

Consumers in Canadian Arthritis Research

Traditionally patient involvement in research has been limited to providing the bodies or “guinea pigs” for clinical trials for the investigators. At the Canadian Arthritis Network (CAN), the model for patient involvement in arthritis research moves far beyond these limitations. Arthritis patients, or consumers as we call ourselves, are involved in every aspect of research and take an active role in monitoring and advocating for the best possible care, treatment and research for people with arthritis.

CAN was established in 1998 and is currently one of 18 Centres of Excellence funded by the Canadian government. CAN is unusual in its structure, governance and research mandate because it includes people with arthritis on all of its committees as well as its funded research. Dr. Robin Poole, the Network’s recently retired Scientific Director, stated, “CAN is unique in the world because we involve, as equal partners, people with arthritis, the pharmaceutical and biotechnology industries, government and non-governmental organizations in the development, conduct and implementation of our research in the marketplace, thereby ensuring its relevance and application.”[1]

CAN’s Consumer Advisory Council (CAC) is comprised of a diverse membership of volunteers representing a wide range of professional experiences, ages, cultures, languages, geographic regions and types of arthritis. The members of the Council are selected for their commitment to arthritis research excellence and their ability to participate in a fairly rigorous agenda. The majority of members bring a wide background of experience from within their own provinces providing arthritis self-management courses, demonstrating musculoskeletal examinations to medical students or working with arthritis advocacy organizations. When they become part of CAN and the CAC, they also receive two training days each year to increase their understanding of research requirements such as research proposals, peer review protocols, ethics and lay summary requirements, as well as information on current arthritis research. The combination of the members’ backgrounds and this extensive training has resulted in CAN developing “Highly Qualified Consumers” (HQC).

At CAN, CAC members are involved in governance, policy making, research prioritizing, providing consumer consultants to research teams, peer review activities, knowledge translation and exchange activities, and they also act as presenters at research conferences and workshops. These roles are explained more fully below.

Role in Governance

CAN includes members of the CAC on each of its committees: the Research Management Committee (RMC), the Scientific and Medical Advisory Committee (SMAC), the Training and Education Committee (TEC), the Training Adhoc Review Committee and the Board of Directors.

There are two CAC members on the Research Management Committee (RMC) and one CAC member has observer status on the Board. RMC is responsible for determining the strategic vision of CAN while the Board administers the general and financial affairs of

CAN. TEC includes two CAC members as well, and oversees the development of policies and strategies to create innovative training programs which will promote the recruitment, training and retention of outstanding new arthritis investigators.

Role as Research Advisors

CAC members assist with problem identification, research study design, survey development and serve as collaborators and co-investigators on research projects. Their impact was felt at the 2002 Osteoarthritis Consensus Conference where consumers identified pain and fatigue as priority concerns for research. As a result, CAN and the Institute for Musculoskeletal Health and Arthritis (IMHA) co-funded three peer reviewed grants on osteoarthritis for a total of \$4.4 million.

In 2006, CAN held a pain workshop that prominently featured consumers as speakers and focus group participants. Following the workshop, consumers produced their own "Perspective on Pain and Arthritis" that complements a scientific White Paper on the topic. Dr. Marc Pouliot, Associate Professor at the Université Laval in Quebec stated, "By understanding how consumers feel pain, I can target my research to the specific area that will help the most."^[2] More recently, the CAC provided HQC members as consultants or collaborators for every research team that prepared a proposal for CAN's Strategic Research Initiative in Bioengineering for the Restoration of Joint Function competition.

Role as Peer Reviewers

CAC members sit on the Scientific and Medical Advisory Committee, an external peer review committee for CAN's investigator driven research. This committee consists of an international group of leading scientific and medical experts as well as two CAC members who have equal voting privileges in relation to reviewing the research proposals. Additionally, three CAC members sit on the Adhoc Training Application Committee which reviews research proposals submitted by new investigators who are working on their post graduate or doctoral degrees.

Role as Knowledge Brokers

The members of the Consumer Advisory Council have many and varied connections to other arthritis groups throughout Canada. Some of these organizations include The Arthritis Society (TAS), the Canadian Arthritis Patient Alliance (CAPA), the Alliance for the Canadian Arthritis Programs (ACAP), Patient Partners in Arthritis (PPIA) and other disease specific groups such as the Ankylosing Spondylitis Association and Lupus Canada. CAC members make every effort to disseminate the results of research through newsletters, websites, community education forums and outreach activities. A new initiative that is being piloted by the CAC is called CAN CARES.^[3]

CAN CARES is a conference for people with arthritis that will feature some of the Canadian Arthritis Network's researchers for one day of dialogue and networking. It will offer the opportunity for patients, their families and friends to listen to a number of researchers present their findings, pose questions related to each presentation and provide written feedback on each topic. The CAN CARES event is a valuable knowledge

translation and exchange tool. CAC members hope to raise the profile of arthritis research in Canada and promote its importance. The long term goal is to create public demand for “a cure for arthritis” and focus attention on the need for more arthritis research funding.

Role as Co-Presenters

CAC members have presented at various international conferences with CAN researchers. Additionally, for the past several years, consumers have presented in each symposium at CAN’s Annual Scientific Conference as well as at the Training Day for new investigators that precedes the conference. Originally, CAC members revealed their own experiences living with arthritis, but more recently, they have been recognized for the unique contributions they make in the arthritis community and have been asked to share their expertise. For example, in 2008, one consumer demonstrated the musculoskeletal examination for shoulders that medical students are taught, and another presented the topic of “Progressive Licensing in Clinical Trials” as a result of her work with the Public Health Committee on tracking negative side effects. Other topics included “Writing a Good Lay Summary” and “The New Highly Qualified Consumer Database”.

A Model to Emulate

The Canadian Network of Centres of Excellence wrote in its 2004 report, “the integration of the Consumer Advisory Council at all decision-making levels is forward thinking and could be an inspiration to all other Networks of Centers of Excellence”[4]. CAC members think that the CAN model of consumer involvement in research is one which can and should be duplicated in all disease areas and in other countries. Consumer participation increases the legitimacy of health research which is primarily pursued for the benefit of the public. The principle of democracy and the right to participate must be considered in all decisions that directly affect the health and lives of consumers [5]. Their knowledge and experience is invaluable.

The Consumer Advisory Council is convinced that in order to ensure the relevance of any research, to ensure the research results are broadly disseminated, to ensure the results are implemented in current health care policies, and to ensure that unmet needs are met within the arthritis community, consumers must be an integral part in all aspects of any research organization.

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References

1. Dr. Robin Poole. Canadian Arthritis Network 2005 Renewal Application. P. 1
2. Dr. Marc Pouliot. Centre de Recherche en Rhumatologie et Immunologie, University Laval, Quebec, Canada.
3. CAN CARES – Canadian Arthritis Network’s Canadian Arthritis Research Exchange Seminars is based on the successful “Roundtable on Arthritis Research” (ROAR)

This article appears in *EULAR Health Professionals News*, Vol. 9 No. 2, 2008

event developed by Colleen Maloney of the Consumer Advisory Board in the Arthritis Research Center of Canada (ARC) based in Vancouver, BC

4. Networks of Centers of Excellence Selection Committee Report, July 2004.
5. Caron-Flinterman, J.F. Broerse, J.E.W. Bunders, J.F.G. (2004). "The experiential knowledge of patients: a new resource for biomedical research?" in *Social Science and Medicine* 60 (2005) 2575-2584.