

Patient priorities in Medical and Social Research

Title: Consumers: Equal Partners in Arthritis Research

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Background:

The Canadian Arthritis Network (CAN) was established in 1998 and is currently one of 21 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. To satisfy CAN's mandate, the Consumer Advisory Council (CAC) was born in 2002. 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

Objectives:

The Canadian Arthritis Network (CAN) provides an excellent model for successful consumer involvement in all aspects of arthritis research. CAN's integration of the Consumer Advisory Council (CAC) at all decision making levels is an innovative Canadian model that is easily transferable to other disease areas.

Methods:

The CAC is comprised of a diverse membership of volunteers representing a wide range of professional experience, age, culture, language, geographic region and types of arthritis. The members of the CAC are selected for their commitment to excellence in arthritis research. They participate in CAN in several ways:

- 1) As Research Advisors – in problem identification, research study design, survey development and as collaborators and co-investigators on research projects. For example, at CAN's 2002 OA Consensus Conference, consumers identified pain and fatigue as priority concerns. As a result, CAN and the Institute of Musculoskeletal Health and Arthritis co-funded three peer reviewed grants totaling \$4.5 million that relate to OA and pain.
- 2) As Policy Advisors – CAC members sit on every CAN committee
- 3) As Peer Reviewers – two CAC members have equal voting privileges during reviews of all research proposals.
- 4) As Knowledge Brokers
- 5) As Co-Presenters

The Consumer Advisory Council, as its name suggests, is responsible for articulating to the CAN directors, management and members the needs and concerns of people with arthritis as they relate to all CAN initiatives.

Results:

Consumers identify research priorities that are more in line with the needs of people living with arthritis. CAN's OA consensus conference mentioned above is one example of this. Dr. Marc Pouliot, at the Universite 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

Researchers also benefit from the consumer involvement in Knowledge Transfer and Exchange activities. Research results must be widely disseminated and implemented and then consumers must be able to inform researchers about new needs to investigate.

Consumers also benefit from their involvement in CAN. Catherine Hofstetter, of Scarborough, Ontario commented, "CAN is giving arthritis consumers something we have never had before: hope."³

Conclusion:

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 involved in all decisions that directly affect the health and lives of consumers.⁴ Their knowledge and experience in relation to their disease is invaluable.

The Network of Centres of Excellence Secretariat wrote in their 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."⁵ The CAC of CAN is certain that in order to ensure the relevance of any research, ensure the research results are broadly disseminated, ensure the results are implemented in current health care policies, and ensure that unmet needs are addressed by the research community; consumers must be an integral part in all aspects of any research organization.

¹ Dr. Robin Poole. Canadian Arthritis Network 2005 Renewal Application. P. 1

² Dr. Marc Pouliot. Centre de Recherche en Rhumatologie et Immunologie, Universite Laval, Quebec, Canada.

³ Catherine Hofstetter, President, McGowan Fence and Supply Ltd., Scarborough, Ontario, Canada.

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

⁵ Networks of Centres of Excellence Selection Committee Report, July 2004.