

## **Consumer Engagement in Research Resource for Consumers**

Traditionally, consumer involvement across the research continuum has been restricted to the role of *research participant*. Consumer engagement, however, is about meaningful collaboration. Consumer engagement in health research can be defined as consumer participation in any stage of the research continuum, beyond the role of study participants. The level of advisory and/or decision-making responsibilities may vary in any stage of the research process, however, participation must be meaningful and actively collaborative. The term “consumer” or “patient” is an overarching term that includes individuals who have personal experiences with a health condition(s) or issue(s) or their caregivers, which may include family or friends.

Arthritis Society Canada strongly values the perspectives of our consumer volunteers and understands that they are key stakeholders in research. We respect that consumer volunteers have diverse backgrounds and varying degrees of knowledge regarding research processes.

The following resources have been provided to help support consumer involvement in research:

The Canadian Institutes of Health Research (CIHR) has established funding partnerships with provinces and territories, philanthropic organizations, academic institutions, and health charities to create Canada's Strategy for Patient-Oriented Research (SPOR). SPOR SUPPORT Units provide the necessary training for consumers to participate in research as a partner rather than as a traditional research participant. Arthritis Society Canada strongly recommends that consumers review the CIHR's [training modules on patient engagement](#) (training modules listed under “Patient Engagement Training”).

Additionally, CIHR has compiled [practical guidelines and resources](#) on consumer engagement in research. This list includes resources on a) planning your research project b) budgeting and compensation, c) evaluation and d) theoretical guidelines and resources. These documents provide a more extensive overview consumer engagement practices across the research continuum.

Two Arthritis Society Canada presentations co-developed by Arthritis Society Canada and Canadian Arthritis Patient Alliance (CAPA) provide a succinct introduction to research and the Arthritis Society Canada grant review processes. For an introductory overview of these topics please view the current presentations: [Intro to Research](#) and [Intro to Grants and Peer Review](#).

Lastly, for background information and updates on study recruitment and clinical trials, please view Arthritis Society Canada's [website](#).

Arthritis Society Canada is committed to supporting consumer engagement in research. For inquiries or comments, please email [research@arthritis.ca](mailto:research@arthritis.ca).