Regional Seniors' Workshop on Research for Quebec

Montreal, Quebec, April 27–28, 2006

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Executive Summary

The Institute of Aging of the Canadian Institutes of Health Research (CIHR) was pleased to present the Regional Seniors' Workshop on Research for Quebec in Montreal, on April 27 and 28, 2006. This, the 5th Regional Seniors' Workshop on Research was the final in a series hosted across Canada. Select participants from throughout Quebec were invited to this important two-day event. All workshops aimed 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. In Ontario and Quebec, other sectors of the community were also included, namely practitioners, non-governmental organizations, policy makers, and researchers.

The Institute of Aging had a number of goals for the Quebec workshop:

- 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 Quebec.
- To increase participants' understanding of the perspectives and expertise of different sectors.
- 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 increase participants' commitment to research on aging through planned engagements, participation and support of research on aging.

The Regional Seniors' Workshop on Research for Quebec offered participants a range of presentations designed to inform them about the research process and the various research initiatives on aging in the province. Other topics included the Canadian Longitudinal Study on Aging.

Among the networking activities, participants of the Regional Seniors' Workshop on Research for Quebec took part in two breakout sessions. The first allowed participants grouped by sector to express their views on which health or social issues should be priorities in research on aging. Issues common to all sectors were as follows:

- Social factors
- Mental health

- Mobility
- Health care services
- Socioeconomic factors

In the second breakout session, participants were asked to probe deeper into the issues that were agreed to be common priorities across the different sectors through the first breakout discussions. They were asked to provide specific statements, ideas, and/or research questions on the issues, in order to guide the Institute of Aging in its future selection of priorities.

Through the hard work of all involved, the Regional Seniors' Workshop on Research for Quebec succeeded in realizing its objectives. This two-day exchange shed new light on regional and sectoral 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 - July 2006

In 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 ongoing consultative process, information on these gaps and concerns is being 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, as well as 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 provinces in November 2004 in Halifax. The third, covering the British Columbian and northern Canadian communities, was held in Vancouver in March 2005. And the fourth brought together participants from Ontario and was held in Toronto in November 2005.

Representatives from all over Quebec took part in this fifth Regional Seniors' Workshop on Research in Montreal on April 27 and 28, 2006. Over 40 seniors, members of seniors' organizations, advocates, practitioners, non-governmental organizations, policy makers, and researchers who work on seniors' issues, participated in this two-day event.

On behalf of the National Organizing Committee, the Chair of the Quebec workshop and the Institute of Aging, I am pleased to present the Proceedings of the Regional Seniors' Workshop on Research for Quebec. Committee members and CIHR 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

Overview of Regional Seniors' Workshops 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) has held a series of Regional Seniors' Workshops on Research (RSWR) across Canada. The IA wanted to hear seniors' views with respect to needs and priorities for research on aging in Canada. The IA also desired to connect with Canadian seniors, seniors' organizations and service providers, and find ways to stay connected. Regional workshops were designed to be active, interactive and relevant to older adults and those who work with them.

Participants

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

As the regional workshops progressed over the course of 2004 and 2005, it became apparent that including other sectors would offer participants a greater opportunity for knowledge exchange on issues of importance to seniors. For the fourth (Ontario) and fifth (Quebec) workshop, in addition to seniors, sectors working with or serving older adults were invited to participate, specifically: practitioners, non-governmental organizations, policy makers, and researchers.

Objectives of the RSWR

The RSWR strived 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.
- To increase participants' understanding of the perspectives of different sectors.

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: Perspectives on Priorities in Research on Aging

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

Breakout Session #2a: Developing an Ongoing Engagement Strategy

The purpose of this session was 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. In reviewing the input received from three diverse Canadian regions through the three earliest workshops (Prairies, Atlantic, and British Columbia), the Institute of Aging felt that this objective had been met.

Breakout Session #2b: Specifying the Priorities

The purpose of this session was to probe deeper into the issues agreed to be common priorities across different sectors following the Breakout Session I; the primary outcome being the key research questions and knowledge translation proposals related to the priority. These would guide the Institute of Aging in its future development of strategic programs. This approach was used for the Ontario and Quebec Regional Workshops.

RSWR for Quebec: Day 1, April 27, 2006

Word of Welcome

Dr. Anne Martin Matthews, Scientific Director, Institute of Aging, and Jean-Guy Saint-Gelais, Program Chair and President of La Conférence des Tables régionales de concertation des aînés.

The Chair of the Program, Jean-Guy Saint-Gelais, opened the Regional Seniors' Workshop on Research (RSWR) for Quebec by welcoming its participants to Montreal. In May 2003, the Institute of Aging of the Canadian Institutes of Health Research (CIHR) held a National Seniors' Forum for Research. At the request of its participants, the IA created the Regional Seniors' Workshops on Research (RSWRs). The purpose of this broad, country-wide IA survey is to help set needs and priorities for research on aging over the next five years.

The last of the five regional workshops is the only one of the five to be held almost entirely in French. Forty-six persons were selected from a list of nominees submitted by the Regional Consultants (Annex B) to participate in this workshop by reason of their expertise and interest in aging and seniors issues. Seventeen Quebec regional roundtables (*les Tables* representing seniors' associations within each of the 17 Quebec administrative regions and together composing the Conférence des Tables régionales de concertation des aînés) and the President of the Conférence were consulted in this selection process.

"This workshop," Dr. Anne Martin-Matthews said, "has been organized with the goal to better serve seniors by recognizing the needs of seniors." She also highlighted the importance of organizing a well-rounded workshop by ensuring that seniors, seniors organizations, researchers, non-governmental organizations, governmental policy makers, as well as health-care practitioners, were all given the opportunity to contribute.

Presentation: It's Time for Research on Aging

Dr. Anne Martin-Matthews, Ph.D., Scientific Director, Institute of Aging and Professor of Family Studies at the School of Social Work and Family Studies at the University of British Columbia

Dr. Martin-Matthews began by apologizing for having to speak in English, as her French is still very basic. French-language slides enabled participants to follow her presentation. She began with an overview of the Canadian Institutes of Health Research.

The Canadian Institutes of Health Research (CIHR) is Canada's major health research agency. Launched in 2000, the CIHR supports over 10 000 research projects at various universities, teaching hospitals, and research facilities.

The CIHR is a federally funded institution, rather than an advocacy organization;

dispersing funds to support research projects and programs around the country, using a multidisciplinary approach. As a federal organization, the CIHR supports research that meets the highest international standards. "As part of CIHR, the IA has a daunting mandate," said Dr. Martin-Matthews, "in ensuring that our initiatives and the research IA supports improves the life of older adults."

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.

CIHR's work is guided by four broad themes that reflect the broad 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)

"Cooperation, partnership and excellence", Dr. Martin-Matthews 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. A total of 13 Institutes within CIHR address domains of health research of immediate and identifiable importance to Canadians. They are each headed by a Scientific Director and guided by an Institute Advisory Board consisting of volunteers from all parts of the health community" (current Board Members of CIHR-IA are listed in Annex E). Dr. Martin-Matthews used the analogy of a jigsaw puzzle to describe the CIHR. There are 13 equally important pieces in the CIHR puzzle. Each separate Institute has its own scientific director and works independently, yet it simultaneously depends on the other institutes. The CIHR 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

Dr. Martin-Matthews outlined the role of CIHR-IA within the CIHR organization, "People have coveted longevity and youthfulness since the beginning of time. The "fountain of youth" is not a modern-day creation. Most women live for an average of 20 years beyond the age of 65; men live an average of 16 years beyond that age. While most of those years over 65 are spent in relatively good health, a portion of them will be spent with some form of disability. The goal of the research supported by CIHR-IA is not simply to extend lifespan, but also to extend quality of life, i.e., to reduce the amount of time that people live with disabilities, be they cognitive, biological, or functional impairments."

"The Institute of Aging," said Dr. Martin-Matthews, "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:

- 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; and
- 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 maintenance of functional autonomy.
- Cognitive impairment in aging;
- Health services and policies relating to older people.

The Institute funds new researchers, supports training through awards and large training programs. It also supports planning and development activities as well as pilot projects that lead to full research programs.

The objective is to ultimately improve the health of Canadians, to help make services and products more effective and to bridge the gap between health researchers and end-users of research."

According to Dr. Martin-Matthews, Quebec has reknowned health research institutes focusing on seniors and aging. "It is here in Quebec", she added, "that Canadian research in this area had its start and has flourished."

Presentation: Research on Aging in Quebec

Dr. Yves Joannette, Research Director, *Institut universitaire de gériatrie de Montréal* (IUGM); Professor at the Faculty of Medicine, Université de Montréal; Researcher at the IUGM's Research Centre

Dr. Joannette expressed his pride in all the research on aging that has been done in Quebec and provided an overview of this research.

An estimated 36% of Canadian research on aging is conducted in Quebec. This is an impressive proportion and helps Quebec serve as a true melting pot for various kinds of research in this field.

Many different basic biomedical research projects are underway as well as projects in clinical research, work on systems and services for seniors, and research on social aspects of health and aging. Numerous areas of expertise contribute to research on aging: biology, biomedical science, geriatrics, nutrition, psychology, sociology, and even geography and architecture. Dr. Joannette emphasized that the study of aging is complex and must not be limited to traditional disciplines.

The FRSQ (*Fonds de la recherche en santé du Québec*) is also making research on aging one of its priorities. The FRSQ is building bridges between researchers, disciplines and research centres; bringing together nineteen centres, two of which conduct research on aging. FRSQ also supports 15 networks, one of which focuses on aging.

Quite a few major projects in Quebec harmonize with IA priorities:

- The Vieillir en santé [healthy and successful aging] project (NuAge project);
- A study on the impact of physical activity on memory;
- A research project on seniors and mental health;
- A study on biological mechanisms of aging;
- Studies on cognitive disorders;
- Research on maintenance of autonomy;
- A research project on autonomy in seniors;
- The PRISMA and SOLIDAGE projects (integrating and evaluating programs dealing in health promotion, prevention and health maintenance);
- Social-based research (violence towards seniors, etc.).

Dr. Joannette emphasized the need to increase the number of researchers on aging and the capacity to attract and train new researchers. A Quebec-led initiative is making efforts to address this need, the FORMSAV project (*Formation interdisciplinaire en recherche sur la santé et le vieillissement* [interdisciplinary training in research on health and aging]). He also spoke of another novel Quebec organization, the *Observatoire vieillissement et société* [observatory on aging and society], a forum aiming to promote reflection as well as individual

and collective decision-making on the challenges arising from aging. He ended by reminding his listeners that our primary objective is to age well.

Report on Breakout Session I: Sector Perspectives on Priorities in Research on Aging

The aim of the first breakout session was to determine Quebec's priorities for research on aging. Delegates broke into groups by different sector (seniors, non-governmental organizations, practitioners, policy makers, and researchers) to discuss and prioritize health issues related to research on aging. Each group reported on its top five priority research items to the full plenary session for discussion. Conference delegates were then asked to agree on the 5 or 6 issues that were common across the sectors. The outcome follows.

Group 1: Seniors (green)

The Facilitator explained that his group's reflections were highly practical, with the viewpoints being those of people with first-hand experience as seniors. He mentioned that his group had had no trouble pinpointing priorities: it was a matter of simple good sense.

1. **Isolation**: all seniors feel isolated, even those who do not admit it.
2. **Mobility** (indoors and outdoors): to enable seniors to stay in their own communities.
3. **Home support**: the government should invest more in home care. The longer older people stay at home, the better it is for their wellbeing, the government, and society.
4. **Family caregivers**: requirements must be clarified and awareness created among the younger generation (e.g., baby boomers) so that they will take care of their parents.

Group 2: Seniors (red)

This group's Facilitator mentioned that her group had just one collective priority to highlight for research on health and aging: the social aspect.

1. We must identify and use as a basis for reflection, the **societal values** regarding seniors; including not only existing and emerging values, but also those that are disappearing.
2. A portrait must be made of the **socioeconomic contribution** made by seniors if we wish to obtain an accurate picture of seniors in society.
3. We need a better understanding of the effects of **age discrimination** on seniors' health.
4. We need to be more familiar with how seniors see themselves (**self image**).
5. We need to understand the relationship between **spirituality** and health in seniors.

Group 3: Representatives of non-governmental organizations

This group listed the following priorities:

1. Assessing **morbidity, mortality, solitude and isolation**: with the decrease in number of family members, there are fewer and fewer people to take care of seniors.
2. Creating a Committee on **ethics and values**: giving serious thought to seniors, as individuals and as a group.
3. Inspiring **motivation with regard to mobility** (autonomy and quality of life); e.g., encouraging young people to study in this field, popularizing technology, and making HLMs (*habitations à loyer modique* [social housing]) wheelchair accessible.
4. Increasing the **link between research and reality**, e.g., in matters of nutrition, physical activity, current programs and overmedication.

Group 4: Practitioners

The Facilitator pointed out that the following priorities were not in order of importance:

1. **Age discrimination**: we must think about society's image of older adults, both in the job market and in laws and policies. Age discrimination has impacts and must be prevented.
2. **Psychological health**: we must investigate the role of factors such as stress, overmedication, abuse, addiction, social development, morbidity, seniors' low income.
3. **Cognition - dementia and other disorders**: we must evaluate approaches to care and measures taken by the existing services.
4. **Service organization and delivery**: evaluate existing services and identify gaps.
5. **Home support**: housing quantity and quality, experience of the caregivers. Major distinctions must be made between daily care and end-of-life care.
6. **Mobility**: encourage seniors to exercise; improve transportation services.

Group 5: Policy makers

1. Foster **conditions for aging well**: perhaps today's seniors will cost more, but young people with disorders related to their inactive, sedentary lifestyles will be seniors who will also require major investment.
2. The media often present seniors in a negative light: sick, unable to get around, heavily handicapped, etc. We need evidence that demonstrates **seniors' wellness and ability** in older aged. At present, there is none.
3. The impact of **poverty** on aging: poverty reduces quality of life. The impact of impoverishment on seniors, especially when in they need care in long-term care facilities or receive care at home.
4. **Suicide** in seniors: isolation, sexual orientation, spirituality, physical and cognitive impairment.

Group 6: Researchers

This group started with the concept that seniors experience handicapping conditions. Priorities were drawn based on this concept.

1. **The source of these handicaps** can drive research questions. These sources may be expressed as follows:
   a. impairments (variable and depend on type of organ damage).
   b. disabilities (variable and depend on level of function and limitations).
   c. environment (determined by social dimensions, ethnic groups, etc.).
2. Organization of **health care** and improvement in practices: especially, care must be better organized when handicaps are present.
3. **Age discrimination**, social representation.
4. **Social solidarity** (e.g., intergenerational challenges, financing health care).

This group added that beyond priorities, there are obstacles, such as the entire ethics question and the discussions surrounding Section 21 of the Civil Code of Quebec[1].

Discussion

The participants were encouraged to react, ask questions and come to an agreement on five major themes common across all sectors.

One participant suggested that the meeting should concentrate on research topics rather than on policy recommendations, to give researchers a list of priorities upon which they can formulate research proposals and funding requests.

Another participant said that she appreciated the research group's recognition of a handicap situation. She also spoke of the impact of family and social policies that have been implemented in municipalities and regions that help seniors feel less isolated.

A third participant spoke of the need for a "social shift" for seniors: the way seniors are perceived in society must be changed. Age is not a handicap. We must study aging and seniors issues in a more positive light, he said, suggesting that more emphasis be placed on basic research in the social sciences.

Lastly, a participant suggested replacing the notion of "handicap" with "social participation." Another proposed whether the opposite of "handicap" can be said to be "social participation."

Summary statements

During the discussions, participants tried to arrive at themes that were common to all sectors. The initial attempt to capture common themes resulted in the following:

1. Social research: age discrimination, ethics and social perception.
2. Care services: home and community care and programs, intermediate care resources, continuum of services, organization and delivery.

[1] Civil Code of Quebec. Section 21. A minor or a person over the age of majority, who is incapable of giving consent, may not be submitted to an experiment if the experiment involves serious risk to his health or, where he understands the nature and consequences of the experiment, if he objects.

3. Mobility: autonomy, access.
4. Psychological health: suicide, addiction, stress, intellectual stimulation.

Some elements of the initial list of common themes did not garner unanimity, notably those concerning quality of services and home care. One participant explained that the concept of integration of services and harmonization with the other services was lost. Another commented that, based on earlier discussions, he was surprised that socioeconomic perspective, especially the value of seniors in society, did not figure among the initial common themes.

One participant, an adult educator, congratulated the Program Chair for succeeding in bringing all these concepts together. He felt that it would be truly interesting if a study could show the contribution of seniors to society.

Another participant recommended that CIHR promote social research.

In conclusion, the Chair of the Program noted that it is said that in Quebec we insure illness, not health. We carry on a traditional approach in which each doctor and social worker attempts to solve a single problem in order to improve the situation for one senior. But there is also the approach by others who seek to ensure a just place for seniors in our society. The ideal most likely lies midway between these two positions.

Review of the morning's activities

A participant commented that no one group should be defended in particular, and that the focus should be maximizing the benefit to the broader population.

Jean-Guy Saint-Gelais, Program Chair, replied that the list of common priorities generated earlier are to be considered as general guidelines drawn up by seniors here today along with those generated at the other previous regional workshops to help guide major research projects and initiatives over the next five years for CIHR-IA. He added that tomorrow's breakout sessions would enable participants to elaborate on individual themes and make specific recommendations.

The themes common to all sectors were simplified to:

- Social research
- Mental health
- Mobility
- Health care services
- Socioeconomic research

A discussion ensued on the topic of seniors' age and the importance of defining age for the following day's discussions. Jean-Guy Saint-Gelais replied that in Quebec, one is considered a senior at age 50; in Canada it is 65 years and in some provinces, 55. He reminded participants that Quebec's figure is unofficial. One participant suggested age 70 and over. Jean-Guy Saint-Gelais brought the debate to an end, saying that agreement was impossible to reach

because age limits cut-offs vary too widely from one program to another and among research projects.

Report on Discussions: Participation in Research by Seniors

Participants were divided into 6 groups of 8 people per table, with representatives from each sector at each table. Each table of participants was invited to discuss the roles seniors can play in research and to share their personal impressions and experiences on the topic. The following possible roles were provided as a basis for discussion:

- Participants/human subjects
- Research staff
- Advisors on user perspectives
- Members of research ethics boards
- Participants in application or transfer of research results
- Seniors who returned to school later in life to obtain MSc or PhD Degree and are now doing research.
- Participants in selection panels for research grants/contracts

Table 1

This table's representative mentioned that several points had been discussed, but that the main difficulty lies in actually recruiting seniors for research involvement, because they are fearful. He said that he had participated in a study himself during which he was discovered to have a brain tumour. "It's nothing serious," he stated, adding that now he would hesitate before participating in another study, because he doesn't want investigators finding any other diseases.

He also mentioned that his group had given thought to compensating seniors for their time, and also towards the transmission of research conclusions to study participants. Section 21 of the Civil Code of Quebec was also a topic of discussion, as well as the fact that the level of participation in research is higher in more affluent socioeconomic circles.

Table 2

Table 2's representative reported that numerous seniors would like to participate in research as resource persons or research assistants. He gave as an example a large research project conducted in Quebec four or five years ago on the satisfaction of seniors living in residential-care facilities. The seniors themselves wrote the research protocol and interviewed other seniors. Interestingly, it was observed that seniors gave much more plausible answers to questions when these were asked by their peers in an informal atmosphere. He summarized by saying that seniors do not necessarily want to be considered only as subjects of research, but would like to actually *do* research. Investigators and seniors could collaborate with one another.

Table 3

The representative for this table stated that the discussion had focused on research experiences. They also recommended that seniors be called upon to validate research instruments and also train research assistants and young researchers.

The participants found the idea of seniors participating in research interesting, both as research subjects and as participants in project development.

Table 4

This table's discussion centred initially on the various possible roles for seniors in research. The participants identified one role to add to the worksheet examples: that of research group leader. Related to this role, they presented the idea of intergenerational transfer of research information.

In agreement with Table 2, mutual benefits are realized when senior research subjects are interviewed by other seniors. To add to this, they suggested that research projects could include one senior as co-lead. "Seniors want to participate and they want to see the results of their contribution," they suggested. It is important to increase interaction with seniors so that investigators will better understand seniors' lives, and so that results more closely reflect real needs. One participant commented that it is not because one or two seniors have participated in a study that its results apply to all seniors.

Several comments were made on the use of research results: often these are not written for the general public; at times they are incomprehensible and do not clearly show how they benefit seniors in their everyday lives.

Table 5

At this table, discussion began with… silence. It is not every day that the topic of seniors and research comes up! This table's participants focused on two major topics.

They spoke of seniors participating in research groups. In the Sherbrooke region there is good participation by seniors and sound supervision by professors from the *Université du troisième âge* (ThirdAge University). These approaches often yield results, with seniors helping younger researchers.

The group's second topic was the consideration of seniors as a target population. Other experiments have been done as well as studies in the social sciences and the humanities. One group even produced documents accessible to all seniors on aging and seniors, issues that should be addressed. All of this research is available for consultation on the Web site of the *Université de Sherbrooke* at www.usherbrooke.ca/uta/ (in French), under *Conditions de vie* (living conditions).

Table 6

The representative for this table stated that his colleagues had started by addressing two issues. The first was the importance of involving seniors in the research process, agreeing with comments from the other tables. The second issue noted was the existence of associations of seniors' and like organizations as resources that could help connect with and engage seniors

in research. In addition, the importance of ensuring research objectives are well defined was noted. Lastly, it was emphasized that researchers should use terminology that is appropriate for the groups they target.

Discussion

A first participant stated that, when we speak of seniors' participation in research, it is evident that research results are submitted to journals read by researchers who are interested in seniors, yet the subjects of the research itself are left out. She did point out, however, that a number of seniors do sit on research ethics committees throughout Quebec. They work alongside researchers in their interdisciplinary approaches, in their reflections, and in studying protocols. Seniors are present and very active and the law requires their presence in this context.

Jean-Guy Saint-Gelais asked this participant how selection is handled. She answered that a senior may submit his or her name or, if they know someone, merely state that person's interest. Their "candidacy" is then examined. The work is voluntary.

One participant asked a question of all those present. Given that the majority of research centres have Web sites, she asked if it would be possible to integrate the projects, their specifications and their objectives on these sites. She suggested that the criteria for involvement could be stated on Web sites.

Jean-Guy Saint-Gelais stated that only 11% of seniors are linked to the Internet and that of these 11%, only 3% are able to carry out searches. He mentioned that although seniors may not have access to the Internet at the present time, this situation is changing. He added that by obtaining information from Quebec regional roundtables, it is possible to find seniors rapidly. These roundtables have been in place in all regions of Quebec since 2000, and participants should use them, as they were established to network seniors.

A participant mentioned that she had had the pleasure of leading a seniors' group and that it would be interesting if students entering Master's programs could meet seniors, who would inform the students of their issues. Jean-Guy Saint-Gelais replied that examples of close links already exist between the Conférence des Tables and the universities. Unfortunately, this structure is not well known, despite the fact that the networking is known to be of great interest; this is one goal of this workshop, in addition to determining the five major research priorities.

Summary statements of Day 1

Jean-Guy Saint-Gelais recapped the day and reviewed the program for the second day. He ended the session by summarizing the highlights of the afternoon's discussions on involving seniors in the research process:

1. Seniors should participate in research.
2. Researchers find it difficult to recruit seniors for research projects (fear of discovering diseases, etc.).
3. Seniors should be involved in the research process from the outset, i.e., at the planning stages, not after the research project is underway.
4. Seniors should be able to understand research that concerns them (popularization).
5. Seniors should be involved in studies on aging and seniors' issues, so as to increase the relevance and usefulness of the findings to the older population.
6. Seniors should benefit from incentives to participate (e.g., financial incentives).
7. Researchers should better define research objectives; making them more comprehensible to seniors.

Presentation: Revealing the secrets of longevity

Dr. Gabrielle Boulianne, Senior Scientist, Hospital for Sick Children; Professor, Department of Medical and Molecular Genetics, University of Toronto; holder of the Canada Research Chair in Molecular & Developmental Neurobiology.

Dr. Boulianne began her presentation by saying that without even knowing the name of a single participant, she could already affirm that all persons present had one thing in common: we are all growing older, whether we like it or not. People are constantly confronted with aging; in the media, youth is often given centre stage. "There are even organizations that exist to prevent aging, such as the S*ociété française des antioxydants*, the Institut de longévité and the *Institut anti-âge*," she said, adding that the notion that life can be extended for up to 500 years is pure science fiction; research shows what can realistically be done to extend life.

What determines lifespan? Can it, in fact, be extended? These were the questions raised by Dr. Boulianne. She affirmed that it is essential to discuss these questions now, before it is too late.

Researchers use organisms such as *Drosophila melanogaster* (the fruit fly) and *Caenorhabditis elegans* (small worms) to study the determinants, or factors influencing aging. Dr. Boulianne explained the advantage of using these creatures.

Worms, with their life cycle of three days and lifespan of two to three weeks, are very practical for studying aging. Their development is well characterized and all their cells are known, including the 302 cells in their nervous system. Worms are also the first multicellular organism whose genomic sequence—17,800 genes—is fully known. "It is much easier to understand genes and important determinants for worms," said Dr. Boulianne, "and then to see if the same phenomena are found in other, more complex, organisms such as mice, monkeys, and humans."

Dr. Boulianne mostly works with fruit flies, which have several characteristics in common with worms, among them a very short lifespan. The fruit fly's 14,000-gene genomic sequence is complete and is fully known; 77% of the genes associated with

human diseases are present in this fly. Alzheimer genes can thus be introduced to see if flies will develop the same symptoms as human patients with the same disease.

Identifying the gene responsible for aging seems to be easier to accomplish in fruit flies than in humans. When older fruit flies are selected for reproduction, they reveal certain particular characteristics such as resistance to stress, as well as high levels of antioxidants such as superoxide-dismatase (SOD). This suggests a link between oxidative damage and lifespan. Studies on neurodegenerative diseases (e.g., Lou Gehrig's and Alzheimer's diseases) conclude that the nervous system is especially sensitive to oxidants.

Dr. Boulianne has studied gene expression during aging. It appears that fruit flies can live longer after researchers insert the SOD-producing gene into certain of their nerve cells. If this gene is modified in humans, could humans perhaps live to age 120, maintaining good quality of life?

Dr. Boulianne concluded by questioning the importance of extending lifespan if quality of life cannot be enhanced. Certain socio-economic factors also have a major influence on quality of life.

A participant wondered if an ethics committee is supervising the question surrounding quality of life and longevity. Dr. Boulianne replied that there are conferences (the Gordon Conferences, for example) exploring such issues in bioethics.

Another participant agreed that quality of life is very important. He pointed out that Dr. Boulianne did not mention the fact that we are the only living species that does not reach its full lifespan potential, which some studies place at 125 years.

A participant concluded on a philosophical note, "We must add life to our years rather than years to life!"

RSWR for Quebec: Day 2, April 28, 2006

Presentation: The Longitudinal NuAge Study

Dr. Hélène Payette, Professor, Department of Community Health Sciences, Faculty of Medicine and Health Sciences, *Université de Sherbrooke;* and Director, Centre of Research on Aging of the Sherbrooke Geriatric University Institute.

According to Dr. Payette, it has been observed that seniors, feeling themselves to be at risk, readily accept healthy life habits and healthy eating patterns even late in life.

The NuAge Longitudinal Study, an interdisciplinary and multi-method research program on nutrition and aging, is being conducted by five principal investigators: H. Payette, P. Gaudreau, K. Gray-Donald, J. A. Morais and B. Shatenstein (and involves various universities: University of Montreal, McGill University, Laval University and University of Sherbrooke).

The NuAge study aims to determine which eating patterns would be the best to encourage in seniors. To find the answer to this question, the investigators are using a stratified sample of 1,793 men and women from Montréal and Sherbrooke in good physical and mental health, and functionally independent.

NuAge is collecting information on the diet and eating patterns of these seniors as well as their muscular strength and physical activities. Added to this information are medical-type data (physical and mental health). A yearly individual interview and a telephone interview every six months complete the information collected.

Results obtained to date show that the body mass index of the study participants fell under the Canadian average range for persons in good health. This is not surprising as older people are generally thinner and are not as strong. Although the risk of nutritional deficiency is greater in seniors, within this study group, nutritional status was in the acceptable range. The investigators have observed that degree of appetite was linked to healthy nutrition.

This research has demonstrated very low levels of depression in the study population. Not surprisingly, the illnesses declared by participants were those that are frequent in seniors, such as arthritis, cardiovascular problems and hypercholesterolemia.

Dr. Payette observed that in most cases the quantity of food consumed was in agreement with Health Canada recommendations. Nutrition was therefore adequate in terms of energy intake in the study's subjects. Some deficiencies in

calcium, vitamins E and D, and folic acid were noted, however.

Dr. Payette mentioned some of the spin-off effects of the NuAge study: promotional programs, prevention strategies, and new, adapted food products.

Dr. Payette stated her belief that we must create a dialogue on nutrition that is suited to seniors. For example, most weight-loss plans are not appropriate for older people, who usually have no need to lose weight, but should make sure they are getting all the essential nutrients in their diets. Optimal weight is in fact higher for seniors than younger adults.

One participant asked if it would be relevant to study persons over 50, to see if they eat better as they age. Dr. Payette replied that a study with this exact goal is soon to start on 40 year olds.

A participant questioned the veracity of study subjects' statements and asked about the attrition rate as well as the replacement of deceased persons. Dr. Payette replied that the NuAge investigators were aware that people's behaviour may differ while under observation. She added that the attrition rate was only 5%; a rate considered very acceptable. The investigators did take account of subjects' withdrawal from the study (causes, consequences, effects on research, etc).

Another participant wanted to know how researchers will use these data. Dr. Payette stated that there are several other studies nested within NuAge. For example, one study is looking at food consumed and its impact on stress. Another is dealing with nutrients and their role on cognitive function. Yet another study is analyzing the relationship between environment and food choices.

A participant noted that some healthy foods are expensive, and asked if this could have a bearing on food choice. Dr. Payette replied that investigators are currently asking such questions.

One participant asked doctors to take motivation into account when considering the question of healthy nutrition, especially regarding weight-loss plans. While agreeing with the participant, Dr. Payette noted that for seniors, diets generally result in loss of muscle mass.

Report on Breakout Session II: Setting Research Priorities

The purpose of this second breakout session was to identify the key research questions that will serve to address the five common issues determined in the first Breakout Session on Day One. Each group had a balanced representation of the different sectors and was asked to probe deeper into the five priorities, defining research questions or knowledge translation challenges specific to each. The outcome would serve to guide the Institute of Aging in its development of future strategic programs. The groups then reported back to plenary.

Social research

Participants discussed the following topics:

- Attitudes and manifestations of age discrimination
- Aging and work
- Elder abuse
- Suicide in seniors
- Aging and the cultural community

They made the following overarching recommendation: Researchers should go to the environment where their subjects are found (their regions, their housing). "When you do research, you have to go into the field."

As for the research priorities, the participants identified the following:

1. Carry out studies on age discrimination (much of the data on this subject has changed over the years).
2. Carry out research on aging and the job market (employment opportunities and workplaces favourable to seniors);
3. Investigate elder abuse.
4. Understand why the suicide rate is so high for seniors compared to the general population).
5. Study cultural communities: women in cultural communities face many problems.

Mental health

In the context of mental health, the participants emphasized the following priorities:

1. We must understand mental health phenomena from an etiological point of view; we must also focus on psychological distress.
2. Intervention must go hand-in-hand with prevention.
3. In research, distinctions must be made between rural and urban settings; gender; age; ethnic background; income level, etc.
4. Knowledge acquired through research must be applied. We must ensure that this knowledge is understood and disseminated.

Mobility

The group emphasized the adaptation of the physical and social environment. More specifically:

1. Cities and towns: these must be more elder-friendly.
2. Housing: accommodations must be adapted (the Régie du bâtiment du Québec must help seniors do this).
3. Transportation: transportation authorities should provide services for seniors, while giving them special rates, adaptations, etc.
4. Ergonomics: ergonomic products and services must be developed with senior consumers in mind. We must also take account of the real use of prostheses and mobility assistance tools.
5. Social: Work must be done on social behaviour with regard to mobility.

The groups also addressed mobility in relation to access to services:

1. Services must be brought closer to seniors' community centres.
2. Access to health care and medical and geriatric services must be improved.

3. Designers, manufacturers, policy makers, users, government agencies, municipalities and professional organizations must intervene to make services accessible for seniors.
4. Priority must be placed on communicating with users of services in centres and organizations by means of bulletins, meetings in residences, Internet, radio and television.

Health care

The following points arose from the group discussion:

1. We must assess practices and management of healthcare services for chronic patients.
2. We must determine the proportion of responsibility inherent in each component of health care (access to services; home support; natural caregivers, etc.).
3. Long-term care must be reorganized.
4. Strategies must be considered for keeping people active and for assessing their health capital.
5. We must determine the most suitable place for seniors to live (for example, in housing facilities; at home).

Socioeconomic factors

The key areas that surfaced through group discussion were as follows:

1. Seniors' socioeconomic contributions must be taken into account (values, knowledge, volunteerism, economic aspects, family, social participation, etc.).
2. Ethical questions must be considered (prolongation of life, aggressive therapy, suicide, spirituality, etc.).
3. Age discrimination must be studied: the social stereotypes with regard to seniors (the individuals themselves, their health, their employability) that are created in the media, for example.

Presentation: The Canadian Longitudinal Study on Aging

Dr. Christina Wolfson, Professor, Department of Epidemiology, Biostatistics and Medicine, at McGill University; Director of the Centre for Clinical Epidemiology and Community Studies at the Lady Davis Institute for Medical Research.

Why Study Aging in Canada?

The average age of the population is increasing: between 1980 and 1999, the average life expectancy for Canadians went from 75 to 79 years. By 2025, one Canadian in five (20%) will be 65 years old or older, compared to one out of eight (12%) in 2000. The first baby boomers will be 65 in 2011 and they will have different needs and expectations than their predecessors. We must therefore generate new knowledge, because it will no longer be enough to rely on old data, which refer to a very different population. The change is so great for seniors that, in some countries, life expectancy has risen from 40 to 85 years.

Why do we age?

According to Dr. Wolfson, it is not because we age that everything must necessarily

degenerate. We must understand why things decline, why they deteriorate. Moreover, disease and decline vary greatly from one individual to the next, and these variations must be taken into account.

Aging is a matter of genes and certain environmental factors such as nutrition, lifestyle, smoking, exercise, and pollution. There is even a certain amount of "luck" involved in aging. In fact, Dr. Wolfson explained that in some cases behaviour defies all statistics. We must try to understand these particularities as well.

Several aging studies have been carried out in the past. The Canadian Longitudinal Study on Aging (CLSA) will, however, cover all the topics relevant to seniors. It will be the world's first study of this size. For it, new study designs have been developed. Also the participation of researchers in the social sciences has been obtained; data that are purely biological, anatomical or clinical will no longer suffice, she added.

Dr. Wolfson explained why the CLSA investigators decided to study aging as such, and not solely the aged. This is why the study will include not only seniors, but also younger people: it will attempt to observe life's progression, and to consider aging from a dynamic perspective. In order to do this, in addition to studying biological problems, all life events will be taken into account so that interacting factors can be examined. Adaptation to diverse life situations will be considered.

Aging is a dynamic process that is constantly changing. That is why we wish to understand the transitions and changes through which people pass, to strengthen our capacity to do research on today's—and tomorrow's—seniors.

Who will participate in the CLSA?

The study will include a total of 50,000 men and women 40 years of age and older to be followed for 20 years. This is what makes the CLSA one of the largest studies ever undertaken. Some measures will be taken every three years, others yearly. Links will be established between the data that emerge from this study and those already contained in existing databases. An example: CLSA data and data on prescription drugs will be cross-referenced.

What questions will the CLSA attempt to answer?

Dr. Wolfson sketched a few of the topics that would be studied under the CLSA:

- Daily living activities and physical health: e.g., disability; comorbidity; chronic diseases and health problems.
- Psychological health, including personality; values and meaning; emotions; psychopathology and psychological distress.
- Social networks: the transition between active life and retirement; inequalities in access to care; mobility and socioeconomic status.
- Biological aspects, including genetic markers for aging, sensitivity to disease, and longevity.

- Behaviour, including nutrition; obesity; physical activity and sleep habits.
- Healthcare services, including medications; functional aids; home care and institutional care.

Dr. Wolfson went on to outline the type of information the CLSA will gather:

- **Active data collection:** there will be telephone interviews, in-person interviews (psychological, social, economic and nutritional aspects), clinical examinations (neurological, medical and physiological testing) as well as blood and urine sampling.
- **Passive Data Collection:** Individual data will be linked to existing databases such as medical, hospital, and social workers' files and death certificates.

Dr. Wolfson spoke about the ethical problems that could be encountered during such a comprehensive study. For example, problems arise in connection with informed consent and confidentiality. "Should we inform family physicians if we discover something that concerns the health of study participants?" A dedicated committee and research projects are addressing key ethical issues. The committee analyzes the legal, methodological and ethical questions related to the CLSA.

One of the benefits of this study will be the availability of data as of the second or third year. Through knowledge transfer efforts the findings will quickly come to the attention of policy makers.
Dr. Wolfson stated that the CLSA will also contribute to stimulating the economy, simply because it will employ a great number of persons (investigators, sociologists, social workers, etc.). In addition, it will serve as a springboard for future research.

CLSA planning started in November 2001, and by March 2004, the study's main protocol had been reviewed and fine-tuned by international experts, as is required for a study of this magnitude. The final protocol is to be released on May 1, 2006. Dr. Wolfson stated that the process is proceeding very rapidly: the study's content has been finalized, some feasibility studies have already been completed, and additional feasibility studies are underway. The protocol will be tested next year and the complete study will begin in 2008.

Dr. Wolfson ended her presentation by inviting all participants to visit the study's Internet site: www.CLSA-ELCV.ca.

"I think this study is absolutely extraordinary!" added an enthusiastic participant.

Closing Remarks: Jean-Guy Saint-Gelais

Mr. Saint-Gelais congratulated the participants on their enthusiastic participation in the discussions. Quebec had shown its uniqueness in its approach to the person as a whole in terms of spiritual and social aspects as well as physical aspects of health. He thanked everyone for their excellent work and

hoped that they would all have another opportunity to exchange ideas on aging and associated health research.

Closing Remarks: Dr. Martin-Matthews

Dr. Martin-Matthews explained that the workshop's goal had been to provide its participants with an opportunity to express themselves on seniors and aging issues that Canadian research should address, and to give participants some familiarity with research projects already underway. She stated her conviction that these goals had been reached during this regional workshop.

The participants spoke about seniors' responsibility in research, and about research funding. According to Dr. Martin-Matthews, the majority of funding is allocated to biomedical research, with clinical research coming in second place. While care delivery and population health (social and psychological factors) have also been covered, it has been to a lesser degree. Good news is that recent trends show a great increase in studies on these topics. This in fact resonates with priorities emphasized by this workshop's participants. The Canadian Institutes of Health Research is increasingly providing funding for research on seniors and aging.

The research priorities emanating from the five Regional Seniors' Workshops on Research will reflect Canada as a whole. Certain topics have been raised in all the regions, while others have been region-specific. Some variations have thus been observed among Canada's five major geographic areas. Dr. Martin-Matthews noted that in many instances during this Quebec workshop, a very province-specific recommendation surfaced: that of social research in the context of health. She promised to take that fact into consideration.

In closing, Dr. Martin-Matthews thanked a number of people for their time and effort, beginning with the participants, indicating her appreciation for their active presence. She reserved special thanks for the meeting's Chair, Jean-Guy Saint-Gelais, for his dedication in preparing the workshop and for his talents as Program Chair.

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Annex B: Regional consultants for Quebec

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- **André Davignon** (Vice-chair), Director, Observatoire Vieillissement et Société
- **Hélène Payette**, Director, Research Centre on Aging, Sherbrooke Geriatric University Institute
- **Nathalie Ross**, Executive Director, Federation of Quebec Alzheimer Societies
- **Mark Stolow**, Care-ring Voice, Foundation for Vital Aging

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 Seniors' Officials
- **Sheila Laidlaw,** Retired, former Head of University of New Brunswick Libraries, and Institute of Aging Advisory Board member
- **Barry McPherson,** Wilfrid Laurier University, President, 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,** Post-Chair, National Advisory Council on Aging
- **Jean-Guy Soulière,** Chair, Coordinating Committee of the National Congress of Seniors' Organizations
- **Sophie Rosa,** Communications Officer, Institute of Aging

Annex D: Facilitators and Speakers

Facilitators

- **Hélène Carbonneau,** Centre de recherche sur le vieillissement, Université de Sherbrooke
- **Robert Dobie,** Acting Chairperson, National Advisory Council on Aging
- **Chantal Laflamme,** Public Affairs Officer, Canadian Institutes of Health Research
- **Martine Lafrance,** Deputy Director, Program Delivery, Canadian Institutes of Health Research
- **Sharon Nadeau,** Project Officer, Institute of Aging, Canadian Institutes of Health Research

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- **Jane Rylett** (Vice-Chair), Robarts Research Institute
- **Huber Warner,** University of Minnesota

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