan Crawford also welcomed participants, noting the full schedule of discussions planned for the next day and a half. The Institute of Aging (IA) is one of the 13 institutes within the Canadian Institutes of Health Research (CIHR). The Institute of Aging is based at the University of British Columbia (UBC). She and her colleagues essentially work together “virtually” for the most part, with connections to Canadian researchers, other organizations interested in aging research, and funding partners.

Dr. Crawford explained the historical context for the workshop and referred to a national forum on health research and outcome for seniors, where the key message that emerged was the need for regional forums to ask seniors what their key issues were and how the IA could best stay connected with them and their organizations. The main focus for this workshop was to listen to seniors, she stressed. At the same time, she hoped to connect seniors with the research process and to help them understand how to get involved in research.





## It's Time for Research on Aging : An Overview of the Institute of Aging and the Canadian Institutes of Health Research

Dr. Susan Crawford for Dr. Anne Martin-Matthews, Scientific Director, IA

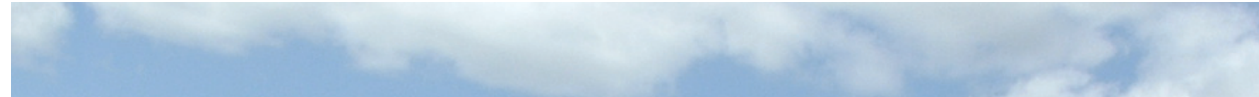
Dr. Crawford gave an overview of the CIHR, the Canadian Institutes of Health Research. As part of the Government of Canada's commitment to research, CIHR was created in 2000 as Canada's major health research funding agency. It has transformed the way health research is conducted in Canada with a new structure based on virtual institutes and emphasis on a multidisciplinary approach that unites diverse specialists, such as engineers and economists, who otherwise never might be involved in health research. The focus is broader than just biomedical and clinical research, and CIHR supports 5,000 researchers in universities, teaching hospitals, and research institutes across the country. The CIHR approach is now being studied as a model by other countries.

The objective of CIHR is "to excel, according to internationally accepted standards of scientific excellence, in the creation of new knowledge and its translation into improved health for Canadians, more effective health services and products and a strengthened Canadian health care system." The emphasis on the "translation" of research knowledge to those who can use and benefit from it makes CIHR unique. When CIHR's performance is evaluated and deemed successful, the essential criterion will not be solely based how much research has been funded, but also whether it translated into improved health for Canadians. Therefore, the emphasis is not just on the creation of new knowledge, it is on getting that knowledge out to the policy-makers, practitioners, and those who need it.

CIHR's work is guided by four broad themes that reflect the expanded mandate of CIHR and cover the full spectrum of health research:

- Biomedical
- Clinical
- Health services and systems
- Health of populations (societal, cultural, and environmental dimensions of health)

Co-operation, partnership and excellence, Dr. Crawford continued, are the principles that guide CIHR. Individual researchers, research teams, universities, hospitals, the federal, provincial and territorial governments, research agencies, the voluntary health sector, health charities, industry and the public are all partners in their implementation.



A total of 13 Institutes within CIHR address domains of health research of immediate and identifiable importance to Canadians. Some of the CIHR's 13 institutes are disease-based (e.g., the Institute for Cancer Research), Dr. Crawford explained, while others focus on health issues that are relevant to certain groups, like aging or Aboriginal people's health.

Each Institute is headed by a Scientific Director and guided by an Institute Advisory Board consisting of volunteers from all parts of the health community. The institutes are as follows:

- Aboriginal Peoples' Health
- Aging
- Cancer Research
- Circulatory and Respiratory Health
- Gender and Health
- Genetics
- Health Services and Policy Research
- Human Development, Child and Youth Health
- Infection and Immunity
- Musculoskeletal Health and Arthritis
- Neurosciences, Mental Health and Addiction
- Nutrition, Metabolism and Diabetes
- Population and Public Health.

## The Institute of Aging

The Institute of Aging (IA), said Dr. Crawford, supports research to promote healthy and successful aging and to address causes, prevention, screening, diagnosis, treatment, support systems and palliation for a wide range of conditions


associated with aging. The fundamental goal of the IA is the advancement of knowledge in the field of aging to improve the quality of life and health of older Canadians. To achieve this goal, the IA aims to do the following:

- Lead in the development and definition of strategic research directions for Canadian research on aging;
- Develop and/or support high quality research programs and initiatives related to aging;
- Build research capacity in the field of aging;
- Foster dissemination and exchange of knowledge and its translation into policies, interventions, services and products.

The IA focuses on five priority areas of research:

- Healthy and successful aging,
- Biological mechanisms of aging,
- Aging and the maintenance of functional autonomy,
- Cognitive impairment in aging
- Health services and policy related to older people

An Institute Advisory Board provides advice to the Scientific Director on strategic directions for the Institute. Board members are recruited from universities, government, the private sector, voluntary organizations and seniors' groups across Canada. Current Board Members are listed in Annex E. Dr. Crawford introduced Sheila Laidlaw a former Advisory Board member and member of the National Organizing Committee.



Dr. Crawford presented examples of research program offered by the IA. “We encourage researchers to team up and find different ways of looking at issues relevant to aging,” she said. She explained that the Institute supports research in a variety of ways:

- Strategic Training Program grants, designed to entice younger researchers into the field;
- New Emerging Team grants and Interdisciplinary Health Research Teams grants, bringing researchers who have not worked together before into cross-disciplinary teams;
- Pilot Project grants, providing one year of funding to enable researchers to flesh out ideas and lay the ground work for turning them into multi-year major projects;
- Training and Investigator awards, particularly aimed at providing salaries for younger researchers;
- The development of the Canadian Longitudinal Study on Aging.

Dr. Crawford ended by acknowledging the excellent work of the British Columbia Regional Implementation Committee members, then introduced them as well as the National Organizing Committee members and IA staff present (listed in Annex B, C and F respectively).

## Research Supported by IA: CanDRIVE

Dr. Holly Tuokko, Centre on Aging, University of Victoria

Dr. Tuokko gave an overview of the Canadian Research Initiative for Vehicular Safety in the Elderly (CanDRIVE), a new emerging team funded by the CIHR Institute of Aging. CanDRIVE aims to ensure that decisions on licensing older drivers are based on their actual skills, not age.

She noted that the data show that older drivers are not over-represented in crashes compared to other age groups. But in terms of miles driven, they are much more likely to be involved in a crash. Although the vast majority are safe drivers, they are often unfairly characterized in the media. Older people have crashes for different reasons than other groups and are far more likely to die or suffer serious injury when they do. Higher crash rates are not due to age itself, but to medical conditions, such as impaired vision and movement, mental functioning, and frailty.



CanDRIVE has identified a more appropriate focus for research in three key areas:

- Extending safe driving
- Understanding older drivers with medical conditions
- Lessening the impact of driving cessation

The IA provided \$1.25 million over five years to establish the CanDRIVE multidisciplinary research network to address health-related safety and quality-of-life issues pertaining to older drivers. Dr. Tuokko gave an overview of what a network like this can accomplish in a short time, noting that while CanDRIVE does not fund the actual research, it facilitates and coordinates research that will be conducted over the next 10 to 15 years. CanDRIVE has brought together researchers, seniors groups, clinicians, ministries of transportation, other governmental organizations and non governmental agencies.

Exciting early outcomes of the two-year old CanDRIVE project include acquisition of a major partner, the Canadian Council of Motor Vehicle Transportation Administrators, and development of a database of national research to gather scattered pockets of knowledge. In the longer term, CanDRIVE aims to enlighten public attitudes about older drivers and increase vehicular safety for all road users.

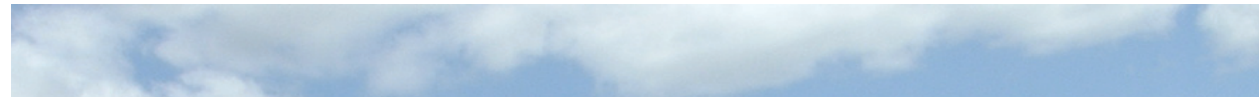
## **From Concept to Results in Chronic Disease Management**

**Dr. Patrick McGowan, Centre on Aging, University of Victoria**

Dr. McGowan discussed lessons learned from his experience in developing self-management programs for chronic health conditions over the past 18 years. Groups and communities interested in helping people with chronic health conditions run these programs, and patients self-refer. Trained individuals who have the same conditions lead the programs, not health professionals. The programs have historically and are currently funded primarily by Health Canada and have seen more than 4,000 participants from across various regions of British Columbia in recent years.

He described key activities in developing such a program from the concept stage to actual results. The type of research needed includes effectiveness research and quasi-experimental research to show that the concept works. Feasibility and viability research must follow to demonstrate that the delivery of the program can be adhered to as intended. Qualitative research is needed next to get input from the beneficiaries of the program, and then feedback to show tangible benefits.

Other important considerations include the meaningful involvement of seniors as researchers, advisers, and champions in research and in the bringing about fruitful



outcomes of research. It is also important that such projects be consistent with federal, provincial, and regional policy. For this, Dr. McGowan illustrated the complexity and the realities of activities important in the success of programs (see Figure 1 on page 36).

Dr. McGowan described the Seniors Independence Program and its implementation in the Yukon. The community was interested in how it could be applied to all chronic health conditions. Tangible benefits and demonstrated effectiveness are a must. One important feature was that it was volunteer driven.

The Canadian Diabetes Strategy Prevention and Promotion Contribution Program was also presented; its key outcomes being enabling environments, public awareness and education, and effective preventative actions.

### Questions and Comments

A participant asked about Dr. Tuokko's comments on age bias in media reporting. She replied that this was her subjective impression and that she had not looked at research on this.

Another asked about issues related to aging in automobile design, including improved lighting and readability of instrument panels. Dr. Tuokko said that auto manufacturers are part of the CanDRIVE partnership, and some are starting to look at such issues.

One participant asked about research on transit in the CanDRIVE initiative. Dr. Tuokko replied that, in studying the impact of driving cessation, the need for alternatives was identified, including transit.


In response to another question, Dr. McGowan confirmed that four staff and thousands of volunteers support the self-management programs. The programs are designed to operate even in small communities, so that isolated seniors can be reached if there is interest in their community.

A participant described a trial program in Vernon by the Insurance Corporation of British Columbia (ICBC) to help seniors drive safely for longer. It includes making signs more visible, providing more left-turn bays, and refresher courses specially tailored for seniors. Dr. Tuokko noted there are a number of such initiatives, and it's important to collect data on whether they are effective.

Another stressed the importance of context and mentioned a TV presentation about seniors and driving that referred to public transit. This is irrelevant in her community, which has no public transit system. Care is also needed in media programs to avoid giving the impression that all seniors have a problem with driving. Dr. Tuokko agreed that these issues are especially important in rural areas, where there are no alternatives to driving.

A participant commented that it is not clear how cultural diversity issues are





addressed in IA-funded research. He noted the high percentage of seniors from visible minorities, especially in urban areas, who may have very different lifestyles and the need to ensure that research addresses their needs.

Another participant asked about causes of accidents and research on alternatives to driving, such as the growth in driving co-ops. She also commented that changes in health care delivery in BC have emphasized the need to drive in order to access health care. Dr. Tuokko said accidents involving older drivers generally don't involve other people; many are left-turn accidents. In terms of alternatives, she said it has been demonstrated in the US that driving co-ops work very well. Regarding the final comment, she noted the hope for national studies that will address geographical (urban/rural) issues and cultural diversity. Transportation also has an important link to mental health and other areas, so it must be ensured that policy-makers consider it as a factor in decisions.

## Breakout Session: British Columbia Research Priorities

Dr. Susan Crawford introduced the breakout sessions and their purpose. Participants were asked to break out into groups representing four geographic regions to identify priorities in health research on aging from a regional perspective. Each group reported its top items to the full plenary session for discussion.

## Lower Mainland

The following priorities were identified:

- Health supports leading to best practice, including policy. No long-term research exists, and there is a need to eliminate duplication in bureaucratic levels and disparities. Develop a definition for policy-makers to make a business case that addresses quality and cost effectiveness. Broaden the lens, especially in terms of health outcomes.
- A continuum of care. From the seniors' perspective, we need to know where we are now and what we need to do with the various stages, including independent living, home support, assisted living, long-term care, and end-of-life care. Look at "campus of care" attitudes and policies for facilitating this, as well as barriers related to effectiveness. Key questions include, "Who funds this? Should it be national, provincial or regional? Is there duplication?"
- Culture. We need to develop culturally based responses and communications into the health system. One example is the availability of interpreters. Look at cultural needs for things like hospital stays; they involve nutrition, religion, and activities.
- Mental health promotion from retirement to end of life. Fill the gaps that exist on fear, loneliness, and grieving and deal with misinformation—especially in the media.
- Training for GPs, family practitioners and other professionals on chronic disease self-management. This touches





on many other issues that were identified.

## BC Interior

The following priorities were identified:


- Evaluate research projects that have already been done, as well as research done but not implemented, and projects that have received long-term funding previously, in terms of the difference these have made. The information needs to get to policy-makers. It's also important to look at international studies.
- Housing needs to be affordable and adequate – it must be more than basic; it must be nice! This has important links to issues like depression. Look at issues raised by privatization, such as the need to have pleasant surroundings. Another key issue is the impact of having to leave home and community.
- The reduction of home care/home support. We're not doing well in terms of aging in place - how does this affect health status? Other key issues include the privatization of services (lack of quality control, extra costs and anxiety), over-reliance on volunteers and admission rates.
- Transportation. Lack of available public transport, as well as winter driving and large distances pose additional challenges.
- The network of health promotion programs. There is a need for a proactive approach and a way to let seniors help each other.

- This group also noted that poverty is a major issue that cuts across all of the above.

## Vancouver Island

The following priorities were identified:

- How to change the orientation of health professionals from drivers to partners in health care. Seniors want a partnership that allows them to explore available options and what works for them. Look at how to make that shift, both in philosophy and in practice.
- Access to health care was a big topic for seniors living in small and rural communities. Transportation is just one part of it; this issue also encompasses mobile health and support teams, resources, frailty, and costs.
- Education to help improve the understanding of aging (and to counter ageism). This requires education across the public domain to address discrimination, product orientation (the marketing of products like Botox instead of accepting people for who they are), and the need for more holistic approaches. The group discussed the role of the media and the culture of youth and how they frame people's thinking.
- How to provide meaningful supports to adults with developmental disabilities as they age. It's important to look at communities of interest that are struggling with aging populations that may be out of the mainstream. Very little has been done in this area of research.
- The impact that government policies



have had on seniors' access to health services – for example, access to physiotherapy, podiatry, etc. – that has been limited. People without financial resources are not getting the care they need, and it is important to look at the long-term impact of this.

## North

This group's facilitator, Dr. Andrew Wister, noted similarities in the research priorities identified by the four groups. Underlying themes include access, affordability, fairness, and the representation of cultural, social, and economic diversity. His group identified the following priorities:

- Seniors' participation and the consideration of their needs and demands in developing housing options. This includes the need for assisted living and multi-level care in all communities. In many communities, there is no access to certain types of housing. This means that seniors have to move, which creates a cascading set of problems.
- Increased access to specialty health services for seniors in rural and remote areas, taking into account cost and cultural barriers.
- Social isolation, vulnerability, and loneliness. There is a need for research on characteristics and the identification of risk factors and solutions to these problems. The group also discussed mental illness and elder abuse. Research doesn't always include all the determinants of health. The group stressed the importance of

connectedness and social support networks.

- The right to die with dignity (living wills, palliative care, advocacy, and related issues). Palliative care can be extremely cost-effective in relation to other types of care.
- Over-prescription of pharmaceuticals. There is a need to examine alternatives and to involve seniors and their families in approaches to treatment. Also needed is an emphasis on increased knowledge and more research that weighs the positive and negative effects of medications (with drug interactions as an obvious example).

## Discussion on Research Priorities Reports

With regard to the issue of over-prescription, a participant noted the high costs of some medical interventions, suggesting the need to expand the topic to include this. Dr. Wister acknowledged this, noting the discussion about the possibility of creating a two-tier system because of such expensive services.

Another participant echoed concerns about decreasing access to services like physiotherapy. Some seniors who can't afford to pay for physiotherapy end up taking more medication for pain.

A participant commented on the issue of over-prescription of pharmaceuticals, expressing concern that some seniors don't report drug interactions, or else the information is never collected and compared to research studies. She stressed



the need to educate seniors and doctors about this.

It was noted that the *Canada Health Act* does not cover pharmaceuticals, which are a major driver of rising health care costs. The participant saw a need for a federal position on prescription drugs to address differences between provinces and other issues such as high drug costs and over-prescription.

A participant asked if this group had discussed the need for research on policies. Dr. Wister said this was indeed discussed, and the point was made that policies may solve one problem and create others. Geraldine Hinton, who facilitated the Vancouver Island group, added that an issue that might be raised was, “Where is the research/policy interface?” What informs government policy? It should be the research and the evidence that inform policy, but that is not always true.

Another participant said that in her seniors’ building, social isolation seems to be voluntary, and this should be researched.

A participant asked who was doing this research and what was being done. Dr. Wister said one view is that people keep talking about these issues, and nothing ever gets done; another view is that the work ebbs and flows. For example, research done in the 70s led to the start of home care in Canada. Now new issues are arising that relate to implementation, such as training. We don’t do enough on evaluating policy and translating research

into action, he added. There is awareness of that among granting agencies, and we will see more of that work in the future.

A participant said affordable housing must be defined. What government considers affordable may not be what seniors think is affordable.

## **Seniors’ Panel: Seniors’ Engagement in Research for Healthier Communities**

**Moderator:** Dr. Linda Mealing, Assistant Director-Ottawa, CIHR Institute of Aging


**Panellists:** Mary Brown, Bev Christensen, Anne Hogan, Yvonne Kennedy and Lillian Zimmerman.

In explaining the purpose of the Seniors Panel part of the day’s program, Moderator Dr. Linda Mealing described CIHR’s move from a traditional research approach to a well-rounded approach that meaningfully involves key consumers, including the public, patients, policy-makers, health care professionals, and private companies. Dr. Mealing introduced the panellists and outlined their unique and diverse backgrounds, noting that they represented key consumers.

### **From Pain to Peace, Thanks to Research**

**Ms. Mary Brown, White Rock**

Ms. Mary Brown’s background includes training as an X-ray technician and managing a senior’s care home. Her



involvement with research began when she signed up for an arthritis self-management program to help her manage the pain of arthritis. She became involved in the project's advisory committee and moved on from there to roles in various research projects. In doing this, she came to realize the importance of having a voice for seniors in research projects.

Other projects that Ms. Brown has worked on include research on seniors' independence, the provincial Excellence in Health program on seniors' medication, a Seniors' Quality of Life project, and an Internet-based program for patients awaiting heart surgery. What is most important, in her view, is that such programs have legitimate health outcomes. Involving seniors in research projects offers benefits in terms of research design and personal benefits for the individuals involved. Seniors who are the focus of the research objective appreciate and display comfort in being interviewed by a peer senior.

### **Research for Change on Seniors' Issues in the North**

#### **Ms. Anne Hogan for Ms. Bev Christensen, Prince George**

Ms. Anne Hogan presented on behalf of Ms. Bev Christensen, who could not be present. She described Ms. Christensen's role in a regional project, sponsored by Health Canada and Veterans Affairs, on falls-prevention factors. Prince George has the highest per capita costs related to falls in the province. Province-wide,

falls among seniors add about \$1 billion annually to health care costs. The study did not fully explain the regional differences, but it did raise awareness of the issue, which led to direct benefits. The city established a pedestrian hazard reporting hotline that serves as a model for other communities and stepped up efforts to clear and sand sidewalks in areas most used by seniors.

Ms. Hogan listed some of the realities of being a volunteer in the research process provided through Ms. Christensen's experience. For example, organizers of research projects sometimes lack experience working with volunteers, and bureaucracy, accountability and confidentiality, which one learns are essential elements of process, can be difficult to understand at first. Overall, however, Ms. Christensen's emphasized that this type of engagement provided many benefits, and said she would repeat the experience with this project any day.

### **Guide to Care Facilities and Seniors' Housing in Prince George**

#### **Ms. Anne Hogan, Prince George**

Ms. Anne Hogan, who worked for 25 years in local government before her retirement, described how her interest in quality, affordable housing for seniors led her to undertake this volunteer research project. She realized there was a need to develop a guide to care facilities and seniors housing in Prince George for seniors and their families who would call the Seniors' Information Hotline in a





panic, looking for care or housing options.

Her research included site visits and detailed questionnaires covering large, publicly funded care facilities, seniors' housing sites, private supportive-living homes, rental apartments, and a single-room occupancy hotel. The project will be completed in May 2005. The information gathered will be useful for seniors and their families, for housing advocacy groups, for the Northern Health Authority, and for the operators of the buildings and facilities who are looking for seniors as tenants. Despite challenges, such as the tedium of filling in the questionnaires after each interview, the positive feedback has been enormously rewarding.

### **Community-based Research on the Relationship Between Abused Older Adults and the Criminal Justice System**

**Ms. Yvonne Kennedy, Kaleden**

Ms. Yvonne Kennedy, whose background is in nursing and health care, also managed a large intermediate-care facility. Following her retirement, she was volunteering in the office of the Public Guardian and Trustee when she was asked to participate in a research project to address the abuse of seniors. The project brought the community and the justice system together as partners to reduce older adults' fears of using the justice system, to ensure the system was meeting needs, and to improve the system's response to needs.

The project involved going out to communities and speaking with the police, with groups that work with seniors, and with groups of seniors. Volunteers asked each group the same questions so that they could compare the answers. They found that the police wanted to know more about how to work with vulnerable people and felt they needed more training.

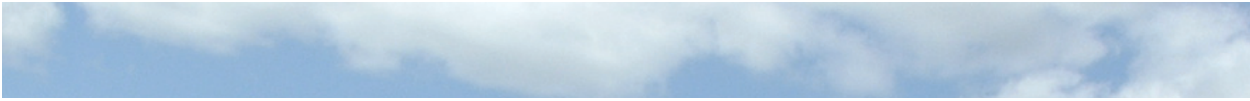
Older people were often very reluctant to get the police involved, either because they didn't trust the police or because they were not sure when it was appropriate to call them. Sometimes seniors don't realize that what is happening is criminal, or they don't want to air family problems, Ms. Kennedy noted. The study revealed much about the realities of abuse, which happens in every community and at every income level, and also about the many myths that persist. Elder abuse can lead to depression, and it often starts with minor neglect that eventually leads to the need for medical intervention.

One outcome was that creation of compact reference guide for the police that covered the guardianship legislation, designated agencies, and circumstances appropriate for making referrals.

### **Seniors' Community-based Research and Prospects for Influencing Policy**

**Ms. Lillian Zimmerman, Gerontology Research Centre, Simon Fraser University**

Ms. Lillian Zimmerman said her new career in gerontology was born from the depression that hit her when she was



forced to retire from a lifelong career in adult education. Realizing that most people don't read gerontology and other related scientific journals, she wanted to make the valuable information contained in these journals more accessible to a general audience, especially women. She is currently writing a book of advice for aging female baby boomers. As part of her research for the book, she set up five community-based focus groups to explore the perspectives of older women.

Ms. Zimmerman shared some facts and figures about poverty among older women, noting that older women are among Canada's poorest citizens. Families headed by a single female are similarly afflicted. This obviously has serious consequences in terms of health, leading to depression, poor mental health, and poor physical health. Addressing this requires changes to social policy, she noted. Changes to the public pension system have reduced the gap between male and female pension benefits, though it is still considerable. She emphasized that Policy-makers are susceptible to community pressure and as such there is an important task for seniors to undertake. Community-based research has a large role to play, and more is required on a number of issues facing seniors.

### Questions and Comments

A participant asked the panellists what happened when they presented their research to policy-makers and local health authorities. Did they feel it had a significant impact? Ms. Kennedy

said her research wasn't intended to influence policy-makers, though this was a very good question. Ms. Hogan said she thought the Prince George Council on Seniors could use her research to make a difference by lobbying for better housing and care. At a policy level, Ms. Christensen's work had already achieved some success in convincing the City Council to make changes. Ms. Zimmerman added that it's important to be persistent in pressing the issues. Even when all the information is there, it can take a lot of time to see results. Ms. Brown said her involvement is at a grassroots level, but in her experience, once people participate in research, it really changes their outlook.


A participant said that although research is important, many other factors also influence policy, so it can be very difficult to effect change. Even if you have great research, budget constraints may be an unsurpassable barrier.

Another asked if the panellists' questionnaires would be made available so that other communities can build on their work. Ms. Hogan said her sample questionnaires will be shared on the website along with the guide, so that others can use them. For more information, please refer to the Prince George Council of Seniors website at:

 <http://www.pgc.ca>

One participant described her involvement 10 years earlier with the Task Force on Seniors' Quality of Life that made 89 recommendations for changes. Many of those changes were implemented at the





time. Participants recently had a follow-up meeting with the current council and pointed out some of the changes that had not yet been implemented. The lesson is that you have to be patient and persistent to keep knocking on the door, she said.

Another participant said she had been involved since 1998 in research on abuse in the lives of older women. When they developed the pilot project on safety and support, they were strong advocates and had a good response, she said. It will now become an ongoing project. If the research is valid and strong, you need to follow up with advocacy, she stressed.

A participant commented on the different types of research and the frustration of seeing work that just sits on a shelf. Some small communities do action research, where they get a group together to tackle a specific problem, and the research is geared toward a project that they will do themselves.

Another said she was very interested in Ms. Hogan's project, which would be a powerful tool for the Seniors' Council. It's important that seniors be part of a project from the very beginning so that they take ownership, she said.

A participant said his group discussed volunteer burnout and the need for support from paid people. He asked the panellists what support they received. Ms. Brown said part of her work was paid and part was voluntary. Ms. Hogan said hers was a volunteer project. Ms. Kennedy said she was paid, but she became so

interested that she took the work further than it was funded. Ms. Zimmerman said the pension system doesn't take into account the volunteer work provided by family caregivers. There is a need to put an economic figure on the value of unpaid caregiving and housekeeping.

Another participant described the experience of his own seniors' organization developing a campaign that involved research and advocacy, noting that more details and tools for advocacy could be found on the website at:

 <http://www.vcn.bc.ca/srsnetbc>

A participant asked about the influence of baby boomers and whether there is awareness that they are going to face issues linked to aging. Ms. Zimmerman said many boomers don't identify themselves as such. Their tremendous impact on society has happened at an individual level, and they have never gotten together as a group to push for change.

Another participant noted that 80% of home care is given by family caregivers—mostly women and mostly employed. For many this means reducing work and, thus, fewer retirement benefits. Without changes, the future doesn't look great for these women. Ms. Zimmerman agreed, noting that these women are giving care at precisely the time that they need to be building savings for their retirement.



## Impressions of Day 1

Phyllis Bentley provided highlights of the day's program. She began by noting Ms. Christensen's experience in Prince George and the need to be patient and persistent, as some outcomes take longer than others to come to fruition. She touched on other highlights. Ms. Bentley remarked on the push for pension reforms and the need for flexibility. As well, although people in the North may get the same as other regions, because of their higher costs of living, the same amount doesn't go as far.

Ms. Bentley acknowledged that the day's activities clearly demonstrated a real need to be able to get together and talk about issues. In conjunction with this however, there is also a need for the professional skills to put our thoughts into words that can be addressed by research. She thanked participants for their valuable input and the lessons shared. Ms. Bentley also noted that a frequent complaint from those who participate in such focus groups is that seldom do the participants hear back from the organizers. If they do, often there are very few outcomes. The CIHR Institute of Aging does plan for future interactions and through partnerships with the participants will develop action and outcomes.

## The Aging Brain

**Dr. Max Cynader, Director of the Brain Research Centre, Vancouver Coastal Health Research Institute and the University of British Columbia.**

Understanding the nature of the processing performed by the cerebral cortex, especially the sensory cortices dealing with vision and audition, and on the neural and molecular mechanisms underlying the development and adaptability of the cortex lie at the heart of Dr. Cynader's research. Stating that the diseases and disorders of the aging brain pose the largest societal challenge of the twenty-first century, Dr. Cynader said that the work of the Brain Research Centre deserves to be better known, and he outlined the main areas of activity among its disciplines. Quipping that he had been urged to be practical by the workshop's organizers, he shared some of the questions being examined by the Brain Research Centre:

- Can we prevent the decline of memory and cognitive capacities that occur with aging?
- Can we better prevent and treat degenerative disorders?
- Can we promote wellness?
- Can we increase lifespan?




Dr. Cynader then listed the elements of the prescription for a long and healthy life:

- Genetic endowment, or choosing a good set of parents, is one of the chief indicators of longevity. Long-life runs in families. In the last decade, much has been learned about the human gene; we now know that there are 30,000 human genes, and advances in knowledge continue apace. Research is seeking the genes that control longevity.
- For men, income level on the day they retire is the best single predictor of longevity. Citing a study of British civil servants – which showed that senior staff enjoyed longer lives, followed by professional, clerical, and support staff – Dr. Cynader suggested that senior staff have someone to delegate their stress to, dealing with problems by making them somebody else’s problems.
- Outlining the elements of “fight or flight” (our stress response system), Dr. Cynader remarked that our responses to stressors are ancient and not necessarily suited to the types and duration of stress we often face in the modern environment. Briefly illustrating the connection between the brain’s stress responses and the body’s immune system, Dr. Cynader described the effect of stress on health and ultimately longevity.
- Overwhelming evidence in many species studied demonstrates that those who eat less will live longer. When lab rats were given 20% less food than a control group, they lived 20% longer; a relationship that holds true where rats given 40% less food, live 40% longer. Metabolic processes that are the result of metabolising food can be damaging to cells, ultimately affecting longevity.

One goal of the Brain Research Centre, stated Dr. Cynader, is to understand the molecular basis of the human gene. Molecular strategies include experiments into the genes over-expressed in the longer-living calorie-restricted animals.

The aging brain is influenced by the fact that both oxygen and glucose become, at a certain point, toxic to the body. By genetically manipulating DNA, studies can focus on factors that affect longevity and health. Alzheimer’s disease, now the fourth most common cause of death in an aging population, creates a major burden on society. Dr. Cynader outlined the physical changes of a brain with this condition, as demonstrated by deposits of amyloid core plaques. Within the Brain Research Centre, Dr. Yu Tian Wang, has demonstrated that mice genetically manipulated with the capacity to inhibit formation of amyloid plaque formation fare better than a control group.

Parkinson’s is a chronic, degenerative disease, which affects 100,000 people in Canada. Dr. Cynader outlined the processes underlying the disease and said that current treatment has focused on making the cells that have not yet died work harder. Although earlier experiments in Sweden using human fetal nigral transplant techniques have



note proven to be successful, current stem cell research represents a more sophisticated approach and shows promise.

“Run, do not walk to get treatment for stroke”, Dr. Cynader urged, emphasizing the critical importance of prompt care. While currently only 5% of those affected reach a stroke unit in time for effective treatment, on the horizon is a revolutionary new treatment involving the introduction of a viral vector into the brain that may buy a stroke victim several days to seek medical treatment.

Dr. Cynader ended his presentation with some good news: research now shows that we make new brain cells at any age and that physical exercise is a key way to enhance the process. The Brain Research Centre is trying to understand the underlying mechanisms at work.

Quoting Wayne Gretzky’s advice to skate where the puck is going to be, Dr. Cynader said we must all look ahead to where the problems are and try to find solutions. “It is”, said Dr. Cynader, “a wonderful time to be a scientist”.

### Questions and Comments

Asked about the relationship of oxygen toxicity to the value of physical exercise, Dr. Cynader stated that there is no evidence that exercise helps people live longer. However, he agreed that exercise, on balance, is a good idea, because it may help to lower other risk factors, such as high cholesterol and obesity.

A participant asked about the effect of environmental factors on Parkinson’s, saying that the disease had been shown to cluster in certain locations, or in one instance, as Dr. Cynader added, in a house where the occupants were not related to each other. Dr. Cynader pointed to the work of Susan Calne at the Brain Research Centre, who has been compiling data on Parkinson’s clusters in Canada.

Another participant questioned why some persons with Alzheimer’s disease degenerated quickly, while others proceeded at a slower pace. Dr. Cynader agreed that the disease could be idiosyncratic in its course and remarked on how little we yet know. There is evidence that certain strategies over a lifetime may protect against Alzheimer’s (e.g., people with university education are less affected by the disease). Research is needed to determine how these factors affect the primary disease processes.





## RSWR for the British Columbia Region:

**Day 2, March 31, 2005** ▶▶

Donelda Eve, Ministry of Health Services Government of British Columbia, briefly described the new toll-free Health and Seniors Information Hotline (1-800-465-4911 outside Victoria or 250-952-1742 in Victoria). Six staff answer calls and provide information on a wide range of programs and services for seniors.

### Research Themes and Projects in BC

**Dr. Lynn Beattie, Professor of Geriatric Medicine, UBC**

Dr. Lynn Beattie briefly outlined the aging research underway in BC along with her own work in this field, before describing the new BC Network for Aging Research (BCNAR).


Within the University of British Columbia (UBC), relevant developments include the new aging program at the Okanagan Campus and the expansion of the medical school to Victoria, both of which bring with them new people and resources. Aging research is also done in many departments across the Vancouver campus.

Simon Fraser University has a new academic Department of Gerontology and the well-established Gerontology Research Centre. Dr. Beattie also highlighted the impressive developments in aging

research at the University of Northern BC, and the important work is also underway at the University of Victoria, some of which was presented in Day 1 of the workshop.

Dr. Beattie's own research includes working as co-investigator and collaborator in several CIHR-funded projects, including the 10-year Canadian Study on Health and Aging (CSHA), launched in 1991 with \$5 million in CIHR funding. This project has produced a wealth of information on Alzheimer's disease (AD) that is still being followed-up. Related projects include a national study to measure quality of life for people with dementia or Alzheimer's disease; working with the Centre for Research on Personhood in Dementia, exploring how people deal with individuals with dementia; drug trials for treating dementia; and the use of neuro-imaging to learn more about parts of the brain that are affected in the development and progression of dementia and AD; and, with her colleagues, mentoring young researchers at the Division of Geriatric Medicine through the Geriatric Medicine Research Facilitation Group

In providing an overview of the BCNAR, Dr. Beattie noted that the vision is to be a visible, flexible, and useful "first source" network for individuals and organizations investing and participating in BC aging research. The network's mission



includes increasing capacity for aging research while transcending disciplines and encouraging creative ideas. Noting seniors' complaints that researchers never tell them anything and only use them as subjects, Dr. Beattie indicated that translating research knowledge and outcomes into action is seen as pivotal for BCNAR.

Several research clusters have been developed by BCNAR to address specific issues:

- Facilitating daily living, which included problems related to large urban centres and geography.
- Prevention was another cluster that covered fall prevention and ways to prevent or delay the onset of dementia.
- Senior's mental health and the need for timely and effective recognition and management,
- Utilizing health services,
- Balancing risk, and
- Understanding resilience.

Many organizations and initiatives represent potential linkages for BCNAR to pursue; these are opportunities just waiting to be harnessed, she commented. In outlining the network's structure, Dr. Beattie also advised participants that the network welcomes volunteers who wish to serve on the advisory committee.

Summing up, Dr. Beattie said BC has a number of research opportunities, many of which may be enhanced by collaboration. There are also important roles for BC researchers in national innovations

and national initiatives, such as the CHSA and the Canadian Longitudinal Study on Aging. The only requirement, she concluded, is having the will and the energy to do it all. She closed by suggesting the raven as a suitable symbol for the BCNAR. It represents many of the vital roles, qualities, and concepts that are relevant to the task ahead: trickster, creator, hero-benefactor, thought and memory, introspection and courage – all of which are needed for successful research in BC.

### Questions and Comments

A participant said research too often approaches aging as a disease, ignoring the importance of childhood influences, the role of environment, diet and other factors and focusing excessively on medical and science aspects while ignoring the arts.

Dr. Beattie replied that the network has tried to present some focus, because there is a need to start somewhere, but it is looking at aging as a topic, not a disease. Indeed, one physician complained that BCNAR focuses too much on the social and psychological aspects. She noted that the research underway at UBC includes looking at the genetics of successful aging and studying databases to get a better understanding of who gets the diseases that accompany aging and who doesn't. We don't want to equate aging with disease, but there are many diseases that are more likely to happen as we age, she said.





## Breakout Session Reporting: Ongoing Engagement Strategy

The purpose of this second breakout session was to identify how the Institute of Aging can continue to connect with older adults, organizations working with seniors, and service providers in BC and northern regions. The four groups, to which participants were randomly assigned, reported their top items to the full plenary session for discussion:

### Group #1

1. Hire a public relations firm to reach the public and seniors and to promote general awareness. Remember the value of community papers.
2. Build on existing networks and infrastructure. Examples of existing initiatives that one could piggyback on include national recreation and sports organizations (like the Canada Seniors Games) and the public library system. Ensure that there is someone representing seniors on the CIHR-IA Advisory Board.
3. Use volunteers, especially seniors, as knowledge brokers to get information to and from the community. Give them training and recognize the credibility they have in their communities.
4. Establish formal networks with regional health authorities, agencies, researchers, etc. One tool that could be used is holding small public forums. Face-to-face meetings are important. Establish a committee of seniors to provide guidance for this network. The

group also stressed the need to use a variety of devices, including Web-based tools and printed versions for those who don't have Internet access.

A final point related to the use of the term "senior." We tend to talk in terms of youth, adults, and seniors, but seniors are still adults. Perhaps they should be identified by interest instead. The importance of a multicultural lens was also stressed.


### Discussion

A participant noted the suggestion to hire a public relations firm and suggested that this be extended to addressing stereotypical images in the media, perhaps to provide a media watch service. She cited the inappropriate remarks of a well-known local columnist who wrote that he was not looking forward to living near "Geezerville."

Regarding networks in Priority #4, a participant noted that other critical partners included post-secondary institutions. The group also discussed other potential partners, such as physicians.

### Group #2

1. The IA should commit to taking the top two issues, developing a pilot project for BC, issuing a call for research projects to address these issues and thereby turning them into action.
2. Information should be distributed through local seniors' associations, and perhaps through the internet,



but it must be specific. Regional organizations include the Seniors' Network of BC and the Council of Senior Citizens Organizations (COSCO). Look at how to get the most out of it and how to get the ripple effect.

3. Facilitate feedback (for example, conduct focus groups to feed into regional groups) and acknowledge the input given by seniors. It's important to demonstrate action and to find ways that seniors in our own region can work with CIHR. Open doors for seniors and their organizations to submit ideas for research.
4. Research is needed on how to communicate with seniors' groups.
5. Emphasis is needed on cross-cultural, multicultural and Aboriginal needs and challenges.

The group also noted that communication in the north would be enhanced with videoconferencing, to draw in more seniors and rural residents and to give them information and get their feedback on projects.

## Discussion

Regarding Priority #2, a participant stressed the need to better define where information originates, to ensure that it is credible.


Another participant said there is a lot of emphasis on communicating with groups, but many seniors do not belong to groups, so there must be ways to reach individual seniors as well.

## Group #3

1. Identify a communications person within organizations and establish a contact person for each region with an emphasis on two-way communication, especially in regional or ethnically diverse communities.
2. Hold meetings outside the Lower Mainland.
3. Identify an Institute person who can build a greater and broader use of the media (all forms, multiple languages) to improve the dissemination of information; including ongoing evaluation of the effectiveness of various media and the need for duplicate media for those not accessed by one form (e.g. internet). Ensure that the information is tailored to the audience.
4. Emphasize the kinds of information that seniors want to know, such as health, research, nutrition, social groups, and ways to keep busy and active. How can we foster inter-group communication?

## Group #4

1. Use radio, existing newsletters, free papers, local TV, and community access cable programs. Provide question and answer sections in newsletters, using a variety of writers, or short layperson summaries of academic publications.
2. Use seniors' events more effectively, for example, sewing shows, health fairs, and seniors' events at local recreation centres.

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3. Establish a speakers' bureau with individuals from the IA who can go out to speak to communities and existing groups like the Elder Friendly Community in Victoria.
  4. Use Internet communications, for example, a website where seniors can communicate with the IA and the CIHR and where these organizations can communicate back.
  5. Develop a follow-up strategy for these workshops. (The group felt that something valuable was happening here through networking and information sharing and did not want to lose the momentum. They proposed meeting in a year to discuss new ideas and their development and to appoint coordinators who could provide ongoing follow up.)

## Discussion

A participant asked if seniors could join IA listserv to keep abreast of research. Dr. Crawford explained that the current listserv is used mostly to share information on research funding opportunities, so this information would not be very valuable to this group. She added that the Institute was hearing loud and clear the message about the need to create information modes and material that is appropriate to this group, including seniors and care providers.

Another participant referred to the mention of community contacts in Priority #1, saying it should be clarified that the local person or agency should identify the radio or newspaper to be used. In

response, it was noted that the Institute has the original, detailed notes submitted by each group and that institute staff would be referencing those notes directly in the follow-up stage.

## The Knowledge Exchange Task Force


**Ms. Flora Dell, Chair of the Knowledge Exchange Task Force (KETF),**

CIHR-Institute of Musculoskeletal Health and Arthritis (IMHA)

Ms. Dell began by reminding participants of the value of health research and the CIHR institutes. As a large network linking researchers and stakeholders across Canada, the institutes play a key role in identifying emerging health needs and key research priorities, as well as communicating research findings and raising awareness about health research in Canada.

Outlining the three strategic research priorities of IMHA (tissue injury, repair, and replacement; physical activity, mobility, and health; and pain, disability, and chronic diseases), Ms. Dell indicated the urgent need for research in this field. Musculoskeletal diseases and conditions cost Canadians \$16.4 billion every year, the second highest cost of disease after heart disease.

The Institute's Knowledge Exchange Task Force (KETF) aims to accelerate the pace of knowledge translation and exchange



among researchers, stakeholders, and partner communities. Distinguishing between research knowledge transfer and research knowledge exchange, Ms Dell pointed to the former as being the interpretation of research into lay language to facilitate the understanding, value, and benefits research to the end-user. In the latter, the end-user becomes an active research partner in the promotion and implementation of the research. Ms. Dell stated that this process contributed to a “feeling of empowerment,” to borrow Dr. Patrick McGowan’s phrase.

Within the KETF model, researchers must interpret their work to the task force in clear and concise language. Research ambassadors help to build and support the vital two-way communication between researchers and task force members. These ambassadors may also develop opportunities to promote research findings with peers, organizations, and the community. Knowledge exchange will enable citizens to make informed personal medical decisions based on scientific research.

Ms. Dell concluded her presentation by acknowledging the IMHA Project Lead, Ms. Elizabeth Robson, the KETF members, as well as the IA staff, for their help.

### Questions and Comments

Concerning the definition of research knowledge exchange, a participant remarked that the statement about the end-user becoming an active research partner in the promotion and

implementation of the research and its conclusions left out how the issue of feedback to the institute would be delivered. Ms. Dell responded by saying that it part of the KETF project is to determine how this is best accomplished.


## The Canadian Longitudinal Study on Aging

**Dr. Parminder Raina, Associate Professor, McMaster University.**

Drs. Raina, Susan Kirkland of Dalhousie University, and Christina Wolfson of McGill University make up the Principal Investigator Triumvirate of the Canadian Longitudinal Study on Aging (CLSA). The CLSA is one component of the Canadian Lifelong Health Initiative (a strategic initiative of CIHR). The other is the Canadian National Birth Cohort. Researchers are determining if these studies can be brought together.

The mandate of the CLSA is to form an understanding of the complexity of aging and health through interdisciplinary research. Dr. Raina indicated the average Canadian’s life expectancy increased to 79 in 1999 from 75 in 1980. In two decades, 20% of Canadians will be 65 or older, compared to 12% in 2000. The first baby boomers will be turning 65 in 2011, creating different expectations from government and society. The evidence-base for decision-making will be an urgent need.





As its conceptual framework, the CLSA will examine aging as a dynamic process and emphasize healthy/successful aging. It will be important to delineate what is “normal” in the aging process (primary aging) and where susceptibility to disease (secondary aging) enters in. Genes, nutrition, lifestyle, environment, and chance all play a role in aging, but are typically studied in isolation. In determining how these factors interrelate, the innovative study design offered by the CLSA will advance knowledge of aging and health, as well as inform health and social policy.


It will be, said Dr. Raina, the largest study of its kind. The study will address issues of physical, psychological, and social health, as well as biology, behaviours, and health services. Research will range from issues such as chronic diseases to everyday competence to transitions from work to retirement. Information will be collected about metabolic markers of aging, such as abnormal glucose as well as areas such as nutrition, physical activity, alcohol and tobacco use, and sleep. Researchers will investigate medications, institutional care and home care, and will look at quality of life and pain issues.

Who will participate in the CLSA? A 20-year study in which 50,000 people (women and men 40 and older) will take part, there will be repeated measurement every three years (more frequently, after the age of 80). The active data collection will include individual interviews and examinations, whereas the passive data collection will focus on topics such as

mortality, climate, and neighbourhood characteristics. Dr. Raina stated that it will be a very transparent process. Indeed, ethical, privacy, and confidentiality issues in the CLSA will be put under intense scrutiny. There are difficult questions to resolve, such as the legal implications of the capacity to consent. If cell lines are taken from biological samples, for example, who owns them? If information is commercialized, what are the implications?


The CLSA will make a difference in the lives of Canadians, because it will provide new knowledge about health and aging; identify ways to prevent disease; and adopt sound research into practice, programs, and policies. As well, the CLSA will provide opportunities for researchers, in Canada and around the world; create recognition of Canada’s position as a leader in health care research; and stimulate the economy through discovery and innovation. Raina said the CLSA will provide a platform available to researchers and others for years and will put Canada on the international map in studies in gerontology.

Apart from the Principal Investigator Triumvirate, there are 180 co-investigators on the research team, representing 26 universities across Canada (and all 10 provinces). The CIHR has also struck a special committee to address ethical, legal, and social issues associated with the CLSA. Dr. Raina praised the CIHR’s support for the CLSA, mentioning Dr. Anne Martin-Matthews, Dr. Alan Bernstein, the CIHR Governing Council,



and all the institutes. Dr. Raina cautioned that the CLSA is not yet a “done deal.” Seed funding has come from the CIHR, but the CLSA is too large a project for any one funding agency. The proposal will soon be taken to the Federal Cabinet with a request for full support.

The proposed CLSA launch date is 2008, with initial data results envisaged by 2010. Raina invited participants to visit the CLSA website at

 <http://www.fhs.mcmaster.ca/clsa> or to email him at [praina@mcmaster.ca](mailto:praina@mcmaster.ca) for information.

### Questions and Comments

Asked whether the 50,000 participants in the study would come from all places and circumstances, including care facilities, Dr. Raina said that a decision had been taken that those already in a care facility would not be selected. However, studies would be conducted as people underwent the transition of moving into care. The questioner added that it was important that the quality of environment of profit versus not-for-profit care facilities be studied.

A participant asked whether the 50,000 respondents would be split equally between men and women or whether they would reflect the proportionate gender statistics in Canada. Dr. Raina replied that it would reflect the latter, depending on factors such as age groupings. Status such as married or single would also be taken into consideration. Asked whether 50,000 was a large enough sample, Dr.

Raina replied that the numbers will dictate what can be studied; whereas it will not be possible to focus on all aspects of cancer, glucose profiles will be well represented by 50,000 people. The study, Dr. Raina said, must be very flexible, to reflect changes in public policy that will take place in the course of 20 years.

Another participant asked whether the CLSA would focus on quantitative data as opposed to qualitative. Where, for instance, do the arts fit into the study? Dr. Raina replied that there will be many partners in the project; discussions have taken place with the National Film Board about filming a series along the lines of the British TV production *Seven Up*. Asked if qualitative results can be considered evidence-based, Dr. Raina also said they are used all the time at McMaster to contextualize quantitative evidence.

In response to a query about the study’s cost, Dr. Raina replied that each of three-year waves has been projected to cost between \$10 million and \$20 million; while it sounds like a lot of money, the CLSA will be cost-effective in that many studies will be conducted at the same time.

Another participant was concerned that homeless persons may be excluded. Dr. Raina replied that the CLSA will not be able to capture every population within Canada. For instance, Aboriginals have not been included in the CLSA, because different methodologies need to be employed to accurately reflect that group.





The final questioner wondered if participants would be added to the original 50,000 as the study progressed over 20 years. Dr. Raina replied that they would not.

## Closing Remarks

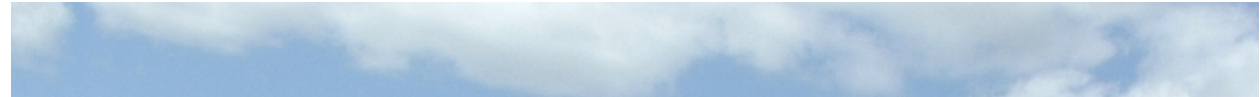
Dr. Susan Crawford, Assistant Director, Vancouver, reviewed the objectives of the Regional Seniors' Workshops. She stated that throughout the two-day session in Vancouver, organizers had heard participants' wishes to continue the dialogue in meaningful ways after the workshop and had promised that it would be provided by collating and distributing the information collected at the sessions and by a summarized version of the workshop. Dr. Crawford said that the British Columbia workshop had provided insights into issues unique to the region, e.g., health care access, particularly to specialists, and northern isolation (both in terms of transportation and social connectedness). British Columbia shares concerns with other regions of the country, such as recognition of the need for policy research, right to die and living will issues, the housing-care continuum, and transportation. Dr. Crawford added that ageism had also emerged as an issue and that questions about the workshop's use of the word "seniors" had been noted.

The workshop enabled participants to become familiar with some of the research projects on aging in BC, through presentations ranging from *The Aging Brain* to *Research Issues, Themes and Projects*, and to learn more about the Canadian Longitudinal Study on Aging (CLSA) in which BC researchers, in common with those in other provinces, are taking part.

Referring to the question of why taking an active role in research programs is important, Dr. Crawford stated, "We hope that the Seniors' Panel on Day 1 gave inspiration." On that panel, four representatives from around BC offered their perspectives of their work in participating in or designing research studies about real aging issues.

Dr. Crawford noted that Dr. Parminder Raina, in his presentation on the CLSA, had dwelt on ethical considerations – also a topic of critical importance to other research studies across the country.

British Columbia is the third location to hold a regional workshop; Ontario's turn comes next in the fall of 2005, followed by Québec in the spring of 2006. A special strategy is being planned for the North Region. A final report on the regional workshops is anticipated for the spring of 2006.



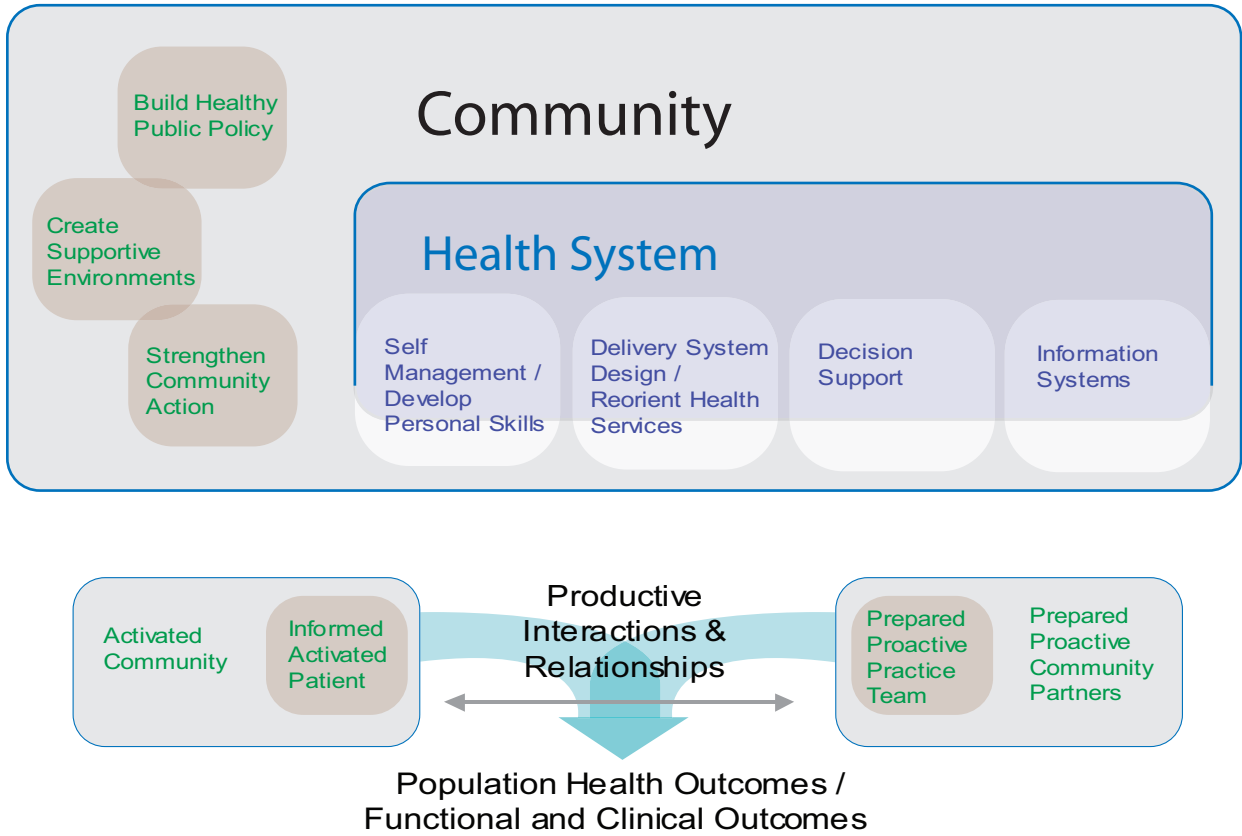
Dr. Crawford also stated that as the series of regional workshops continues, “we will be starting to formulate a ‘what-are-we-going-to-do-about-it’ strategy” to better connect the IA with seniors, seniors’ organizations, and service providers.

Dr. Linda Mealing, Assistant Director-Ottawa, thanked all participants for their input. She also thanked Ms. Phyllis Bentley, Co-Chair of the Regional Implementation Committee, for “ably guiding us through the process,” and paid tribute to the work of the national organizing committee. Dr. Mealing reminded participants that the first meeting of the organizing committee was held in July 2003. In each region, the IA relies heavily on the knowledge and dedication of regional implementation volunteers. Before formally closing the workshop, Dr. Mealing acknowledged, on behalf of the Institute of Aging, the generosity of the sponsorship contributions of the following organizations in supporting the 2005 BC Regional Seniors’ Workshop on Research:

- Canadian Nurses Foundation
- CIHR External Relations Branch
- CIHR Institute of Health Services and Policy Research
- CIHR Institute of Musculoskeletal Health and Arthritis
- CIHR Knowledge Translation Branch
- Ministry of Health Services of the Government of British Columbia

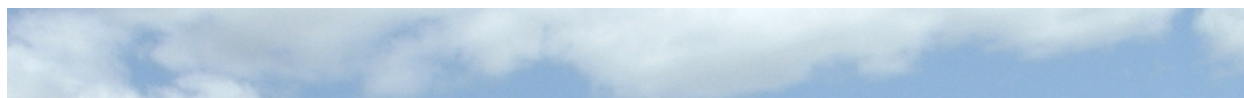


**FIGURE 1**  
THE EXPANDED CHRONIC CARE MODEL:  
INTEGRATING POPULATION HEALTH PROMOTION



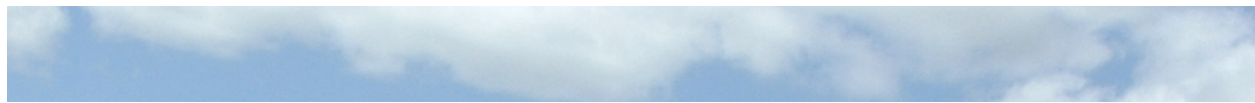
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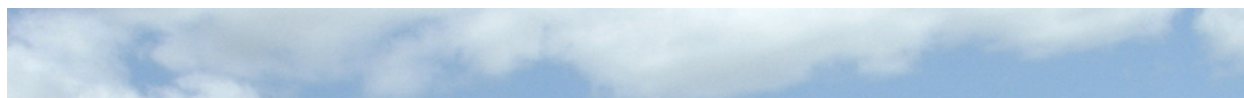


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## Annex B: British Columbia Regional Implementation Committee Members

- **Phyllis Bentley**, Penticton, Co-Chair
- **Lorna Hillman**, MA, Co- Chair
- **Lillian Baaske**, Acting Manager, Adult Health, Health Canada, REGIONAL OFFICE
- **Susan Crawford**, Assistant Director-Vancouver, Institute of Aging
- **Lois Edgar**, Media Relations Officer, Centre on Aging University of Victoria
- **Tessa Graham**, Director & Special Advisor Women and Seniors Health, Ministry of Health Planning
- **Joan Reichardt**, Nelson
- **Ruth Schiller**, National Advisory Council on Aging
- **Margaret Reilly**, Penticton
- **Donelda Eve**, Children, Women's and Seniors' Health, Ministry of Health Services Government of British Columbia
- **Sophie Rosa**, Institute of Aging, Project Officer



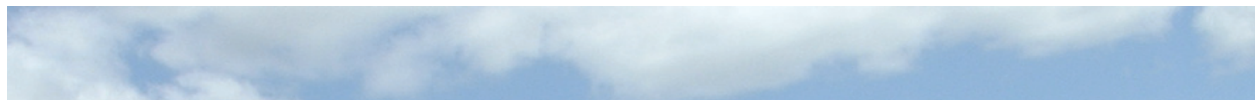
## Annex C: National Organizing Committee Members

- **Anne Martin-Matthews**, Chair, Scientific Director, Institute of Aging
- **Flora Dell**, former Provincial Consultant for Special Populations in the New Brunswick Provincial Government
- **Elizabeth Esteves**, Ontario Seniors' Secretariat, Ministry of Citizenship, Government of Ontario • representative of Federal-Provincial-Territorial Committee of Senior's Officials
- **Sheila Laidlaw**, Retired, former Head of University of New Brunswick Libraries, and Institute of Aging Advisor Board member
- **Barry McPherson**, Wilfrid Laurier University, President, Canadian Association of Gerontology
- **Linda Mealing**, Assistant Director, Partnerships, Institute of Aging
- **Louise Plouffe**, Manager, Knowledge Development, Division of Aging and Seniors, Health Canada
- **Patricia Raymaker**, National Advisory Council on Aging (Chair)
- **Jean-Guy Soulière**, Coordinating Committee of the National Congress of Seniors' Organizations • (Chair)
- **Sophie Rosa**, Communications Officer, Institute of Aging

## Annex D: Facilitators and Speakers

### Facilitators (for contact information, refer to Annex A)

- **Dr. Andrew Wister**
- **Ms. Geraldine Hinton**
- **Ms. Kathryn Andrews-Clay**
- **Dr. Norm O'Rourke**
- **Mr. Rae Westcott**

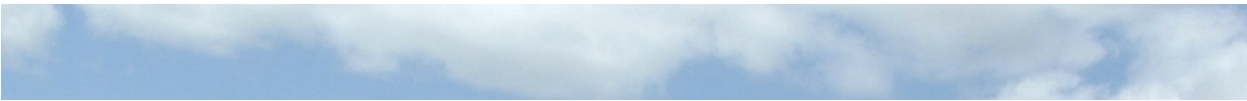


## Speakers

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<b>Dr. Parminder Raina</b>	Associate Professor Clinical Epidemiology and Biostats McMaster University	praina@mcmaster.ca	905-525-9140

## Annex E: Institute of Aging - Institute Advisory Board Members

- **Dorothy Pringle (Chair)**, University of Toronto
- **Howard Bergman**, McGill University
- **Phillip Clark**, University of Rhode Island
- **Max Cynader**, University of British Columbia (appointed September 2004)
- **Geoffrey R. Fernie**, Toronto Rehabilitation Institute
- **Yves Joannette**, Institut universitaire de gériatrie de Montréal
- **Janice Keefe**, Mount Saint Vincent University
- **Daniel Lai**, University of Calgary
- **Sonia Lupien**, Douglas Hospital Research Centre, McGill University
- **Mary Ellen Parker**, Alzheimer Society of London and Middlesex
- **Louise Plouffe**, Division of Aging and Seniors, Health Canada



- **Douglas Rapelje**, Welland, Ontario, Consultant (appointed September 2004)
- **Karl T. Riabowol**, University of Calgary
- **Kenneth Rockwood**, Centre for Health Care of the Elderly, Dalhousie University
- **Jane Rylett**, Robarts Research Institute, London
- **Huber Warner**, U.S. National Institute on Aging (appointed September 2004)
- **Betty Havens**, University of Manitoba (2001-2004)
- **Sheila Laidlaw**, former Head of the University of New Brunswick Libraries (2001-2004)
- **Graydon Meneilly**, University of British Columbia (2001-2004)

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