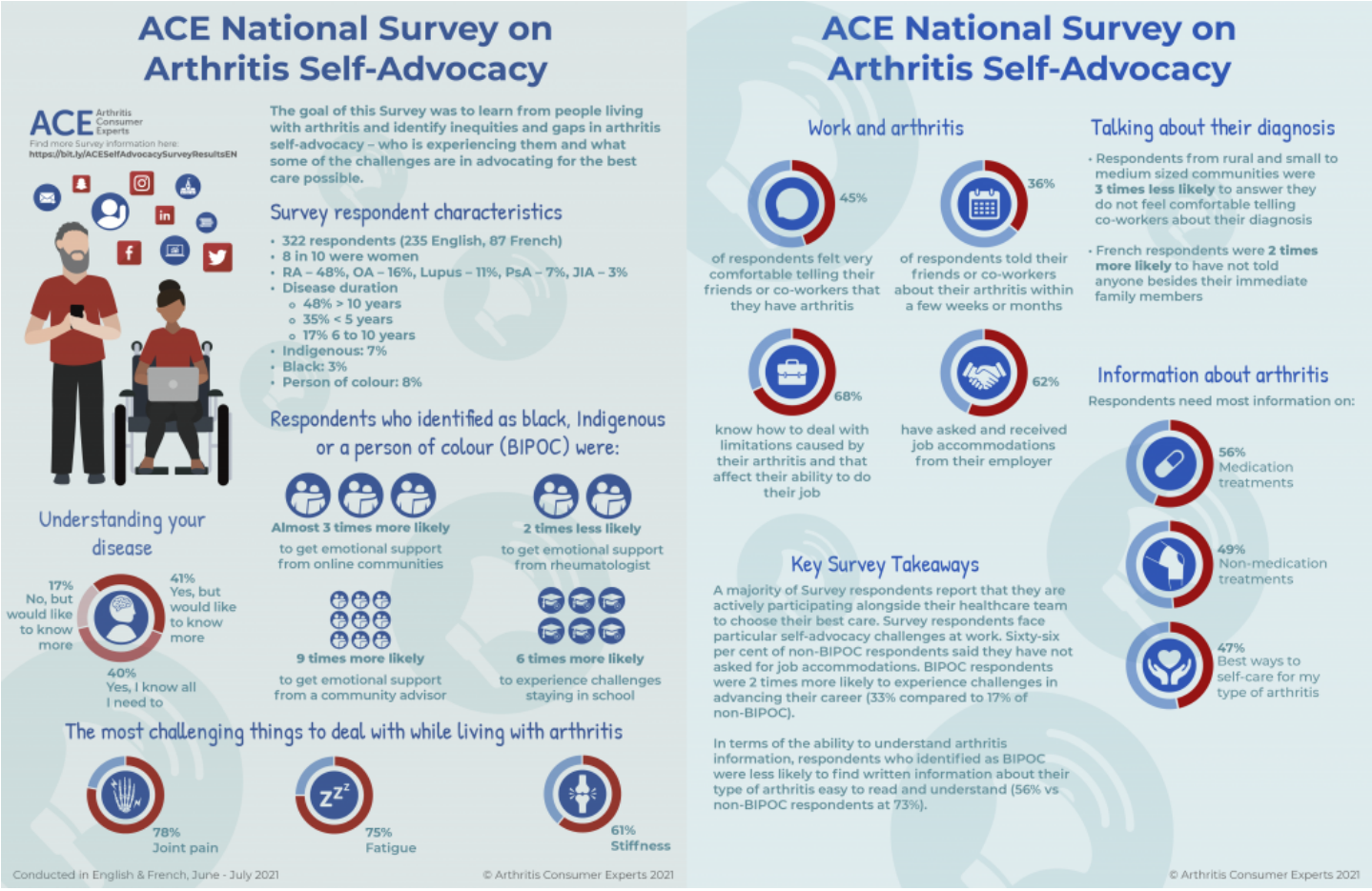
# New Arthritis Consumer Experts National Survey Looks at Arthritis Self-Advocacy

## Survey reveals how well arthritis consumers understand their disease, where they go to learn about treatment and care, and challenges of self-advocacy




**British Columbia, Vancouver, Sep 18, 2021 (**Issuewire.com**)** - Arthritis Consumer Experts (ACE) today released the results of a National Survey on Arthritis Self-Advocacy that measures Canadian patients' understanding of their disease, where they go to learn about treatment and care, and how they go about self-advocating for what they need. ACE's latest national survey findings also uncover inequities and gaps in arthritis self-advocacy in Canada – who is experiencing them and what are some of the challenges they face advocating for care.

"We are pleased to be sharing the results of our National Survey on Arthritis Self-Advocacy during Arthritis Awareness Month in Canada. No one knows arthritis better than those who live with it every day. The Survey results provide insights into the level of awareness and confidence arthritis consumers have to share their experiences with family and friends, healthcare team, work colleagues, community leaders, and elected officials to help ensure they understand how their actions affect patients. When we look closely at the different experiences between different patient populations, we can see there is still much work to be done to educate patients and provide them self-advocacy strategies and tools to live their best lives," said Cheryl Koehn, President, Arthritis Consumer Experts.

Although survey respondents generally expressed a solid understanding of their disease, there still exists a significant demand for current, fact-based information. Nine in 10 or 87% respondents said they know all they need to about their arthritis – half or 48% of these respondents said they would also like to learn more. A similar number of people – 8 in 10 or 81% said they feel well informed to make decisions about their disease treatment. Out of the 81%; however, 4 in 10 or 41% would also like to know more about treatments for their type of arthritis.

Respondents in both the English and French populations identified a close friend, spouse/partner, and family as the top 3 sources of emotional support. However, the Findings were significantly different for respondents who identified as black, Indigenous, or a person of colour (BIPOC). BIPOC respondents were:

- Almost 3 times more likely to get emotional support from online communities
- 2 times less likely to get emotional support from their rheumatologist
- 9 times more likely to get emotional support from a community advisor
- 6 times more likely to get emotional support from a patient organization representative

Getting information on arthritis

ACE's Survey also asked respondents where they usually go to find information about their type of arthritis. The top 5 sources were:

- websites (8 in 10 or 85%)
- members of my health care team (8 in 10 or 77%)
- patient organizations (3 in 10 or 30%)
- other people living with my type of arthritis (3 in 10 or 26%)
- printed pamphlets or guides (2 in 10 or 24%)

In terms of the ability to understand arthritis information they consume, respondents who identified as BIPOC were less likely to find written information about their type of arthritis easy to read and understand (6 in 10 or 56% vs non-BIPOC respondents, at 7 in 10 or 73%).

"This is a strong reminder for our community of arthritis educators, healthcare providers, and knowledge translators of the work that still needs to be done to ensure arthritis patients in Canada are able to access, understand, evaluate, communicate and use information related to their disease to self-advocate and make appropriate health decisions," said Koehn.

Self-advocacy at work

The Survey asked respondents if they know how to deal with physical limitations caused by their arthritis and that affect their ability to do their job – the majority of respondents answered yes (7 in 10 or 68%), followed by not sure (2 in 10 or 23%) and no (1 in 10 or 8%).

Respondents who identified as BIPOC were more likely to talk about their arthritis diagnosis with their employer than their non-BIPOC counterparts (3 in 4 or 76% compared to 5 in 10 or 55%).

ACE's Survey also revealed statistical significance related to asking for and receiving job accommodations from an employer:

- BIPOC respondents were 2 times more likely to ask for job accommodations

- 7 in 10 (66%) of non-BIPOC respondents said they have not asked for job accommodations

When asked to identify the most challenging things for them to deal with while living with their type of arthritis, BIPOC respondents were:

- more likely to experience challenges in advancing their career (3 in 10 or 33% vs 2 in 10 or 17%)
- 6 times more likely to experience challenges with staying in school (1 in 10 or 12% vs 2%)

**About the Arthritis Consumer Experts National Survey on Arthritis Self-Advocacy**

ACE conducted its online survey of people who self-reported having a physician-diagnosed form of arthritis from June 23 to July 24, 2021, in English and French. The Survey included 39 questions on respondents' experiences with arthritis self-advocacy at work, in their social life, during medical appointments, and with mass media, Throughout the survey, respondents were able to provide additional comments about what would help improve their experience with arthritis self-advocacy. The data were aggregated, and global and subset analysis was performed by a data specialist.

Arthritis Consumer Experts received 322 responses for the community-led survey, 235 in English, and 87 in French.

Respondents were patients living with different forms of arthritis, including osteoarthritis, rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis, lupus, juvenile idiopathic arthritis, and scleroderma. The three most common forms of arthritis among respondents were rheumatoid arthritis (accounting for almost half of the respondents), osteoarthritis (16%), and lupus (11%).

**About Arthritis Consumer Experts**

Arthritis Consumer Experts (ACE) is a national organization that provides free, science-based information and education programs to people with arthritis. ACE serves people living with all forms of arthritis by helping them take control of their disease and improve their quality of life through education and empowerment. Founded and led by people with arthritis, ACE also actively advocates on arthritis health and policy issues, through ACE's JointHealth™ family of programs and the Arthritis Broadcast Network, directly to consumers/patients, healthcare professionals, media, and government. ACE is guided by a strict set of guiding principles, set out by an advisory board comprised of leading scientists, medical professionals, and informed arthritis consumers.

**Media Contact**

Kelly Lendvoy

lendvoy@jointhealth.org

6043799898

1529 West 6th Avenue, Unit 210

Source : Arthritis Consumer Experts

See on IssueWire