Consumers informing research: A survey of Canadians’ views and research priorities in chronic inflammatory diseases

Cheryl Koehn1,2, Gail Attara3,4, Allan Stordy5, Pam Montie6, John M. Esdaile7,8, Linda C. Li7,8, the PRECISION team

Background
Incorporating consumers’ views in grant proposal development is a crucial step that ensures research aligns with consumers’ needs.

Objective
To assess the public’s views and priorities in chronic inflammatory disease research.

Methods
- This study was led by consumer leaders from three inflammatory disease groups:
  - Arthritis (C. Koehn, P. Montie)
  - Gastrointestinal disease (G. Attara)
  - Skin disease (A. Stordy)
- A cross-sectional online public survey was developed to address two areas:
  1. Individuals’ views about research on medication and treatment adherence.
  2. Priorities in research related to physical activity.
- The survey invitation was sent to members of participating consumer organizations.
- Survey recruitment was also promoted by a newspaper, Vancouver Sun, as an example of consumer engagement in arthritis research.

Results

What did consumers think about...

...MEDICATIONS?
97.5% of respondents believed it was important to invest in research on medications for decreasing heart attacks, leg clots or premature death, all of which are consequences of chronic inflammatory diseases.

...PHYSICAL ACTIVITY?
81.7% wanted to increase physical activity.

Top 5 physical activity research questions
1. How to be physically active while having inflammation?
2. How much physical activity is “good” for people with multiple chronic inflammatory diseases?
3. How to motivate people to STAY physically active?
4. What is the best way for people with inflammatory diseases to learn how to be physically active?
5. How to motivate people to START being physically active?

...ADHERENCE?
61.1% had concerns about doing strenuous exercises

Although medication adherence is an issue in chronic disease management, nearly 58% of respondents were not interested in ways to help them remember taking medications as prescribed and on time.

...MANAGING DISEASE?
90 (16.2%) preferred to manage disease with medications
464 (83.8%) preferred to manage disease with healthy lifestyle

Partner Organizations
- Arthritis Consumer Experts
- JointHealth
- Gastrointestinal Society
- Canadian Society of Intestinal Research
- Canadian Association of Psoriasis Patients
- Consumer Advisory Board of the Arthritis Research Centre of Canada
- University of British Columbia
- Arthritis Research Centre of Canada

Conclusion
- Consumers indicated strong support for research on medications to prevent consequences of inflammation, although there was less enthusiasm for research to improve medication adherence.
- Consumers also identified research priorities in physical activity participation.