

CANADIAN ARTHRITIS NETWORK
WHITE PAPER

**CONSUMERS AS PARTNERS
IN RESEARCH KNOWLEDGE
TRANSLATION AND
EXCHANGE**

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CANADIAN ARTHRITIS NETWORK | LE RÉSEAU CANADIEN DE L'ARTHRITE

INTRODUCTION

The Canadian Arthritis Network (CAN) is a national, federally-funded, not-for-profit organization that supports integrated, multi-disciplinary and multi-institutional research and training. CAN involves consumers in all of its committees, funded research, and training programs. Its consumer group is called the Consumer Advisory Council (CAC).

The CAC is comprised of a diverse membership representing a wide range of professional experience, ages, cultures, languages, geographic regions and types of arthritis. Members, identified as consumers because they are knowledgeable and informed patients, also have extensive advocacy and self-management experience. All members of the CAC are volunteers and are chosen because of their interest in arthritis research.

This booklet was written by the CAC, with input from arthritis researchers. The goal is to provide guidance in understanding and conducting Knowledge Translation and Exchange (KTE) with consumers. It is directed at consumers who want to become collaborators in arthritis research, and trainees and investigators wanting to incorporate consumers in their KTE efforts. The authors want to ensure researchers' and consumers' expectations for KTE, in any research project, are recognized, acknowledged and fulfilled. To maximize KTE contributions by consumers, their involvement should begin long before a research proposal is submitted for peer review. It is hoped that this booklet will be a useful guide on how to include the patient perspective and knowledge dissemination tactics in research and KTE activities.

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I. EXPLANATION AND PURPOSE OF KTE

The Canadian Institutes of Health Research's (CIHR) definition of KTE¹ is:

“Knowledge translation (KT) is the exchange, synthesis and ethically-sound application of researcher findings within a complex system of relationships among researchers and knowledge users.”²

People with arthritis are among the many users of arthritis research.

The Director of the Canadian Cochrane Centre, Dr. Jeremy Grimshaw, used the following definition of KTE in his presentation entitled, “Smoke and Mirror – Where is the ‘K’ in KT?”

“Knowledge translation is about ensuring that:

- **stakeholders are aware of and use research evidence to inform their decision making; and,**
- **research is informed by current available evidence and the experiences and information needs of stakeholders.”**

The CAC considers that the goal of KTE is to ensure that:

- **the public and policy makers are aware of the personal, social and economic costs of arthritis and how arthritis research impacts arthritis care as well as the health-care system;**
- **researchers are aware of the needs of people with arthritis and these needs are considered in the development, implementation, evaluation and dissemination phases of research;**
- **people with arthritis are aware of, and use, best evidence to inform their decision-making;**
- **people with arthritis know the risks and benefits of participating in research; and,**
- **the public, researchers and decision makers are aware of the CAC's activities**

This booklet on KTE includes suggestions for enabling researchers and consumers to work together to achieve successful knowledge translation and exchange as well as some examples of KTE.

II. BENEFITS OF CONSUMER COLLABORATION IN RESEARCH

Consumers and researchers alike reap many benefits from the process of collaboration and consultation in relation to KTE activities and throughout the research process. Listed below are some of the advantages of including consumers in research.

For researchers, there is the:

1. Access to people with the specific disease being studied who can be consulted about the daily reality and impact of the disease.
2. Access to the consumer/patient perspective on issues and ideas, as well as the research priorities that matter most to them.
3. Opportunity to ensure that plain language in the summaries and reports are truly clear to the patients, public and decision makers.
4. Opportunity to be sensitized to, and address cultural issues, of specific populations of patients under study.
5. Value-added opportunity to connect with the patient groups/organizations who can inform the public about progress and results of the research.
6. Development of research advocates in their area of study.

For consumers, there is the:

1. Opportunity to be kept abreast of the most recent and current knowledge and evidence-based information in relation to their specific disease.
2. Opportunity to be a member of a highly-skilled research team and learning more about the research process, the importance of methods utilized and how evidence-based messages evolve from the findings.
3. Ability to learn and further appreciate the importance of research and advocating for more funding, along with the complexities involved in obtaining funding and the accountability that goes hand in hand.
4. Gratification and reward from contributing to such important endeavours that could lead to finding a cure for your specific disease.
5. Opportunity to disseminate information on research to other consumers, patient organizations, and policy/decision makers.

The CAC has many examples from its involvement in research projects at the Canadian Arthritis Network (CAN) that demonstrate the benefits of consumer collaboration. A number of these were highlighted in the CAC publication entitled “Consumer Impacts on Research at

the Canadian Arthritis Network.” For example, the CAN-funded (2003–2008) research project “Tooling Up for Early Osteoarthritis (TUFEOA): Measuring What Matters” included consumers as members of the research team who undertook various knowledge dissemination activities, including: writing articles for websites and newsletters, giving presentations at scientific conferences, producing a glossary of scientific terms in plain language and presenting at public forums.

A research project involving consumer collaboration to take advantage of their unique perspective to aid in knowledge dissemination is the “Peer to Peer Mentoring: Facilitating Individuals with Early Inflammatory Arthritis to Manage their Arthritis.” Consumers worked closely with medical trainees to help design a peer mentor training program based on their experiences with inflammatory arthritis. Consumers were also given authorship roles in submitted publications and posters presented at conferences.

These are two instances that demonstrate how consumers are integrated into the research team as partners and how they bring their own perspectives, networks and skills to the table to complement those of the researchers.

III. HOW RESEARCHERS CAN INCLUDE CONSUMERS IN THEIR KTE PLANS

Traditionally, the results of arthritis research have been published in scientific journals that, unfortunately, the general public is frequently unable to access. This method of KTE enables the scientific community to access innovations, but fails to ensure that the value of research is fully appreciated by other audiences or potentially acted upon in the best interests of the public. It is important for stakeholders, such as consumers, to gain access to research information and, for the sake of ensuring the relevance of this research to those stakeholders, it would be optimal for them to be consulted during the research planning and selection processes.

The model of involving consumers at every level of the research process addresses these deficits. Consumers help set the priorities for the research funding agenda and they review, recommend and vote on grant applications, provide guidance and support to research trainees, and act as consultants and collaborators in the development and knowledge dissemination planning activities for research projects.

As explained in the opening definitions, the ideal form of KTE moves beyond traditional methods of knowledge transfer. The process ideally begins with the development of an effective KTE dissemination plan as the research project itself is being planned. If possible, consumers should be included as members of the research team at this early planning stage of the research project to help in the development of KTE objectives and with planning how to communicate the research results to the public. It is important that costs related to consumer involvement in planning and disseminating research results be discussed and included in the research proposal's budget. Some KTE tactics to involve consumers in the research process are listed below.

Traditional KTE Approach

The researcher:

1. Prepares manuscripts for scientific journals.
2. Prepares posters and presentations for scientific conferences.

Ideal KTE Approach

In addition to the two points listed above, the researcher:

3. Includes consumers as team members in discussions about the research questions and objectives and potential ways that consumers can help with KTE.
4. Communicates with consumer team members regarding funding decisions and the progress of the research project. If the project is funded for multiple years, it is advisable that the research team, including the consumers, develop a website and a newsletter to broadly disseminate research progress, findings and outcomes in addition to conference presentations and peer-reviewed publications.
5. In consultation with consumers, prepares a plain language summary of the study's purpose and findings, along with other relevant information (e.g., investigators, funding source, location of study) so that consumers are able to inform members of their organizations, post the summary online and/or print it in their newsletters for discussion. In the arthritis community, consumer organizations would include the Canadian Arthritis Network's Consumer Advisory Council (CAN-CAC), the Canadian Arthritis Patient Alliance (CAPA), The Arthritis Society (TAS), Arthritis Consumer Experts (ACE), Arthritis Research Centre's Consumer Advisory Board (ARC-CAB), and Patient Partners®. Guidelines for lay summaries can be found at http://www.arthritisresearch.ca/images/stories/cab/documents/lay_research_summary.pdf
6. Prepares manuscripts for scientific journals. Consumers may be acknowledged in manuscripts or included as co-authors according to appropriate guidelines for authorship.
7. Prepares posters and presentations for scientific conferences and involves consumers when possible.
8. Works with communications professionals, often at the university or hospital, to prepare news releases and plain language summaries for the media and other audiences. Where possible, consumers should be involved to provide input on the release.
9. Participates in research webinars or podcasts. Consumer involvement is desirable.
10. Presents at public forums and conferences where government and industry representatives have been invited, as well as events developed specifically for the

public (such as CAN CARES, Roundtable on Arthritis Research (ROAR), The Arthritis Society's Forums, Cochrane Symposiums, etc.). Consumer involvement is desirable.

11. Includes representatives from consumer groups in subsequent research planning activities (e.g. small working group meetings at CAN's Annual Scientific Conference, Canadian Rheumatology Association annual meetings, or any other national conference where collaborative research endeavors are initiated).

IV. THE ROLE OF THE CONSUMER IN KTE

Consumer involvement in any research team's project should begin before the research application is submitted. In order to maximize a consumer's input to the research project, it is advisable to seek the patient perspective and develop KTE plans at this early stage. Consumer involvement continues until the project is complete. The following activities are some of the many ways in which consumers can help support a research project. The examples given are specific to arthritis, but may be generalized to other research areas.

The consumer, pre-submission:

1. Reviews the research proposal and lay summary.
 - Provides input on the proposal to help highlight and strengthen the relevance to people with arthritis.
 - Reviews the ethics proposal, consent forms, and patient information sheets.
 - Provides input and suggestions on the proposed dissemination strategies.
 - Provides input on the conceptual model and tools used in the study (e.g., questionnaire).
 - If desired, writes a letter of support for the research proposal that also outlines the consumer's role in the KTE process.

The consumer, post funding:

1. Participates in pilot testing of tools and instruments for the study.
2. Participates in research team meetings, providing suggestions and recommendations as needed (e.g. ethics forms, questionnaires and information sheets).
3. Provides feedback/assists in writing plain language summaries for the research project.
4. Contacts appropriate consumer organizations to obtain comments/input on proposals.
5. Contacts appropriate consumer groups to ensure that non-confidential results are communicated to the arthritis community.
6. Assists in developing posters for presentation at conferences.
7. Co-presents or presents at conferences when considered desirable and feasible by the researcher or host organization.

V. WAYS TO ENGAGE IN KTE TO INFORM ALL STAKEHOLDERS

Knowledge translation is aimed at including relevant stakeholders in research and working with them to translate research findings into useable messages that allow stakeholders to make decisions based on the best evidence. Stakeholders include other researchers, patients or consumers, government policy makers, clinicians, non-profit organizations, industry and the general public. The following examples are some of the ways both researchers and consumers can ensure that research knowledge results reach all stakeholders.

1. Participate in public events (e.g. CAN CARES, Roundtable on Arthritis Research (ROAR)) to ensure that research information is presented, questions are answered and results are discussed. (Material that is discussed in small groups is better absorbed, remembered and implemented as opposed to simply listening to the research passively.)
2. Provide opportunities for the public to question and give feedback to researchers to help them formulate future directions or subsequent research projects. (Dialogue between researchers and consumers who live with a disease encourages research accountability.)
3. Create public forums and workshops that include consumers and encourage input from all stakeholders (e.g. Canadian Arthritis Network's Pain Workshop).
4. Make presentations about research results to government and other public policy decision makers when it impacts health-care decisions. (Consumers should work to be included at the policy development stage.)
5. Write letters or submit story ideas to media (online, newspapers, radio and television) when research will impact patient care and personal health-care strategies.
6. Take advantage of articles about research that have been published in the newspaper and write letters to the editor. By continuing this dialogue, thousands of people will become even more informed.
7. Develop information campaigns that will inform the public about research results and post materials at public health venues.

VI. ALIGNING EXPECTATIONS OF RESEARCHERS AND CONSUMERS

Researchers and consumers need to have similar and realistic expectations to ensure a smooth consultative and collaborative research process. For example, it is important that the researcher allows enough time for the consumer to read, review, ask questions and comment on the research proposal both in relation to the proposal's content as well as the consumer's proposed role in the research project prior to writing the letter of support.

For a lay person who may be working full-time or volunteering extensively, it's important for researchers to know that this process requires time to fully digest and comprehend the proposal. Consumers must be aware that researchers are often working toward tight deadlines that require rapid turnaround; consequently, they must respond quickly if they are available and interested in providing a collaborative or consultative voice in the research proposal.

Discussions about the KTE aspect of the research and who is responsible for which parts should happen prior to submitting the proposal. Sometimes, there is the mistaken assumption that the consumer will be completely responsible for communicating research information to the public. If discussions about KTE are held after the proposal is funded, opportunities may be lost and resources (e.g., funds) may be unavailable for consumer involvement. Budgets should be flexible to accommodate new dissemination plans as results are obtained.

Consumers need to be aware that any discussion, report, proposal, piece of information or communication they receive from a researcher must remain confidential until the research proposal is funded or intellectual property needs have been met and the researcher has indicated that KTE activities may begin. Even as work gets started by the research team on the initially-funded proposal, activities generally remain confidential.

Most researchers and consumers find that CAN's model of consumer involvement in research is a very rewarding experience. Ensuring that these few precautions are followed reinforces a professional attitude and provides a productive and responsive atmosphere in the research arena for all parties involved.

VII. EXAMPLES OF SOME SUCCESSFUL KTE PROJECTS, TOOLS AND PRODUCTS

One of the most important results of research is its ability to become translational and effective in changing health outcomes for people with arthritis. Provided below are some great examples of KTE initiatives that have helped to improve outcomes for people with arthritis and that are continuing to have an impact long after the research is over.

1. CAN CARES

CAN's Canadian Arthritis Research Exchange Seminars (CAN CARES) feature CAN researchers and their work. These events bring together the Network's scientists and people with arthritis for half a day of dialogue and networking. They offer the opportunity for patients, their families and friends as well as other interested individuals to:

- a. learn about the latest in arthritis research;
- b. provide feedback on each topic and ask questions directly to the researcher;
- c. discover ways to become involved with arthritis research; and,
- d. Learn about new ways to manage arthritis.

The CAN CARES event is a valuable KTE tool based on ROAR – the Arthritis Research Centre's Roundtable on Arthritis Research (Vancouver, BC). It not only reaches the public with important information about their disease and educates them on current research advances in arthritis, but it also gives CAN researchers greater public exposure and increased knowledge transfer opportunities. It creates a venue where current research findings are discussed by patients (the experts living with the disease) and CAN scientists who translate the study findings into plain language. It is an example of KTE at its best because both parties benefit: the public gets to ask questions directly to the scientists and they receive feedback that may influence their current work and/or future research projects.

2. People Getting a Grip on Arthritis

"People Getting a Grip on Arthritis" was led by Dr. Lucie Brosseau of the University of Ottawa, Dr. Sydney Brooks (Lineker), Director of Research at The Arthritis Society, Ontario Division, Dr. Mary Bell (CAN researcher) of Sunnybrook Health Sciences Centre in Toronto and a number of other researchers³. As part of their research project, they developed a series of interventions, a manual and videos – narrated by people with arthritis – to accompany a workshop program to help people with arthritis. These interventions include body strengthening,

Tai Chi, weight management, insoles and footwear, Transcutaneous Electrical Nerve Stimulation (TENS), acupuncture, and an aerobic walking program. These strategies were developed to help people with both Rheumatoid Arthritis and Osteoarthritis. The workshop is now accessible online on The Arthritis Society's website at www.arthritis.ca/peoplegettingagrip

3. Health Improvement and Prevention Program (HIPP) and the Lupus Health Passport

CaNIOS, which stands for Canadian Network for Improved Outcomes in Systemic Lupus Erythematosus, is led by Dr. R. Paul Fortin, a CAN investigator.

Systemic Lupus Erythematosus (SLE) is a chronic disease in which a person's immune system attacks its own organs. In a majority of cases, the arthritis is a sign of even more severe inflammation of vital organs. Controlling SLE is difficult because there are many symptoms that differ from person to person. Both SLE and the drugs used to treat it may lead to premature cardiovascular disease or osteoporosis. In addition, coping with SLE can be very stressful.

In this CIHR-funded study co-directed by Dr. Fortin and Dr. Deborah DaCosta (a CAN investigator), persons with SLE were tested to see if they would benefit from HIPP. In HIPP, participants increased their knowledge of SLE and learned ways to improve their coping skills, and were taught an adapted exercise program and how to decrease their risk for cardiovascular disease and osteoporosis. They did this by working with a nurse who tailored a coping and risk-reduction program to fit each person's needs. A handy Lupus health passport contained this information to allow the patient and the health-care team to track progress.

This program has been so successful that it has been adopted by other disease groups to avert preventable comorbidities. Information on this program can be obtained by following this link http://www.canios.ca/About_canios_studies_HIPP.aspx

4. 2002 Osteoarthritis Consensus Conference

Throughout its years of existence, CAN has hosted a number of important workshops that have brought together researchers, clinicians and people with arthritis to help determine the priorities and next steps in arthritis research. A particularly significant conference for patients that CAN co-developed and hosted was the 2002 Osteoarthritis (OA) Consensus Conference.

The OA Consensus Conference represented the first time that consumers were actively involved in identifying priorities for OA research. Their participation facilitated the first

nation-wide consumer survey entitled *Determining the research priorities of people living with arthritis – listening to patients*. Over 300 consumers responded validating six research questions and highlighting an unexpected addition – **fatigue**. Without consumer participation, this important area of research might not have received the increased attention that it subsequently did. It is clear that consumers and researchers both need this form of dialogue and knowledge transfer opportunities in order to help shape future research directions.

5. Public Health Agency of Canada’s Arthritis in Canada

One of the most important KTE reports about arthritis currently available is *Life with Arthritis in Canada: A personal and public health challenge* published in 2010. It was produced by the Public Health Agency of Canada (PHAC) and is a follow-up to *Arthritis in Canada: An ongoing challenge* published in 2003. PHAC produced both of these reports by collaborating extensively with arthritis stakeholders.

The 2003 publication was a joint effort of the whole arthritis community and input was sought from researchers, clinicians, consumers, industry, NGO’s, allied health professionals, doctors and government agencies. Dr. Elizabeth Badley (Arthritis Community Research & Evaluation Unit) and Marie DesMeules from Health Canada are credited with being co-editors. The report was sponsored by several organizations – Health Canada, The Arthritis Society, Canadian Arthritis Network, and the Arthritis Community Research and Evaluation Unit – and is a stellar KTE example of groups working in partnership. Similar input was sought for the 2010 report.

Following the publication of the 2003 report, PHAC listed arthritis as a condition of interest for ongoing surveillance research and commissioned a follow-up report.

“Arthritis in Canada” 2003 and 2010 offer statistics and compelling arguments for stakeholders to use when advocating for change in public health-care policy. The research and facts provided in *Life with Arthritis in Canada* (2010) are expected to play a very important role in advancing the cause of arthritis. Arthritis advocacy organizations, like the Canadian Arthritis Patient Alliance (CAPA), the Arthritis Alliance of Canada (formerly the Alliance for the Canadian Arthritis Program, ACAP), Arthritis Consumer Experts (ACE) and The Arthritis Society, have on many occasions used this research to support their arguments when presenting to government organizations or creating impact in public awareness campaigns.

Life with Arthritis in Canada (2010) can be found at
<http://www.phac-aspc.gc.ca/cd-mc/arthritis-arthrite/lwaic-vaaac-10/index-eng.php>

6. Acronym Glossary

It is difficult to make sense of the many acronyms and research terms and phrases that are employed in the arthritis research community. In order to deal with this challenge, Jean Légaré, an Emeritus member of the CAC, with help from other CAC members and researchers, developed an acronym and reference glossary to decipher the language commonly used in arthritis research. This knowledge translation project helps everyone. For your own copy of this helpful reference tool, download a PDF copy here:

<http://www.arthritisnetwork.ca/consumers/downloads/Research%20Glossary%20for%20Consumers%20-%20draft%201%20Jan%202006.pdf>

7. Summit on Standards for Arthritis Prevention and Care

KTE is not just limited to the dissemination of research findings. It is also, through the collaborative efforts of different stakeholders, a tool to influence public policy changes based upon the discoveries of research findings. A relevant example of this is the 2005 Summit on Standards for Arthritis Prevention and Care, which was spearheaded by the Arthritis Alliance of Canada, a group consisting of over 30 organizations interested in improving the lives of people with arthritis (with membership consisting of researchers, consumers, government, NGO's, industry, clinicians and allied health professionals).

These diverse stakeholder groups met to deliberate on which standards, in arthritis prevention and care, would be targeted priorities. After much discussion, three provisional standards and 12 standards of care were agreed upon. The provisional standards are as follows:

1. To prevent arthritis, every Canadian must understand and implement prevention strategies to reduce sport and recreation injuries.
2. Every Canadian with arthritis must have timely access to appropriate integrated health care appropriate to their age and disease stage.
3. Every Canadian with arthritis will be enabled to participate in life roles that are important to them.

For more information on the Standards, check out the link at http://www.arthritisalliance.ca/activities/activities_sapc.html

8. Consumer Advisory Council's Posters and Research Impacts Paper

Traditionally patient involvement in research has been limited to being a respondent (i.e. subject) in research studies. It has not included patients as partners in the entire research process. The CAN model of consumer involvement in arthritis research moves far beyond this role to active participation, including roles such as collaborator on basic research projects, advisor or consultant for working clinicians and community health researchers, and in one instance, even as a Co-Principal Investigator for a research grant application.

Arthritis consumers, as members of the CAC and various other arthritis organizations, are currently involved in every aspect of research and take an active role in monitoring and advocating for the best possible care, treatment and research for patients with arthritis. In order to promote CAN's model of consumer involvement, the CAC created a poster, "Consumers: Equal Partners in Research", which has been presented at several national (ASC Toronto 2008; CDPAC Ottawa 2008) and international (EULAR Paris 2008; IBMO Boston 2008) research conferences and has also been used to educate provincial and local community groups.

A second poster, "Consumer Impacts on Arthritis Research" has been presented at CAN's 2009 ASC and at the International Cochrane Symposium in Keystone, Colorado in 2010. In addition, the "Consumer Impacts on Research" paper was created to inform the research community about the value of including the patient perspective in their research design, preparation, implementation process, and knowledge translation activities. The posters and papers are available on the CAN website at www.arthritisresearch.ca

9. The Highly Qualified Consumer Database (HQC)

The HQC Database was created by CAC members to help guide researchers in their search for the right consumer to assist with their research project. It is an online resource where researchers can choose from a large group of volunteers, living across Canada and representing all the different types of arthritis, and willing to act as consultants or collaborators on research projects. This tool for KTE is primarily focused on enabling researchers to find highly qualified consumers to involve them on research teams to enable these individuals to contribute their expertise to enhance and inform current and future arthritis research projects. You can find the HQC Database here: www.arthritisnetwork.ca/hqc

VIII. CONCLUSION

The purpose of this KTE booklet is to demonstrate how consumers can participate in KTE efforts that will improve the care and treatment of people living with arthritis and to improve their quality of life. Investigators, trainees and consumers can work together successfully to achieve maximum impact of their research results by respecting what each group brings to the research team and by creating a KTE plan to follow.

It will require collaboration from the whole arthritis community to ensure that we achieve CAN's vision of "A world free of arthritis" and KTE activities are key to this endeavour.

Endnotes:

¹ In the authors' experience, Knowledge Translation (KT) and Knowledge Translation and Exchange (KTE), are frequently used interchangeably. This booklet prefers the term KTE because it emphasizes the exchange of knowledge with the public.

² Canadian Institutes of Health Research: <http://www.cihr-irsc.gc.ca/e/39033.html>

³ "People Getting a Grip", by Lucie Brosseau, Sydney Lineker, Mary Bell, George Wells, Lynn Casimiro, Mary Egan, Ann Cranney, Peter Tugwell, Keith G Wilson and Gino De Angelis. School of Rehabilitation Sciences, University of Ottawa, Canada, The Arthritis Society, Ontario Division, Arthritis Rehabilitation and Education Program (AREP), Toronto (Ontario), Canadian Rheumatology Association & Sunnybrook and Women College of Health Sciences Center, Toronto (Ontario), Department of Epidemiology and Community Medicine, University of Ottawa, Canada, Clinical Epidemiology Program, Ottawa Health Research Unit, Ottawa Hospital, Civic Campus, Ottawa, Canada, Centre for Global Health, Institute of Population Health, University of Ottawa, Ottawa, Canada, Psychology Discipline, The Ottawa Hospital, Rehabilitation Centre, Ottawa, Canada, University of Ottawa, Canada. This study was supported financially by The Canadian Institute for Health Research (grant #KRS-79768) The Arthritis Society (Canada) for In-Kind; Pace Canada for educational material and instructor; Career Scientist Salary Support Programme for LB, University of Ottawa: University Research Chair Program for LB and the Ministry of Human Resources, Summer Students Programme (Canada).