

CANADIAN ARTHRITIS NETWORK
CONSUMER PERSPECTIVE

**CONSUMER IMPACTS
ON RESEARCH AT
THE CANADIAN
ARTHRITIS NETWORK**

November 2009



CANADIAN ARTHRITIS NETWORK | LE RÉSEAU CANADIEN DE L'ARTHRITE

Canadian Arthritis Network Consumer Impacts on Research at the Canadian Arthritis Network November 2009

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INTRODUCTION

Since the Canadian Arthritis Network's (CAN) funding in 1998, consumers, or people living with arthritis who are knowledgeable about research and advocate on behalf of its importance, have been an integral part of the Network. Consumers are involved in every aspect of CAN, with membership on each of its committees. Consumers also have their own working committee called the Consumer Advisory Council (CAC) that is composed of volunteer consumer representatives from each province/territory in Canada.

Specific to research, consumers provide a patient's perspective on relevant topics for consideration by both Network Investigators and trainees. Consumers also participate in research projects in various capacities: as advisors to Network Investigators as they brainstorm research projects and write grant applications, as active participants in the research project itself, and, in disseminating the important outcomes of research. Consumers also act as peer reviewers for research and training grants.

This document is the first of its kind that has been put together by consumers to track specific impacts consumers have had on research projects within CAN. The document is structured to demonstrate impacts consumers have had on research in various capacities:

- 1. Impact on Research Strategy and Direction:** explains how consumers are active members of CAN's committees and participants in and organizers of CAN's Annual Scientific Conference.
- 2. Impacts on Research and Trainee Projects:** shows how consumers participate in different ways in research projects; for example, as consultants in planning research projects, to help disseminate outcomes of the research projects, and to work with trainees on their research projects and provide (usually) their first exposure to consumers early in their research careers.
- 3. Other Initiatives:** outlines other areas in which consumers have impacted research in some capacity; for example, by building a database with information on consumers, by representing CAN at international arthritis meetings, and through the creation of various publications to benefit both researchers and consumers.
- 4. Future Directions:** this section recommends how consumers can continue to be integrated in all research activities associated with CAN. It is important that consumer involvement in research is supported by all members of CAN, and that consumers truly be

integral to the research team, not present simply as supporters of the research idea. Additionally, when consumers have the chance to demonstrate the value they bring to the CAN research model through posters, presentations, etc., other organizations can see for themselves how consumers could benefit their own research efforts.

It is hoped that this document can serve as a reference for how consumers have impacted research in CAN to date, and can also be a dynamic document that is updated as consumer influence on research continues to grow.

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IMPACT ON RESEARCH STRATEGY AND DIRECTION

This section outlines how consumers are integral to all of CAN's committees and have had an impact in the overall research direction of the Network. Consumers have become regular participants at CAN's Annual Scientific Conference, have been strong proponents of the need to communicate research and training projects in lay terms through the use of plain language summaries, and have highlighted the need for the arthritis research community to study specific research themes that deeply impact patients with arthritis.

Membership on CAN Committees

Board of Directors

A member of CAC sits as an Observer on CAN's Board of Directors, a seat which has been held since 2007. Although this member does not have voting privileges on the Board, this person is able to speak on behalf of CAC and consumers when input is sought. By simply being present at Board meetings, this individual brings the CAC's interests in research to light in this forum. There are Board members who are also living with arthritis who offer the patient perspective, but they are not formally members of CAC.

Research Management Committee (RMC)

The RMC sets the research strategy at CAN and makes all recommendations to the Board of Directors associated with funding the research and training programs. The CAC reports to RMC in CAN's governance structure. In addition, there are two consumer representatives who are members of the RMC and who both have voting powers. This means that consumers have a direct voice in recommending which research projects are funded, which new research directions are proposed for the Network, as well as which trainees are funded. Consumers also provide input to determine the kinds of research workshops that are hosted by CAN, as well as which workshops delegates may attend who represent CAN.

Scientific and Medical Advisory Committee (SMAC)

The SMAC is comprised of research experts in various topics related to arthritis, and also includes two consumer representatives. SMAC meets to review all grant applications that are submitted to CAN, and the consumer representatives review all of the grants and vote in the same manner as the research experts on the committee. As SMAC members, consumers are directly involved in recommending to the RMC which grant proposals should be funded based on relevance in the arthritis research landscape and alignment with consumer priorities. The fact that consumers vote alongside the experts on this particular committee demonstrates the trust and faith that CAN places on its consumer participants.

Training and Education Committee (TEC)

TEC maintains the training program at CAN and membership is comprised of CAN researchers, a representative of the Arthritis Society, and two consumer representatives. TEC members meet several times a year to review training applications, set the agenda for the training day program at CAN's Annual Scientific Conference, and also set agendas for other trainee events throughout the year. In addition to dedicated CAC members on TEC, representatives of CAC form an *ad hoc* committee on TEC during the training application review process. The number of consumers needed for the *ad hoc* committee is based upon how many applications are received, but is generally 1 – 2 people. As with the other committees at CAN, consumer members have an equal voice and the opportunity to share the consumer perspective.

Annual Scientific Conference (ASC) Planning Committees and Participation in the ASC

Every year, consumers participate on CAN's Annual Scientific Conference planning committee. In this capacity, consumers help determine which topics and presenters will be part of the ASC. It is consumers who ensure the participation of their peers in every panel of the ASC. Yearly ASC surveys of delegates have praised the ASC's substantive consumer involvement.

In addition to being presenters in the symposia, consumers participate in other ways at the ASC. With the launch of the first Training Day in 2007, consumers have been given the task of leading a Consumer Lunch that features short lectures on a variety of topics of interest to trainees. The remaining CAC members who are not presenting join the trainees at their tables for lunch and an opportunity to interact. This CAC initiative is supplemented by a guide the Council produced for new trainees. Consumers also participate as judges of the scientific posters at the ASC and offer the trainees new perspectives into arthritis research during the poster presentation. It is hoped that this exposure to consumers, and the active discussions that occur during the lunch and poster sessions, cause the trainees to reflect on their research projects and what impact their research has on people living with arthritis.

It is strongly believed that the exposure of consumers to both researchers and trainees, and hearing how research impacts their lives and what research topics are most relevant to them, has a very real influence on the types of research that are carried out in the Network. It is essential for researchers to be exposed to consumers for this to occur; therefore, patients must continue to be given opportunities to speak at and participate in these meetings.

Plain Language Summary

All grant and trainee applications that are submitted to CAN and all poster presentations at CAN meetings require a plain language summary (i.e. one that does not utilize scientific terms or acronyms). Consumers have championed the need for plain language summaries that provide important insights into research findings and also demonstrate the need for the general public to understand research outcomes. Plain language summaries have further contributed to the overall understanding that research scientists have of each other's work. Furthermore, consumers are involved in helping teach trainees how to produce plain language summaries and why they are important. Consumers continue to stress the value of these summaries and how these positively impact knowledge translation of research that is carried out by CAN participants.

Pain and Fatigue as Topics of Research

Pain is something with which all consumers have an intimate relationship. Many consumers advocate for resources to be allocated towards pain research - the etiology and origins of arthritis pain, to new treatments for pain. Fatigue is also something that is all too familiar to consumers. In May 2006, CAN hosted a Workshop on Pain and Arthritis in Calgary. Outcomes of this meeting included a consumer perspective white paper (http://www.arthritisnetwork.ca/home/pain_and_arthritis_research_workshop_en.php) and heightened awareness of the importance of pain and fatigue research to the people they impact the most: patients. As a consequence of this workshop and several other initiatives stemming from the CAN/TAS/CIHR¹-sponsored OA (osteoarthritis) Consensus Conference in 2002, pain and fatigue have become topics that are increasingly studied in the Network. For example, CAN also funded two New Emerging Team grants on pain and fatigue in 2003. Each has consumer representatives.

IMPACTS ON RESEARCH AND TRAINEE PROJECTS

This section outlines very specific impacts that consumers have had on research and trainee projects within CAN. In the first section, key contributions are highlighted that consumers have made to different types of research projects. The second section summarizes how members of CAC have been involved in working with trainees on their research projects.

Research Projects

Consumers collaborate and advise on research projects in many ways at CAN, including: dissemination and communication of results and progress; provision of expert consultant

¹ The Arthritis Society and the Canadian Institutes of Health Research's Institute of Musculoskeletal Health and Arthritis

advice on projects; participation as collaborators; and, contribution in developing and defining research questions and facilitation of the project as co-investigators. Specific examples of consumer participation and contribution to research projects at CAN are provided in **Appendix A**.

Trainee Projects

Typically when CAN trainees are introduced to consumers, this is their first exposure to patients working in the research arena. It is felt that this exposure provides trainees with valuable insight that will impact their subsequent research decisions and projects. To date, consumer participation in trainee research projects has been minimal, and this is an area in which CAC would like to become more active in the coming years.

Summer Research Program for Medical and Allied Health Professional Students

CAN supports a Summer Research Program for Medical and Allied Health Professional Students, whereby students conduct research in the lab of a Network Investigator. Consumer involvement in the program has evolved since the program began in 2006. Consumers initially participated in the orientation day provided to students, presenting anecdotes on themselves and their arthritis, interacting with the students over lunch and during the day, and afterwards participating in teleconference updates that the students provided on their research projects over the summer. Consumer involvement has become more integrated in the program with participation in these activities as well as acting as mentors via 'assignment' to assist specific students in the program. Students are also encouraged to consult with their consumer mentor for help writing plain language summaries of their work as well as when they present at teleconferences. This valuable introduction to consumers early in their research careers and exposure to arthritis research through the patient perspective is believed to bring new meaning to the students about their work. It is also hoped that this experience will provide students the motivation to consider rheumatology as their specialty or consider arthritis research in their future career. Consumer involvement in this program is listed in **Appendix B**.

Trainee Workshop

Two trainee workshops have been hosted by CAN: in Montreal in March 2009 and in Toronto in March 2008. Consumers were present at both of these events to interact with the trainees and to provide exposure to patients living with arthritis.

Annual Scientific Conference

Consumer activities associated with trainees that occur at the ASC are described above in the section titled Impact on Research Strategy and Direction.

OTHER INITIATIVES

This section describes consumer participation in a number of initiatives not already documented. As outlined, consumers are active participants in all scientific meetings and workshops that CAN hosts; however, consumers often represent CAN at other meetings, which is a great privilege in itself. Additionally, members of CAC have, of their own initiative, provided more research resources to both CAN members and other consumers. In the course of a decade of working closely with researchers, consumers would like to demonstrate additional value they can bring to research through their own ideas.

Participation at Scientific and Non-Scientific Meetings

CAC members participate in all meetings and workshops that CAN hosts. They also represent CAN at meetings hosted by other organizations to which CAC members have personal affiliations. Outside of the ASC, CAC members have also attended a number of conferences, which are listed in **Appendix C**.

Highly Qualified Consumer Database

Consumers on CAC have undertaken to produce a database of Highly Qualified Consumers (HQC) that will be available to all membership in CAN. The database will be a storehouse of information on consumers who have the capacity and knowledge to work in different areas of research with either Investigators or trainees. The database will be dynamic and searchable, and will be easily accessed to find a consumer to participate on a research project or work with trainees on their projects. It is anticipated that the HQC database will have its pilot launch in 2009 and its public launch in 2010.

Poster Presentations

CAC has created its own poster to be presented at arthritis meetings. The poster follows a scientific format and provides an introduction to and overview of CAC with respect to how the Council functions and how it is part of CAN's organizational structure. The poster was created to specifically demonstrate to international groups how consumers can bring value to a research Network such as CAN, and was first presented at the European League Against Rheumatism in 2008. CAC has also developed another scientifically-formatted poster on impacts that consumers have had on research at CAN. This poster debuted at the Segal North American Osteoarthritis Workshop in 2009 and will be presented at other meetings to demonstrate additional value that consumers can bring to research.

Publications

Consumers have published a number of documents that may be useful to other patients as well as to researchers. These publications are listed in **Appendix D** along with descriptions of their contents.

Consumer Education and Training

Consumers always strive to gain more knowledge about research and the research process, with the goals of better educating ourselves and working more effectively with researchers and trainees. CAC meets three times a year and education and training are components of these meetings. Past training sessions for consumers are listed in **Appendix E**. Future training topics for consumers include how to write poster abstracts and research ethics related to involving humans as research participants.

Additionally, CAC strives to educate other patients with arthritis and the public in general about arthritis research. Local consumers are invited to interact with CAC members for a portion of CAC meetings and are also invited to attend CAN's ASC.

In the spring of 2009, CAC hosted a successful public event in Toronto called CAN CARES (CAN's Canadian Arthritis Research Exchange Seminars) that highlighted different types of arthritis research and initiatives that are being led by Ontario researchers. The event was designed to encourage audience interaction and participation, and was aimed at educating the public on arthritis research. This inaugural event will hopefully be the first of many to come for CAC.

FUTURE DIRECTIONS

It is important to consumers that we remain fully integrated in all aspects of CAN, particularly within the research program. Consumer involvement in CAN has come a long way since its inception in 1998. However, as with any initiative, improvements can always be made. As consumers, we encourage CAN to continue to involve us in research at CAN through:

- **Active involvement in all types of research projects:** Consumers have valuable insights into arthritis and research and need to be included on all CAN-funded research projects. In some research teams, consumers are simply there to provide a supportive opinion of the research, without true integration, which consumers hope to change in coming years.
- **Additional involvement in trainee research projects:** In the past 2 years, consumers have gained considerable access to interface with trainees, both as part of the annual ASC Training Day as well as the Summer Research Program for Medical and Allied Health

Professional Students. CAN is strongly encouraged to maintain or ideally increase trainee exposure to consumers. For example, there has been little specific interaction between trainees and consumers on specific research projects; to date interactions have been during workshops, the Consumer Lunch at the ASC, and during poster judging at the ASC. It would be incredibly beneficial for trainees to begin working with consumers on their research projects at this early time in their research career instead of at a later date when they become Principal Investigators.

- **Continued involvement as presenters at the ASC:** The 2008 ASC marked the first time that consumers spoke as research equals on the presentation panels. Consumers demonstrated their knowledge of arthritis and the research landscape by making presentations that were not simply personal accounts of living with arthritis. That consumers could stand side by side with renowned researchers and present compelling data and outcomes could not help but improve consumer credibility within the research community. One 2008 ASC symposium was moderated by a consumer, Ms. Linda Wilhelm, whose professionalism and knowledge provided increased consumer credibility with researchers. CAN is strongly encouraged to provide consumers with these opportunities at future ASCs.
- **Continued representation at international meetings:** Consumers bring a valuable perspective to research that is supported by CAN so their attendance at international meetings is tremendously important. Consumers have now demonstrated their aptitude for presenting scientifically-formatted posters at such meetings, which helps demonstrate the success of the CAN research model. It is firmly believed that consumers demonstrating their own strengths as part of a research team is immensely valuable to convince other research organizations how consumers could successfully integrate into their research programs.
- **Continued education of consumers and their peers:** The importance of educating the general public and arthritis patients of the value of arthritis research cannot be underscored enough. CAN CARES presented a unique forum to do this and feedback indicated that it was very successful. Consumers also need to keep increasing their own competencies with respect to research, and learning more about research ethics and clinical trials from research experts is a priority going forward.

Since we know that CAN funding from the Government of Canada's Networks of Centres of Excellence will cease in 2012, we are beginning to work on initiatives that will be considered legacy when this happens. Perhaps the most important of these initiatives is to remain integrated in arthritis research in Canada.

CONCLUSION

As this document demonstrates, consumers have made valuable contributions to the arthritis research community in Canada. Consumers play important roles in research projects and they bring unique skills and resources to disseminating the information that results from these research projects. In November 2008, former CAC member Jean Légaré's substantial contributions to research were recognized with an honorary doctorate degree bestowed on him by the University of Laval, upon nomination by his researcher colleagues. This honour from research peers publicly acknowledges the value a consumer can provide to arthritis research and reinforces the important role consumers perform in research projects. Through demonstrating the impacts that consumers have had on CAN over its eleven-year history, it is our hope that consumer participation in research will continue to grow within CAN and also beyond CAN's borders to be adopted by other research organizations.

APPENDIX A CONSUMER PARTICIPATION IN RESEARCH PROJECTS

Determinants and Consequences of Pain and Fatigue in Osteoarthritis (OA) Using a Biopsychosocial Approach

SRI-OA-03, funding period: 2003 – 2008

PI: Dr. Gillian Hawker

Co-Investigators: Drs. Elizabeth Badley, Monique Gignac, Aileen Davis, Sarah Romans, Allan Gordon

Consumers: Ms. Patricia Cooper, Ms. Margaret Elliott, Ms. Anne Fouillard, Ms. Carol Halberstadt, Mr. Dennis Jeanes, Ms. Ann Kay, Ms. Sheila Kimmel, Ms. Colleen Murray, Ms. Sophie Phillips, Ms. Olive Thorne, and Ms. Gail Webster

A consumer advisory group was established to provide the perspective of persons living with OA, and included membership from across Canada, and one member from the USA. This consumer group was actively involved in all aspects of the research: from research decision-making to communication.

Consumer collaborators on this project have been involved in:

- Introductory team meeting
- Attendance at all team meetings in person or by teleconference
- Pilot testing and feedback on new instruments and questionnaires
- Participant perspective of feasibility of new studies
- Interpretation of study results

- Writing articles for newsletters (including the *OA and You* newsletter and the *Study of Arthritis in Your Community* study newsletter)
- Participating in conferences including CAN (2005, 2006, 2007) and Segal (2007) conference as OA consumer representatives
- Presentations at conferences including CAN
- Collaboration on grant application submissions.

Tooling Up for Early Osteoarthritis (TUFEOA): Measuring What Matters

SRI-OA-02, funding period: 2003 – 2008

PI: Dr. John Esdaile

Co-PI: Dr. Monique Gignac

Co-Investigators: Drs. Elizabeth Badley, Jacek Kopek, Diane Lacaille, Robin Poole

Consumers: Ms. Pam Montie, Ms. Cheryl Koehn, Ms. Jay Fiddler, Ms. Anne Fouillard, Mr. Jean Légaré, and various members of the Canadian Arthritis Patient Alliance, and the Consumer Advisory Board at the Arthritis Research Centre

This research project has considered input from consumers to be integral to its design. In addition to being responsible for knowledge translation activities, the consumers have been involved in all aspects of the project, from defining areas of greatest interest to people living with arthritis, to reviewing the existing research, designing a new measure (Social Role Participation Questionnaire), creating a conceptual model and decisions about piloting the measures.

More specifically, consumer collaborators on this project have been actively involved in dissemination of research results:

- **Website:** A website has been launched called Osteoarthritis and You: Your Link to Osteoarthritis Research in Canada (<http://net.arthritisresearch.ca/oapublic/default.htm>). The user-friendly website built awareness and knowledge about early OA and introduced the program to key target audiences. The dynamic website contains information such as biographies on all the TUFEOA team members including the consumers, the plain language research summaries for the TUFEOA projects, the “OA and You” newsletters and links to other relevant sites. Since its launch in November 2004 there have been over 17,000 visitors to the site.
- **Plain Language Research Summary:** The involvement of consumers as co-investigators and advisors has ensured the inclusion of appropriate questions and means of evaluation relevant to people with OA. Consumers have facilitated the interpretation and dissemination of results to the general public by creating a plain language template for the

team's research summaries. Each of the TUFEOA funded projects has had a plain language summary vetted and approved by the consumer group.

- **Newsletters:** Through effective translation of TUFEOA team projects into plain language, the "OA and You" newsletter has facilitated the rapid "uptake" of emerging news about the research on early OA with a view to improving the health and well being of Canadians. This consumer-inspired newsletter reaches those individuals who do not access the web. It has been disseminated to government officials, family physicians and the public. The TUFEOA team is developing relationships with professional and consumer organizations to broaden the reach of the publication. An educational grant from Novartis was received for distribution of the newsletter. This initiative has also brought together other research teams.
- **Glossary:** A glossary of arthritis research terms has been developed by Mr. Jean Légaré and published on the "OA and You" website.
- **Public Forums:** The TUFEOA's consumers and investigators have presented at public forums such as the Roundtable on Arthritis Research (ROAR). There are plans to air this forum on educational TV and via podcast to reach a wider audience, as well as the potential to develop a DVD that would be used by The Arthritis Society. The consumer collaborators also participated in workshops such as the Pain and Arthritis Research Workshop hosted by the Canadian Arthritis Network. Ms. Jay Fiddler, one of the team's consumer collaborators, was a co-author of the white paper that was produced following the workshop.

Biology and Outcomes in Spondyloarthritis: A Transdisciplinary Prospective Multicentre Study

04-SRID-IJD-05, funding period: 2004 - 2005

PI: Dr. Rob Inman

Co-PIs: Drs. Dafna Gladman, Walter Maksymowych, Proton Rahman, Millicent Stone

Consumers were involved in this project as advisors and provided information about research that is relevant to patients via patient forums. In one instance, the researchers analyzed questionnaires completed by 2,600 individuals with spondyloarthritis (SpA). The results of the study provided new determinants of disability, which have since been presented at international meetings and submitted for publication. This represents an example of the value of using patient-generated data in large studies on SpA. There has also been a patient forum conducted in Toronto for AS patients, sponsored by the Ontario Spondylitis Association. The event was conducted at a Toronto teaching hospital and simulcast to patient groups meeting at the same time in Thunder Bay, Atikokan, and Kenora. The session provided real-time interaction between the patients and experts from the fields of rheumatology, physiotherapy, and occupational therapy, as well as with other patients. This has proved to be an extremely

effective means of communicating with individuals across large areas, particularly those from remote regions of the country.

The investigators of this work have developed a world-class research program, and their interactions with patients have provided such positive feedback and knowledge that they will continue to utilize these types of forums.

Disability at Work: Measuring the Progression of At-Work Disability and Workplace Productivity Loss

05-SRID-IJD-01, funding period 2006 – 2007

PI: Dr. Dorcas Beaton

Co-PIs: Drs. Aslam Anis, Elizabeth Badley, Claire Bombardier, Diane Lacaille, Monique Gignac

Consumer: Ms. Pam Montie

The lead consumer was involved in the initial design as well as the data analysis and interpretation of the results of the project. The project's success was based on the high level of patients who answered the questionnaire: of 250 participants, 213 of them answered questions at baseline, 3, 6, and 12 months. The consumer feedback on the baseline questionnaire has prompted the investigators to publish a paper on just this aspect. The investigators attribute the high participation rate to the rapport they developed with consumers and their ability to successfully manage expectations. Early results from the study were presented at an international meeting, Outcome Measures in Rheumatoid Arthritis Clinical Trials (OMERACT).

Development of a Self-Management Distance Treatment for Adolescents with Arthritis: Phase 1

05-SRID-IJD-04, funding period 2005 – 2006

PI: Dr. Brian Feldman

Co-PIs: Drs. Patrick McGrath, Bonnie Stevens, Rae Yeung, Ciaran Duffy, Peter Malleson, Adam Huber

Consumers: Ms. Jacqueline Lukas, Ms. Corrie Billedeau, Ms. Laurie Proulx

Consumers were recruited to assist with knowledge translation and results analysis purposes. They were instrumental in helping analyze the results from patient interviews (phase one). The investigators aim was for these consumers to enable “consumer detailing,” i.e. through the translation of the study's findings to consumers across Canada, who would then educate their own health care providers. This has been demonstrated as one of the most potent methods for changing practices and disseminating new knowledge.

Due to such a positive experience with consumers in the first phase of this study, the investigators enlisted an additional consumer to aid in the second and third phases (see Development and Usability and Feasibility Testing of a Web-based Self-Management Intervention for Adolescents with Arthritis). Consumers participated in all phases of the research process from grant writing, website content development, data analysis and dissemination.

Quality of Care for RA at the Population Level

05-SRID-IJD-06, funding period: 2005 – 2006

PI: Dr. Diane Lacaille

Co-PIs: Drs. John Esdaile, Aslam Anis, Michal Abrahamowicz

Consumers: Ms. Pam Montie, members of the Consumer Advisory Board at the Arthritis Research Centre of Canada

The investigators on this research project utilized consumer expertise for knowledge dissemination as well as for input on any materials that were communicated to patients. For example, a consumer presented at the Roundtable on Arthritis Research (ROAR) to help engage other consumers to participate in this project, while consumers were also involved in helping to select relevant educational materials to send to patients who might participate in this study, and to review consent forms and letters to patients.

Pharmacist-initiated Intervention Trial in Osteoarthritis (PhIT-OA)

2006-SRID-OA-01, funding period: 2006 - 2007

PI: Dr. Carlo Marra

Consumers: Ms. Cheryl Koehn (Arthritis Consumer Experts), and members of Canadian Arthritis Patient Alliance, Canadian Arthritis Network Consumer Advisory Council, and Consumer Advisory Board at the Arthritis Research Centre

The lead consumer on this project consulted with the project team to determine the relevant questions to be answered by the project, appropriate methods to use, pertinent outcomes to assess, and effective knowledge translation strategies. In addition, news of the PhIT-OA projects have been communicated in Arthritis Consumer Experts' (ACE) JointHealth™ monthly newsletter (national subscription: 15,000) and in ACE's communications with the BC Ministry of Health and Ministry of Advanced Education. These efforts support the research team's plans to partner with government to better meet the educational, research and treatment needs of British Columbians living with osteoarthritis.

Autologous Embryonic Stem Cell-Based Therapy for Articular Cartilage Repair in a Large Animal Model: Preparation of Cell Lines

06-SRID-BIO-02, funding period: 2006 – 2007

PI: Dr. Sheila Laverty

Co-PIs: Drs. Lawrence Smith, Janet Henderson, Michael Underhill

Consumer: Mr. Jean Légaré

The consumer role on this research project was mainly in a support and reviewing capacity: to review the research proposal and provide comments, to provide a letter of support, and, to review the abstract presented at the CAN ASC in Halifax and a progress report.

Development of a SPECT/MR Camera for Imaging Bone and Joint Integrity in the Hand

06-DAP-Webber, funding period: 2006 – 2007

PI: Dr. Colin Webber

Consumer: Ms. Mary Knowland

The consumer involved in this project had a minor advisory role: attending a research team meeting where the ultimate design of the instrument was considered, particularly with respect to the ability of patients with arthritis to remain stationary during an imaging procedure.

Getting a Grip on Arthritis: 12 Month Evaluation

SP-2006-Badley, funding period: 2006 – 2007

PI: Dr. Elizabeth Badley

Co-PI: Dr. Mary Bell

Consumer: Ms. Anne Lyddiatt

The consumer was involved from the initial planning stage and felt that the workshops raised awareness of arthritis and the impact it has on Canada, from both the health care and economic aspects, and provided ways to address these issues. The consumer's role was to coordinate the project's patient involvement: a total of 94 consumers participated across Canada. These consumers were able to share not only specific medical information but also the reality of life with arthritis, and they offered workshops to other people with arthritis on various topics.

Development and Usability and Feasibility Testing of a Web-Based Self-Management Intervention for Adolescents with Arthritis

07-SRID-IJD-02, funding period: 2007 - 2008

PI: Dr. Patrick McGrath

Co-PIs: Drs. Ellen Hodnett, Brian Feldman, Ciaran Duffy, Adam Huber, Lori Tucker, Ross Hetherington, Rae Yeung

Consumers: Ms. Jacqueline Bretzler Lukas, Ms. Laurie Proulx, Mr. David Prowten (father of a child with JIA)

Ms. Bretzler Lukas and Proulx, also members of the Canadian Arthritis Patient Alliance (CAPA), were involved in the refinement of the initial application and members of the website development committee. They contributed to the development and revision of educational content for several modules of the website and videos. They also reviewed other JIA websites and rated them in terms of content and relevance to be included as resources in this self-management program. This review will be written up for publication and submitted to the British Medical Journal, with the consumers as authors. They have reported back on the project's progress to CAPA and linked the investigators with other CAPA initiatives in Canada (e.g., website development in BC). Mr. David Prowten was involved in the project as a website reviewer.

In addition to the consumers involved formally on this project, one of the members of CAC (Ms. Linda Wilhelm) was contacted by the mother of a 13 year old girl who had JIA. Ms. Wilhelm's knowledge of the research landscape allowed her to put the family in contact with Dr. Jennifer Stinson, who has since given the girl an opportunity to be part of this study.

Peer to Peer Mentoring: Facilitating Individuals with Early Inflammatory Arthritis to Manage their Arthritis

09-SRP-IJD-16, Funding period: 2009-2011

PI: Dr. Mary Bell

Co-PIs: Drs. Joyce Nyhof-Young, Joanna Sale, Joan Sargent, Peter Tugwell, and Ms. Paula Veinot

Consumer: Dr. Dawn Richards

Dr. Richards has been involved in this project since its inception, working closely with the team in writing the grant and providing advice as a relatively newly diagnosed person with inflammatory arthritis. She has participated in helping train medical students who were involved in acquiring information from patients, their families, and healthcare providers about their needs for the proposed peer to peer mentoring program. She has participated in team

meetings and as part of the Peer Training Working Group that will design the peer training module and implement the pilot training of peer mentors. She has also worked side by side with the team in their qualitative meta-ethnography efforts to perform a targeted review of the literature on peer mentoring programs that exist in the chronic disease space.

Joint Motion Program: Transdisciplinary Training in Musculoskeletal Health Research and Leadership

Funding period: 2009-2015

Co-Directors: Drs. Jeff Dixon and Trevor Birmingham

Consumer: Mr. John Coderre

This project is funded by CIHR under its Strategic Training Initiative in Health Research (STIHR) program. Dr. Jeff Dixon is a CAN Network Investigator and is very intimate with the consumer model of research at CAN. Mr. John Coderre has been asked to be the consumer representative on the grant's Program Advisory Committee (PAC). The PAC will provide advice and guidance to the program on sustainability, knowledge translation, commercialization and scientific priorities. Additionally, the PAC will be the final approving authority for accepting new trainees and mentors and will assess the program's annual report and activities, including curriculum, outreach and management. The PAC's recommendations will be passed to the Program Operations Committee (POC) for implementation.

Appendix B Consumer Participation in the Summer Research Program for Medical and Allied Health Professional Students

2009

Ms. France Gervais
Ms. Janet Gunderson
Ms. Simone Hughes
Mr. Jean Légaré

2008

Molecular Control of Articular Cartilage Degeneration by Transforming Growth Factor Alpha
Student: Mr. Tom Appleton, Supervisor: Dr. Frank Beier
Consumer Mentor: Ms. Iris Maurstad

Correlation Between Synovitis and Cartilage Degeneration in Naturally Occurring Equine Osteoarthritis

Student: Marie-Pier Binette, Supervisor: Dr. Sheila Laverty

Consumer Mentor: Ms. France Gervais

Measurement Testing of an Exercise Attitudes Questionnaire in a Group of Patients 5-11 Years After Anterior Cruciate Ligament Reconstruction

Student: Jason Essue, Supervisor: Dr. Iris Weller

Consumer Mentor: Ms. Linda Wilhelm

Study of Equine Epiphyseal Development Towards Understanding of Osteochondritis

Dissecans: MR, CT Imaging & Histology

Student: Pascal Fontaine, Supervisor: Dr. Sheila Laverty

Consumer Mentor: Ms. France Gervais

Skeletal Muscle Derived Mesenchymal Stem Cells used in Tissue Engineering for Subchondral Bone and Articular Cartilage Repair of Damaged Joints

Student: Colleen Hock, Supervisor: Dr. Laurie McDuffee

Consumer Mentor: Ms. Linda Wilhelm

Determining whether Paper-based and Web-based Methods of Patient Reported Measures are Comparable in PsA

Student: Heather MacKenzie, Supervisor: Dr. Dafna Gladman

Consumer Mentor: Ms. Linda Wilhelm

Functional-Molecular MR Imaging for the Characterization of Early Hemophilic Arthropathy

Student: Kedar Patil, Supervisor: Dr. Andrea Doria

Consumer Mentor: Ms. Diane Scribe-Niiganii

A Window of Opportunity for Returning to Pre-Disease Functional Ability in a Cohort of Patients with Early Inflammatory Arthritis

Student: Andrea Simpson, Supervisor: Dr. Vivian Bykerk

Consumer Mentor: Ms. Diane Scribe-Niiganii

Rehabilitation Therapists' Perceptions of Barriers to Determine Physician's Tendencies to Refer Patients to Physical and Occupational Therapy Services

Student: My Tram Van, Supervisor: Dr. Debbie Feldman

Consumer Mentor: Ms. Iris Maurstad

2007

Ms. Jay Fiddler

Ms. Anne Fouillard

Ms. Joyce Greene

Mr. Gordon Whitehead

Appendix C Consumer Participation at Scientific and Non-Scientific Meetings

- Osteoarthritis Consensus Conference 2002
- Frontiers in Inflammatory Joint Diseases Conference (2004)
- Summit on Standards for Arthritis Prevention and Care (2005)
- Consensus Conference on Systemic Autoimmune Rheumatic Diseases (SARD) (2005)
- Pain and Arthritis Research Workshop (2006)
- Consensus Conference on Preclinical Models of Osteoarthritis (2006)
- Workshop on Bioengineering for the Restoration of Joint Function (2006)
- Segal North American Osteoarthritis Workshop (2007, 2008, 2009)
- Co-Management Models of Care for Early Diagnosis of Inflammatory Arthritis (2007)
- Advanced Bone and Joint Symposium - Japan Society for the Promotion of Science (2007)
- Childhood Arthritis Rheumatology Research Alliance (2007)
- Outcome Measures in Rheumatology Clinical Trials (OMERACT) (2008)
- International Workshop on Osteoarthritis Imaging (2008)
- European League Against Rheumatism (EULAR) (2008)
- International Symposium on Biotechnology in Musculoskeletal Repair (2008)
- Health Canada's Expert Advisory Committee on the Vigilance of Health Products Meeting (2008)
- Chronic Disease Prevention Alliance of Canada (2008)
- Canadian Rheumatology Association Annual Meeting (2007, 2008, 2009)
- The Drug Information Association Canadian Annual Meeting (2008)
- Arthritis Research Centre of Canada's Roundtable on Arthritis Research (2008, 2009)
- The Banff Inflammation Workshop (2009)
- Canadian Pain Society Conference (2009)
- International Alliance of Patients Organization World Health Organization Workshop (2009)
- Canadian Agency of Drug and Technology in Health Symposium (2009)
- Canadian Agency Drugs Technology in Health (2009)
- Atlantic Canada Chronic Disease Congress (2009)
- Osteoarthritis Research Society International World Congress (2009)

Appendix D Consumer Publications

- *Guide for Researchers and Consumers: Consumer Involvement in Research Projects*: The pamphlet is a guideline for both consumers and researchers on issues that require discussion and consideration when involving a consumer as a team member on a research project. (http://arthritisnetwork.ca/consumers/consumers_arti_en.php)
- *The Role of Consumers in Research and the Expectations and Responsibilities of Researchers*: Related to the above-document, however this one is much more detailed about the specific roles of a consumer in research. (http://arthritisnetwork.ca/consumers/consumers_arti_en.php)
- *Acronyms and Glossary for Consumers Involved in Research*: This document provides a comprehensive listing of acronyms that consumers are likely to encounter in their work with CAN. Acronyms and definitions are from scientific and research language and the arthritis landscape. (http://arthritisnetwork.ca/consumers/consumers_arti_en.php)
- *Consumer Perspective White Paper on the Arthritis and Pain Workshop*: As discussed previously, consumers wrote a white paper on their perspective of the outcomes of CAN's Arthritis and Pain Workshop. (http://arthritisnetwork.ca/home/pain_and_arthritis_research_workshop_en.php)

Appendix E Consumer Education and Training

- 2004: 'Understanding Health Research Statistics' provided by Drs. John Esdaile and Jolanda Cibere; pharmacology introduction given by Dr. Ian Rollo; health economics training given by Dr. Aslam Anis
- 2005: medical imaging overview provided by The Canadian Light Source; a summary of the drug review process in Canada provided by Dr. Roy Dobson; 'Research 101' (quantitative vs. qualitative research; absolute vs. relative risk; trials and interpretation of results) provided by Tracey Weiler; 'Scleroderma 101' and 'Lupus 101'
- 2006: Consumer Health Informatics and participation in Cochrane Review Groups; 'Chronic Pain: Life from the Inside' given by Dr. Lynn Breau; 'What's New in Arthroplasty' provided by Dr. Michael Dunbar
- 2008: The peer review process for grant applications at CAN through working examples provided by Drs. John Esdaile and Robin Poole; how to create a poster using the scientific format presented by Dr. Dawn Richards.