

Consumer Engagement in Research Resource for Researchers

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 or issue(s) or their caregivers, which can include family or friends.

The Canadian Institutes of Health Research (CIHR) has created a [guide](#) to researcher and knowledge-user collaboration in health research, which provides an outline of the history and basic principles of participatory research and provides evidence-based guidelines for engaging with consumer partners.

CIHR has also created a master list of [practical guidelines and resources](#) from across reputable organizations, such as CIHR, the Patient Advisors Network, the National Institute for Health Research, and more. This list includes resources on a) planning your research project, including a plain language checklist, b) budgeting and compensation, c) evaluation and d) theoretical guidelines and resources. Arthritis Society Canada strongly recommends that all researchers review CIHR’s consumer engagement in research resources prior to engaging with consumers across the research continuum.

CIHR has also 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 researchers with information and resources on best practices in consumer engagement. Many SPOR SUPPORT Units offer training sessions, access to clinical and administrative data, and other types of support. Please view CIHR’s website for more information.

Arthritis Society Canada is committed to supporting consumer engagement in research. For inquiries or comments, please email research@arthritis.ca.