

CAPA Research Involvement: It's about asking meaningful questions

By: Anne Dooley

“So, just what does CAPA have to do with research?” I was asked this recently, and it's a very good question.

One of CAPA's strategic priorities is to expand patient involvement in arthritis research, planning and policy development. In fact, CAPA members are encouraged to become involved in all areas and levels of arthritis research, from determining the central research issue and writing research proposals, volunteering as research subjects, acting as investigators and advisers, interpreting research outcomes, and the writing and distribution of research results.

CAPA has been involved with research from the beginning. At the first Steering Committee meeting in December of 2001, we established a set of strategic priorities one of which was for CAPA members to help set the arthritis research agenda. Patients possess knowledge and experience about health care that others don't have, so it makes sense for consumers to be stakeholders at the table for discussions and when research and policy decisions are made.

CAPA participation on the planning committees for the Osteoarthritis (OA) Consensus Conference (2002), for the Frontiers in Inflammatory Joint Disease Conference (2004), and for the consumer conferences that preceded them are examples that help illustrate the point. We acted as panel members, and by fully participating in discussions, helped to define the research issues. One particularly significant contribution was the survey that determined the research priorities of people living with arthritis that was conducted by four consumers, all of whom are CAPA members. The OA conference has led to three major research projects currently underway that are funded by the Canadian Institutes of Health Research Institute on Musculoskeletal Health and Arthritis (CIHR-IMHA) and by the Canadian Arthritis Network (CAN), which is the multi-disciplinary Network Centre of Excellence for Arthritis Research. On these and other projects, including some currently being planned, our members help to guide the research process by serving as advisers and investigators. Many others contribute by volunteering as research subjects and by participating in surveys, a process that collects patient experience, opinion and need.

CAPA members are also members of various advisory panels that encourage both sound research and the protection of the individuals who participate as research subjects. CAPA has members who have been appointed to the CIHR CIHR-IMHA Knowledge Exchange Task Force (KETF), the CIHR Interagency Advisory Panel on Research Ethics (PRE), and Health Canada's Advisory Council on Governance of Research Involving Humans. In addition, we encourage people living with arthritis and other musculoskeletal conditions to apply for membership on Research Ethics Boards (REBs) to provide the patient perspective that would otherwise be absent. However, because of the nature and confidentiality of the material dealt with, and decisions that must be made, this role is not right for everyone.

CAPA also encourages members to join other arthritis and research related organizations and to serve as knowledgeable consumers on boards and panels. We enjoy good working relationships with many such groups and our collaborations and allied memberships help to promote innovative arthritis research as well as bring knowledge gained from research to people living with arthritis. As examples, we are proud to be a contributing member of the Steering Committee of the Alliance for the Canadian Arthritis Program (ACAP), on the board of the Consumer Advisory Council (CAC) of CAN, members of the Consumer Advisory Board (CAB) of the Arthritis Research Centre of Canada (ARC), Arthritis Consumer Experts (ACE), Cochrane Musculoskeletal Review Group (CMSG), and active in Patient Partners in Arthritis, The Arthritis Society, and many more.

Without good communications the knowledge gained from research would gather dust on a shelf. The process of getting this information “from the research bench to the patient's bed” where it can best be used, and also carrying the needs of both patient and clinician back to the research bench, is called KT. This acronym refers to knowledge translation, or as it is also known, knowledge transfer or knowledge exchange. KT is an important part of research. CAPA actively encourages KT primarily through our involvement with the Cochrane Musculoskeletal Review Group (CMSG), which specializes in synthesizing research results and providing reliable best-evidence health care information. For our part, CAPA's Communication and Research Committees work together to help disseminate research based information in a clear and usable form. We also assist the process of bringing the needs and research priorities of consumers to the attention of researchers to complete the KT loop. We encourage the use of CMSG reviews and synopses to help make well-informed treatment decisions, and some of our members are Cochrane Consumer Reviewers who help ensure that this material is clear and understandable to all who will use it. A regular Cochrane feature is also carried in CAPA *Voices*.

In the end perhaps the most basic involvement in research, and most valuable contribution that a CAPA member or any consumer can make, is to ask meaningful questions. Questions drive research, and research is providing the answers to the complicated riddle that is arthritis.