ACE National Survey on Arthritis Self-Advocacy

The goal of this Survey was to learn from people living with arthritis and identify inequities and gaps in arthritis self-advocacy – who is experiencing them and what some of the challenges are in advocating for the best care possible.

Survey respondent characteristics
- 322 respondents (235 English, 87 French)
- 8 in 10 were women
- RA – 48%, OA – 16%, Lupus – 11%, PsA – 7%, JIA – 3%
- Disease duration
  - 48% > 10 years
  - 35% < 5 years
  - 17% 6 to 10 years
- Indigenous: 7%
- Black: 3%
- Person of colour: 8%

Respondents who identified as black, Indigenous or a person of colour (BIPOC) were:

Understanding your disease
- 17% No, but would like to know more
- 41% Yes, but would like to know more
- 40% Yes, I know all I need to

Almost 3 times more likely to get emotional support from online communities
9 times more likely to get emotional support from a community advisor

2 times less likely to get emotional support from a rheumatologist
6 times more likely to experience challenges staying in school

The most challenging things to deal with while living with arthritis
- 78% Joint pain
- 75% Fatigue
- 61% Stiffness

Conducted in English & French, June - July 2021 © Arthritis Consumer Experts 2021
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Work and arthritis
- 45% of respondents felt very comfortable telling their friends or co-workers that they have arthritis.
- 36% of respondents told their friends or co-workers about their arthritis within a few weeks or months.
- 68% know how to deal with limitations caused by their arthritis and that affect their ability to do their job.
- 62% have asked and received job accommodations from their employer.

Talking about their diagnosis
- Respondents from rural and small to medium sized communities were 3 times less likely to answer they do not feel comfortable telling co-workers about their diagnosis.
- French respondents were 2 times more likely to have not told anyone besides their immediate family members.

Information about arthritis
Respondents need most information on:
- 56% Medication treatments
- 49% Non-medication treatments
- 47% Best ways to self-care for my type of arthritis

Key Survey Takeaways
A majority of Survey respondents report that they are actively participating alongside their healthcare team to choose their best care. Survey respondents face particular self-advocacy challenges at work. Sixty-six per cent of non-BIPOC respondents said they have not asked for job accommodations. BIPOC respondents were 2 times more likely to experience challenges in advancing their career (33% compared to 17% of non-BIPOC).

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

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