

ACE National Survey on Arthritis Self-Advocacy

ACE Arthritis Consumer Experts

Find more Survey information here:
<https://bit.ly/ACESelfAdvocacySurveyResultsEN>

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:



Almost 3 times more likely
to get emotional support
from online communities



2 times less likely
to get emotional support
from rheumatologist

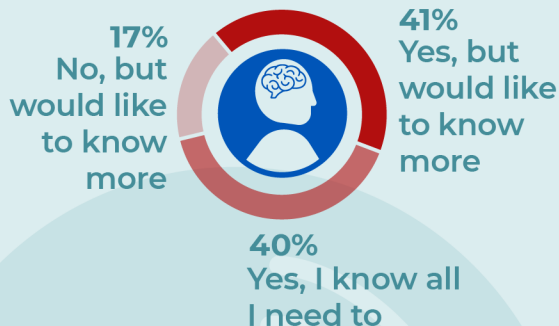


9 times more likely
to get emotional support
from a community advisor

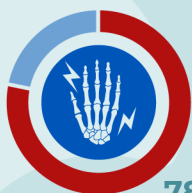


6 times more likely
to experience challenges
staying in school

Understanding your disease



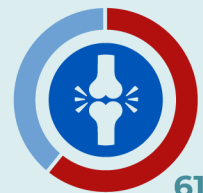
The most challenging things to deal with while living with arthritis



78%
Joint pain



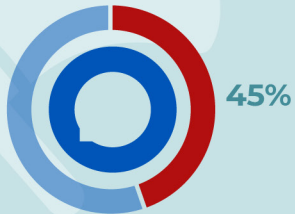
75%
Fatigue



61%
Stiffness

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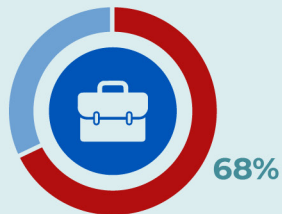
Work and arthritis



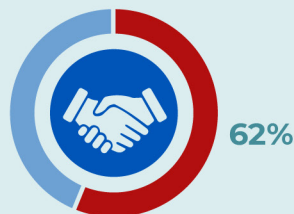
of respondents felt very comfortable telling their friends or co-workers that they have arthritis



of respondents told their friends or co-workers about their arthritis within a few weeks or months



know how to deal with limitations caused by their arthritis and that affect their ability to do their job



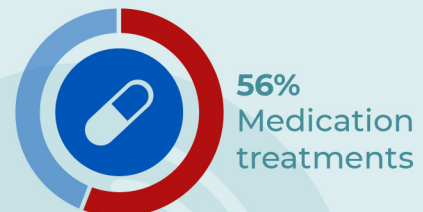
have asked and received job accommodations from their employer

Talking about their diagnosis

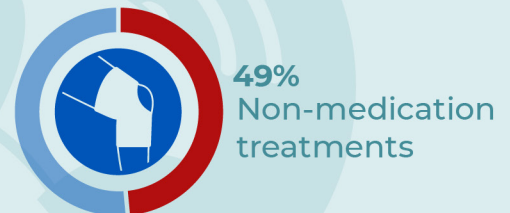
- Respondents from rural and small to medium sized communities were **3 times less likely** to answer they do not feel comfortable telling co-workers about their diagnosis
- French respondents were **2 times more likely** to have not told anyone besides their immediate family members

Information about arthritis

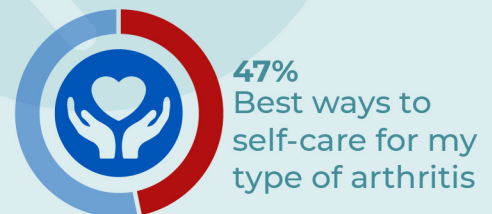
Respondents need most information on:



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%).