

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





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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

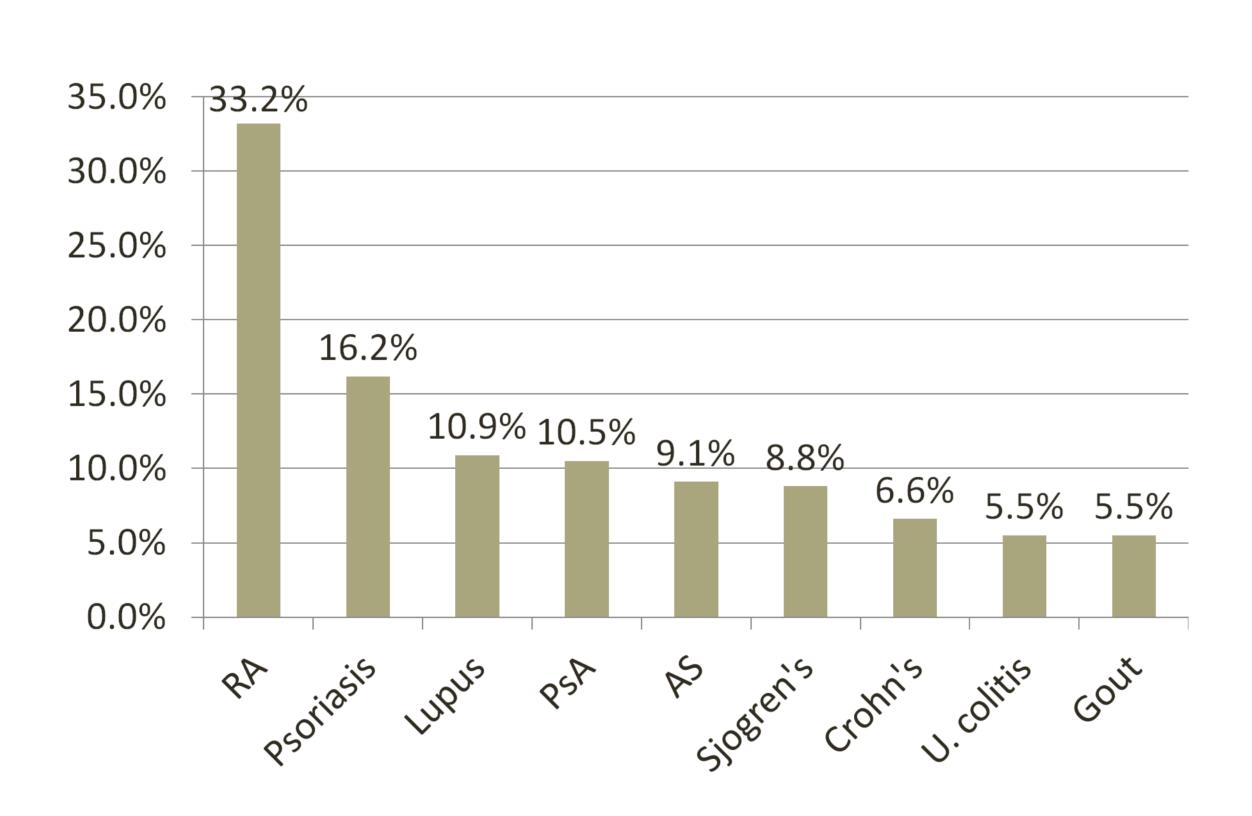
- This study was led by consumer leaders from three inflammatory disease groups:
 - Arthritis (C. Koehn, P. Montie)
 - Gastrointestinal disease (G. Attara)
 - Skin disease (A. Stordy)
- A cross-sectional online public survey was developed to address two areas:
 - 1. Individuals' views about research 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.

636 unique responses were received between July 11 and August 2, 2013.

Sample Characteristics (n = 636)

Gender, female	509 (80.0%)
Living in city with at least two hospitals	414 (65.1%)
Between age 54 and 73 years	396 (62.3%)
Living in British Columbia	453 (71.2%)
Disease duration	
Less than 1 year	31 (4.9%)
1 to 10 years	287 (45.1%)
More than 10 years	318 (50.0%)

Diagnosis (n = 636)



Partner Organizations









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.

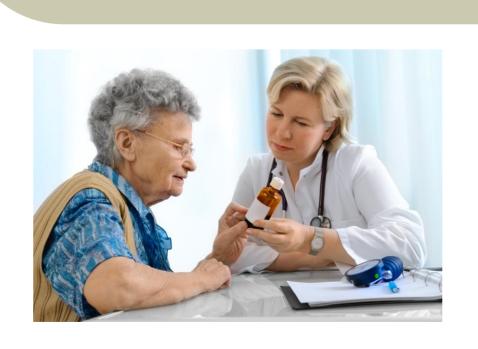


How likely is it that you would take such a medication in addition to your regular treatment?

very likely	239 (42.0%)
Somewhat likely	144 (25.3%)
Neutral	128 (22.5%)
Not very likely	34 (6.0%)
Not at all likely	24 (4.2%)

...ADHERENCE?

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.



...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?

81.7% wanted to increase physical activity.



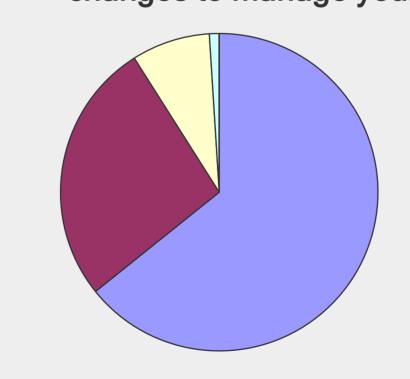


61.1% had concerns about doing strenuous exercises

...MANAGING DISEASE?

90 (16.2%) preferred to manage disease with medications 464 (83.8%) preferred to manage disease with healthy lifestyle

> How likely would you be to start or maintain lifestyle changes to manage your disease?



Very likely ■ Somewhat likely Neutral ■ Not very likely ■ Not at all likely

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.