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INFLAMMATORY DISEASE PATIENTS NEED MORE INFORMATION ABOUT BIOLOGICS AND BIOSIMILARS: REPORT

Focus group study finds patients experience stress, anxiety around treatment decisions

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2.25 million Canadians are living with inflammatory diseases such as ankylosing spondylitis, Crohn's disease, psoriasis, psoriatic arthritis, rheumatoid arthritis and ulcerative colitis. And as a new report released today makes clear, many of them lack the critical information necessary to be able to properly understand and evaluate their treatment options.

The [Biosimilar Focus Group Project Report](#), prepared by a group of patient advocacy organizations representing Canadians living with inflammatory disease, highlights the need for more education and patient support in the treatment decision-making process for people living with inflammatory disease.

The project set out through a series of focus groups to understand patients' experience and perception of biologic medications; to evaluate their awareness and understanding of biosimilars; and to identify any implications and issues arising related to a change in medication, including switching from a biologic to a biosimilar.

- Related: [About biosimilars](#)

"The arrival of biosimilars in the Canadian market is creating pressure for changes in the way inflammatory disease treatments are selected and paid for," explains Janet Yale, president and CEO of The Arthritis Society. "This report aims to help inform decision makers and health care providers alike about the experiences of people living with inflammatory disease, so they can consider the needs of those patients in any decisions around access to these treatments, and the supports that may be required."

Focus group participants had all been on more than one biologic already in their treatment journey, and their experience and perspective proved very important in informing the findings.

"Whether you are newly diagnosed with an inflammatory disease or someone who has gone through a number of treatments, it is important to be informed about the options available," says Mina Mawani, President and CEO of Crohn's and Colitis Canada. "Understanding what is available can alleviate anxiety and provide hope for the many people living with chronic diseases. The focus group results underscore the need for more education about treatment options – and more engagement and involvement in the treatment decision process for patients."

KEY FINDINGS

- **NEED FOR EDUCATION:** More education and awareness is needed around treatment options. Participants showed a general lack of understanding of the health care process and the treatment options available to them for their inflammatory disease, and in particular a poor understanding of biologics and biosimilars.
- **EMOTIONAL IMPACT:** Patients experience a high degree of emotional impact from their inflammatory disease journey, from delays in diagnosis and access to treatment, to considerable uncertainty throughout the journey. Better resources and support are needed to help them cope with the non-physical impacts of their diseases.
- **SWITCHING TO BIOSIMILARS:** One aspect of those impacts relates to stress and anxiety associated with switching medications. Participants were open to the role of biosimilars for new patients who had not been on the originator biologic, but were strongly opposed to the idea of people who are currently stable on an originator biologic being switched to a biosimilar for non-medical reasons, until research could determine that it was safe and effective. There was also a concern expressed that switching would reopen access and coverage questions for patients.
- **PARTNERS IN THE TREATMENT DECISION PROCESS:** All treatment decisions need to be made by the patient and physician together based on the clinical evidence and the best interests of the individual patient. Patients want to be better informed, more empowered and involved in the treatment decision process, and want to be better connected to sources of support.
- **A 'NEW NORMAL' – ACHIEVING STABILITY:** Patients don't expect a silver bullet – they are just looking to achieve 'new normal' of symptom and treatment stability that allows them to carry on with their lives.
- **SUPPORT FOR PSPs:** Patient support programs (PSPs) provided by the manufacturers of their current medications are highly valued by patients. There were concerns that switching to a biosimilar might eliminate access to this kind of program.

The six diseases covered by the report, including ankylosing spondylitis, Crohn's disease, psoriasis, psoriatic arthritis, rheumatoid arthritis and ulcerative colitis, are autoimmune conditions accompanied by inflammation, and collectively affect the lives of 2.25 million Canadians. While they manifest differently, these diseases share many similarities: their causes are unknown; there is no known cure or prevention strategy; all are prone to episodic, unpredictable flares; and while effective treatments are available, they are complex, and response varies by individual.

The study was led by The Arthritis Society in collaboration with [Canadian Arthritis Patient Alliance](#), [Canadian Psoriasis Network](#), [Crohn's and Colitis Canada](#), and the [Gastrointestinal Society](#).

About The Arthritis Society

The Arthritis Society has been setting lives in motion for over 65 years. Dedicated to a vision of living well while creating a future without arthritis, The Society is Canada's principal health charity providing education, programs and support to the over 4.6 million Canadians living with arthritis. Since its

founding in 1948, The Society has been the largest non-government funder of arthritis research in Canada, investing more than \$195 million in projects that have led to breakthroughs in the diagnosis, treatment and care of people with arthritis. The Arthritis Society is accredited under Imagine Canada's Standards Program. For more information and to make a donation, visit arthritis.ca.

About Canadian Arthritis Patient Alliance

Canadian Arthritis Patient Alliance (CAPA) is a grass-root, patient-driven, independent, national organization with members across Canada and supporters both Canadian and International. CAPA believes the first expert on arthritis is the individual who has the disease, theirs is a unique perspective. We assist members to become advocates not only for themselves but all people with arthritis.

CAPA facilitates links between Canadians with arthritis and their support systems through collaboration and partnerships with other organizations, representatives from all levels of government, researchers, and other individuals to help achieve CAPA's strategic priorities. The organization communicates the latest news on health policy issues, research, technology and emerging issues relevant to members through its website and Facebook pages. CAPA welcomes all Canadians with arthritis and those who support CAPA's goals to become members. arthritispatient.ca

About Canadian Psoriasis Network

Canadian Psoriasis Network (CPN) has a goal is to improve the quality of life of all Canadians who are living with psoriasis and psoriatic arthritis while vigorously pursuing a cure. Our mission is to provide all current information on treatment and continuing care through education, outreach, research and leading by example. cpn-rcp.com

About Crohn's and Colitis Canada

Crohn's and Colitis Canada is a national, volunteer-based charity focused on finding the cures for Crohn's disease and ulcerative colitis and improving the lives of children and adults affected by these chronic diseases. We are one of the top two health charity funders of Crohn's and colitis research in the world, investing over \$100 million in research to date. We are transforming the lives of people affected by Crohn's and colitis (the two main forms of inflammatory bowel disease) through research, patient programs, advocacy, and awareness. crohnsandcolitis.ca

About Gastrointestinal Society

Gastrointestinal Society as the Canadian leaders in providing trusted, evidence-based information on all areas of the gastrointestinal tract, the Gastrointestinal Society and the Canadian Society of Intestinal Research are registered charities committed to improving the lives of people with GI and liver conditions since 1976. They do this by supporting research, advocating for appropriate patient access to health care, and promoting gastrointestinal and liver health. badgut.org

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