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What is CAPA?

- Virtual, patient-driven, national arthritis advocacy organization
- CAPA is about: education, awareness, collaboration, advocacy and involvement in research
- Partners: Patient organizations, Researchers & clinicians, Professional associations, NGO's, Government, Industry
- Priorities:
 - Obtain timely access to treatments
 - Support the priorities of the Arthritis Alliance of Canada
 - Expand patient engagement into all areas of health policy decision making including research

CAPA Activities

- Website & Facebook page - www.arthritispatient.ca
- Quarterly Newsletter
- Knowledge Translation and Exchange
- Circulation of research opportunities throughout our networks
- Dissemination of research results
- Letters of support for research projects

CAPA Activities

- Collaborators and partners on Research Grants
- Grant reviews on value of proposed research to patients
- Patient Initiated Research on Patient Reported Outcomes
- Communicate the value of research to other patients and policy makers
- Mentorship

CAPA Believes

- The first expert in arthritis is the person living with arthritis.
- People with arthritis have the right and responsibility to be included in the policy, health care and research decisions related to their health and quality of life.

“Those affected by the decision must be involved in making the decision”

What expertise do patients bring

- Lifelong burden of disease across the entire continuum of care
- Interaction with all aspects of health care system
- Knowledgeable about their disease
- A broad understanding of research gaps

Success in Engagement

- The Canadian Arthritis Network's Consumer Advisory Council
- Canadian Agency for Drugs and Technology in Health Patient Input Process
- Health Canada Patient and Public Involvement

Success in Engagement

- Strategy for Patient Oriented Research (SPOR)
 - Chronic Pain Network
 - Provincial/Regional Support Units
- James Lind Alliance
 - Priorities for Chronic Kidney Disease and Fibromyalgia

Successful Engagement

- Full Representation and Membership on Decision Making Bodies; Committees, Boards
- Compensation for Time and Input
- Reimbursement for out of pocket expenses
- Validation that participation has been valuable
- Patient Input has changed the direction

Barriers to Engagement

- Value of having patients engaged not recognized or appreciated
- No compensation for time or reimbursement of expenses
- Not all patients want or are able to engage
- Lack of knowledge on both sides to engage
- Unsure how to engage

Wrap up

- Thank you
- Questions and Answers

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