

Arthritis Consumer Experts Survey Report on Arthritis and Mental Health

Arthritis Consumer Experts (ACE) has recently completed a national survey to understand what steps people living with arthritis take to take care of their mental health and what specific challenges they may face when accessing timely professional care. The survey findings also help us understand how patient organizations, health care providers and the healthcare system can better support people living with arthritis with their mental health and overall wellbeing.

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Survey background

People with arthritis are more at risk for developing mental health issues because of the interaction of anxiety, depression, and fatigue with chronic arthritis pain. Arthritis Research Canada reports up to 70% of patients with rheumatoid arthritis experience anxiety and up to 38% experience depression; up to 40% of lupus patients experience anxiety and 30% experience depression.



Free support is available 24 hours and 7 days a week, whether you are in crisis or need someone to talk to:

Canada Suicide Prevention Service:
1-833-456-4566 or Text 45645

Quebec residents: 1-866-277-3553
or suicide.ca

Kids Help Phone: 1-800-668-6868 or
Text CONNECT to 686868

Hope for Wellness Help Line for
Indigenous people across Canada:
1-855-242-3310



A study from 2018 by **Marrie et al** analysed Canadian population-based administrative health data and it showed that individuals with rheumatoid arthritis (RA) have an increased risk for depression, anxiety, and bipolar disorder. These mental disorders can make arthritis symptoms worse and lead to poor health outcomes. The researchers concluded that within the first year of RA diagnosis, depression and anxiety have been shown to delay joint remission (as measured with the Disease Activity Score).

Survey goals

ACE members and subscribers have shared with us the many mental health challenges they experienced during their disease journey. With this survey, ACE's goal was to understand what steps people living with arthritis take to care for their mental health and what specific challenges they may face when accessing timely professional care. We hope to identify gaps in the care and how patient organizations, health care providers and the healthcare system can better support people living with arthritis with their mental health and overall wellbeing.

How the Survey was conducted

ACE conducted an online 35-question survey of people living with a physician diagnosed form of arthritis between May 11, 2022, and June 8, 2022, in English and French. The Survey included questions on respondents' mental health and arthritis experience and accessing support and care for their mental health. At the end of the Survey, respondents were able to provide additional comments to any of their answers in the Survey and share what ACE can do to support their mental health self-care.

ACE extends its sincere thanks to the people who took time to participate in this important community-led research and to our community partners who helped promote the Survey.

Survey analysis

Survey analysis was conducted for four Survey groups:

- English respondents versus French respondents
- Black, Indigenous, and people of colour (BIPOC) respondents versus non-BIPOC respondents
- Rural respondents versus non-rural respondents
- Women respondents versus men respondents

Who were the Survey respondents?

Arthritis Consumer Experts received 258 responses, including 223 in English and 32 in French.

Respondents were people who self-reported living with various forms of arthritis, including:

- rheumatoid arthritis (39%)
- osteoarthritis (35%)
- psoriatic arthritis (9%)
- ankylosing spondylitis (5%)
- other (5%)
- Sjögren's syndrome (2%)
- do not know what type of arthritis they have (1%)
- lupus (1%)
- gout (1%)
- polymyalgia rheumatica (1%)
- vasculitis (1%)
- non-radiographic axial spondyloarthritis (<1%)
- fibromyalgia (<1%)

Half of the respondents have been living with arthritis for more than 10 years, while 2 in 10 have been living with arthritis between 6-10 years and 3 in 10 have been living with arthritis for 5 years or less.

Nine in 10 respondents identified as women. This comes as no surprise as women are affected in greater proportions than men by most types of arthritis.

One in 10 respondents identified as Indigenous or a person of colour. Nine in 10 respondents were white. This represents a significant gap in ethnic and racial representation.

Representation refers to research studies where the research participants do not reflect the racial identity, ethnicity, age, or sex and gender of the population that's affected.

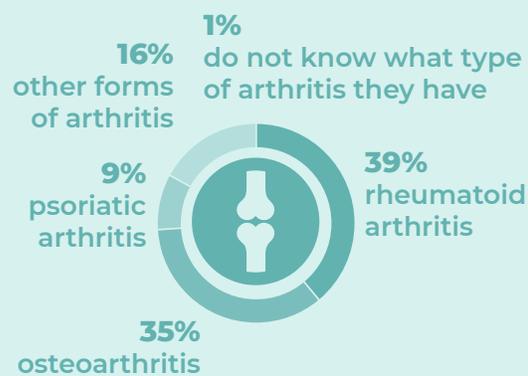
ACE is committed to continuing its work to bring equity to representation and knowledge translation and exchange for everyone in our community. To learn more about this topic, read [this ACE article](#) on who is and who is not represented in research.

Who were the Survey respondents?

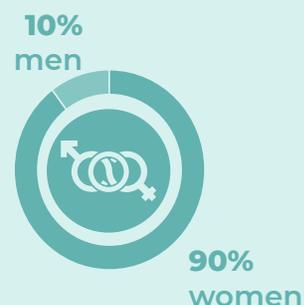
Years living with arthritis



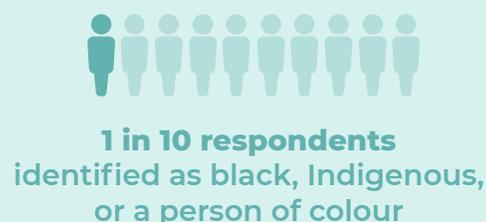
Form of arthritis



Gender identity



Race

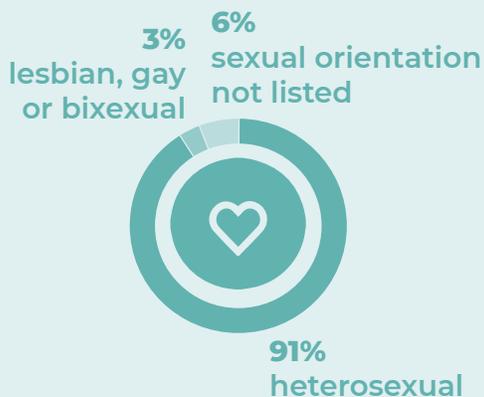


Are you a member in the black, Indigenous, and people of colour community and interested in addressing health inequities?

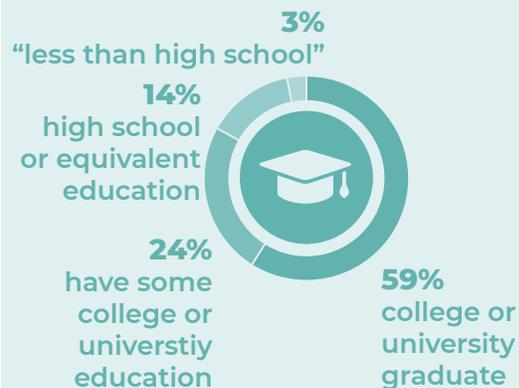
Please email us at feedback@jointhealth.org for collaboration opportunities.

Sexual orientation and education

Sexual orientation



Highest level of education completed



Sexual orientation and education

ACE included two survey questions to better identify gaps in mental health care – one asked about the respondent’s sexual orientation and the other asked the respondent about their highest level of education completed.

Ninety-one per cent of respondents were heterosexual, three per cent of respondents were lesbian, gay, or bisexual, and six per cent of respondents said their sexual orientation is one that is not listed above.

In terms of highest level of education completed:

- 59% of respondents is a college or university graduate
- 24% of respondents had some college or university education
- 14% of respondents had high school or equivalent education
- 3% of respondents indicated highest level of education as “less than high school”

Highly statistically significant findings include:

- English respondents were half as likely as French respondents to be a college or university graduate or have some college or university education
- BIPOC respondents (59%) were less likely than non-BIPOC respondents (86%) to be a college or university graduate or have some college or university education
- Male respondents were one-and-a-half times more likely than female respondents to have an education level of high school or equivalent or less than high school
- Respondents living in rural communities were half as likely than respondents living in non-rural communities to have an education level of high school or equivalent or less than high school

Where respondents live

Fifty-four per cent of Survey respondents reported living in British Columbia, followed by Ontario (13%), and Alberta (5%). There were respondents from all Canadian provinces and territories except for Prince Edward Island, Yukon and Nunavut. Sixteen per cent of respondents lived outside of Canada.

Respondents lived in both rural or small to medium sized, and urban communities:

- 63% of respondents live in large urban centres with population of 100,000 or more
- 37% of respondents live in either rural (population of 15,999 or less) or small to medium sized population centres (population of 16,000 to 99,999)

Thirty-eight per cent of respondents travel 0-10km to see the health care provider for their arthritis, followed by:

- 11-25km (32%)
- 26-50km (14%)
- 51-100km (8%)
- 101-250km (6%)
- 251-500km (1%)
- 500km or more (1%)

Mental health and arthritis experience

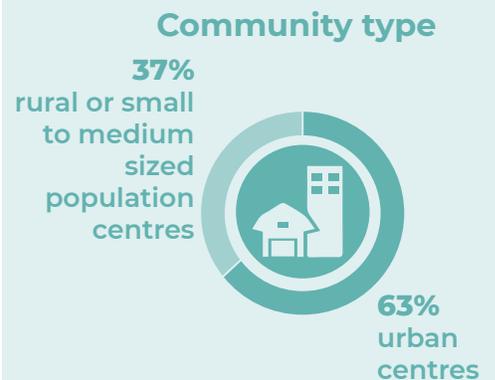
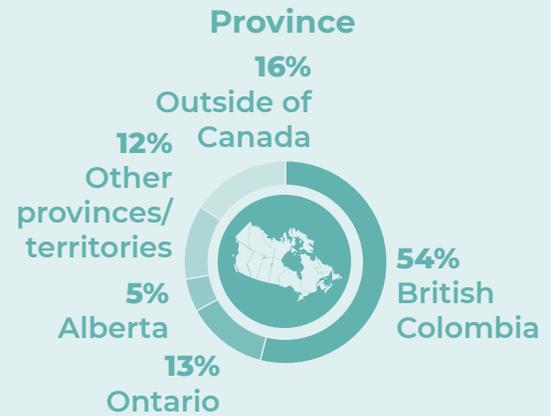
Interactions with healthcare provider

To understand the bigger picture of respondents' mental health and arthritis experience, we asked Survey respondents about the state of their mental health and their interactions with their healthcare provider.

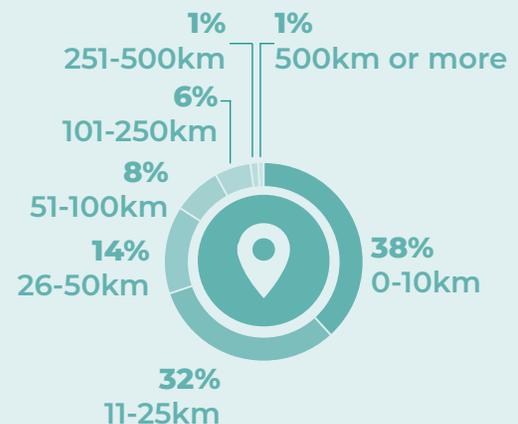
Has a healthcare provider asked about mental health during clinic visits?

Family doctors and rheumatologists offer unique perspectives about mental health treatment, care, and advice. Family doctors are the people most familiar with a patient's overall health and can offer insights on mental health based on a patient's medical history. They are the first step in navigating the mental health system.

Where respondents live



Distance travelled to arthritis health care provider





A rheumatologist, because of the specialized care they offer, can provide insights on whether your mental health concerns are a result of arthritis, a comorbidity of arthritis or a symptom of arthritis. For example, they may determine that a patient may be experiencing depression because their pain limits their ability to participate in social activities. As a result, they may have a treatment for the pain and can reassess the patient’s mental health concerns to determine if there are any other underlying issues.

Below are Survey findings on whether respondents’ family doctor or rheumatologist discussed mental health concerns with them:

	Family doctor	Rheumatologist
No	Half of respondents (50%)	7 in 10 respondents (69%)
Yes	3 in 10 respondents (33%)	2 in 10 respondents (19%)
No, I brought it up myself during our conversation	2 in 10 respondents (17%)	1 in 10 respondents (12%)

Respondents were asked to consider their mental health, which includes stress, anxiety, depression, and emotional distress, and indicate how many days during the past 30 days they were concerned about their mental health. Below are the Survey findings:

- 6 in 10 (56%) respondents said they were concerned about their mental health for 1 to 14 days
- 3 in 10 (27%) respondents said they were concerned about their mental health for 15 to 30 days
- 2 in 10 (17%) respondents said they were concerned about their mental health for 0 days.

Comparing English and French respondents, French respondents were three times more likely to say they were concerned about their mental health for 0 days. English respondents were twice as likely to say they were concerned about their mental health for 1 to 14 days (58% vs 36%).

ACE's Survey found the number of days that respondents were concerned about their mental health is strongly related to whether their arthritis symptoms have ever affected their mental health. Eighty-nine per cent of respondents who indicated they had 0 days in the past 30 days where they were concerned about their mental health said their arthritis symptoms have never affected their mental health. In comparison, 71% of respondents who indicated they had 15 to 30 days in the past 30 days where they were concerned about their mental health said their arthritis symptoms have affected their mental health.

Diagnosis of depression or anxiety

Survey respondents were asked if their healthcare provider have ever diagnosed them with depression or anxiety and/or recommended medication to treat symptoms of depression or anxiety. Six in 10 respondents said no, while 4 in 10 respondents said yes.

Statistically significant data exist between respondents living in rural communities and respondents living in non-rural communities. Half of the respondents are living in rural communities and half reported they had been diagnosed with depression or anxiety and prescribed medication. By comparison, respondents living in non-rural communities were twice as likely to say they had not been diagnosed with depression or anxiety.

Mental health and its effects on physical health and quality of life

What we know from research is that people with inflammatory arthritis (IA) are more likely to experience mental health conditions such as depression, anxiety and “brain fog” than the general population. Recent research suggests there is a complex relationship between these conditions and arthritis, and the impacts are profound. People with osteoarthritis (OA) may also experience depression because of significant physical limitations from their disease.

Researchers from West Virginia University found that the people who had both RA and depression experienced more work-related challenges and lower productivity than those living with RA.¹ Arthritis pain, anxiety, and depression,



What we know from research is that people with inflammatory arthritis (IA) are more likely to experience mental health conditions such as depression, anxiety and “brain fog” than the general population.



Half of respondents said their arthritis symptoms have affected their mental health

combined with inflammation and fatigue, may cause lifestyle changes, such as engaging less in physical or social activity, adhering or not adhering to arthritis medication treatments, and experiencing fluctuations in your diet and nutrition.

The Survey identified respondents' understanding of how their type of IA or OA may have contributed to a decline in their mental health. ACE asked respondents if their arthritis symptoms have ever affected their mental health. Overall, half of the respondents said yes, followed by 3 in 10 respondents who said no, and 2 in 10 respondents who selected "other" and were given the opportunity to expand on their answers. Key findings include:

- English respondents were twice as likely as French respondents to say yes, their arthritis symptoms have affected their mental health
- Female respondents were almost twice as likely as male respondents to say yes, their arthritis symptoms have affected their mental health

What effect did COVID-19 have on people's mental health?

ACE also wanted to know if the COVID-19 pandemic has ever affected respondents' mental health. Most of the respondents (47%) said their mental health was a little worse, followed by "no overall impact" at 29% and "a lot worse" at 20%. Only four per cent of respondents said their mental health was a little better and one per cent of respondents said their mental health was a lot better.

Key findings include:

- English respondents were twice as likely than French respondents to say their mental health was a lot worse during the COVID-19 pandemic
- French respondents were nine times more likely than English respondents to say their mental health was a lot better during COVID-19 pandemic
- Non-rural respondents were almost twice as likely than rural respondents to say the COVID-19 pandemic had no overall impact on their mental health
- Non-BIPOC respondents were five times more likely to say their mental health was a lot worse during the COVID-19 pandemic.

Mental health and physical activity

The Survey found most people participated in regular physical activity or exercise:

- 33% of respondents said sometimes (2-3 days a week)
- 25% of respondents said often (4-6 days a week)
- 14% of respondents said daily
- 29% of respondents said rarely (bi-weekly or monthly)

A little over half of the respondents said that their mental health has made it difficult for them to be physically active or exercise, followed by 4 in 10 respondents who said their mental health has not made it difficult for them to be physically active or exercise.

English respondents were more likely to say yes, their mental health has made it difficult for them to be physically active or exercise than French respondents (55% vs 32%). This finding was statistically significant.

[Click to read what respondents told us >>>](#)

Mental health effects on diet and nutrition

Survey findings show that 55% of respondents said that their mental health caused them to interrupt or stop following their healthy eating habits or nutrition plan, while 41% of respondents said it had not.

A highly statistically significant finding is that English respondents were three times more likely than French respondents to say that their mental health caused them to interrupt or stop following their healthy eating habits or nutrition plan.

A statistically significant finding is that non-BIPOC respondents were twice as likely as BIPOC respondents to say their mental health caused them to interrupt or stop following their healthy eating habits or nutrition plan.

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Mental health and arthritis medications

Eighty-one per cent of Survey respondents reported that their mental health has never caused them to stop taking their prescribed arthritis medication, compared to 11% who said that their mental health has caused them to not take their prescribed arthritis medication.





This is supported by research, including a study published in *Rheumatology* that found that experiencing symptoms of depression at the start of biologics treatment (at baseline) is associated with reduced treatment response, and over time, impacts change in disease activity.² The researchers found that depression at baseline contributes to approximately 30% reduced odds of good biologics treatment response in rheumatoid arthritis. Furthermore, patients who reported a history of depression or experienced symptoms of depression were more likely to switch biologics. The study recommends patients should receive repeated screening and management of their mental disorder from their rheumatologist and rheumatology nurse.

[Click to read what respondents told us >>>](#)

Mental health and work

When it comes to mental health's effects at work, 81% of Survey respondents said mental health has not affected them at work. Of the respondents who said mental health has affected them at work, the most common to least common responses were:

- Yes, I have had to take time off: 15%
- Yes, I have challenges keeping up with my work: 9%
- Yes, I have had to take unpaid time off work: 3%
- Yes, but I have received work accommodations from my employer: 3%
- All of the above: 3%

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Mental health support and care

This section of the Survey focused on mental health support and care. It included questions that looked at understanding the relationships between other healthcare providers and respondents' mental health and the challenges and access to mental health.

When asked if other healthcare providers talked to them about their mental health, respondents selected all that apply. Sixty-nine per cent of respondents said other healthcare providers did not talk to them about their mental health. Among the list of

healthcare providers that did talk about mental health with the respondents, they were (ranked from most common to least common answer choice):

- Physiotherapist: 6%
- Occupational therapist: 6%
- Rheumatology nurse: 4%
- Pharmacist: 4%
- Dietitian: 3%

Four per cent of respondents did not feel comfortable talking to a healthcare provider about their mental health and two per cent did not have access to a healthcare provider.

[Click to read what respondents told us >>>](#)

When asked if a healthcare provider ever suggest they see a mental healthcare provider, respondents' answers were:

- No: 56%
- No, I looked for psychotherapy care and guidance on my own: 14%
- Yes, a psychiatrist: 8%
- Yes, a psychologist: 8%
- Yes, a clinical counsellor: 5%
- Yes, a licensed therapist: 4%
- Yes, a licensed social worker: 4%
- I do not have access to a healthcare provider: <1%

The Survey found that 31% of respondents experienced challenges finding mental healthcare providers in their community, while 34% had no challenges and 35% said the question did not apply to them.

In terms of accessing mental health care resources and support, these were the findings:

- No problem accessing mental health care resources and support: 45%
- Yes, I am not sure where to find mental health resources and support: 8%
- I do not feel comfortable seeking mental healthcare resources and support: 12%
- Yes, I cannot afford to see a mental healthcare provider: 11%



- Yes, the wait list to see a mental healthcare provider: 7%
- Yes, my public and/or private healthcare plans do not cover mental health services: 5%

[Click to read what respondents told us >>>](#)

What we learned

Respondents report how depression and anxiety weaken a person's ability to deal and cope with pain. ACE's survey confirms the research that shows depression and anxiety in people living with an inflammatory arthritis or osteoarthritis are underdiagnosed and many of those affected don't receive timely mental health treatment, which could potentially help with their arthritis related symptoms.

In their written comments, respondents spoke about finding themselves in a negative cycle of pain, poor health and negative mood, which led to significant changes to the management of their arthritis. People living with inflammatory arthritis and depression reported having more functional limitations, being less likely to adhere to their treatment plans and developing other health problems.

There are many ways to prevent and manage depression and anxiety. It is important for patients to understand that it is not their fault they are depressed and that they are not alone in their disease journey. One step in self-care for patients is to be aware of the warning signs for depression:

- Being angry when your body can no longer do what you want it to do
- Feeling lonely or isolated
- Eating more or less than usual
- Feeling that you are a burden on others
- Lethargy or having little energy
- Thinking things will never get better
- Sleeping more or less than usual
- Having little interest in sex
- Crying more easily
- Feeling overwhelmed by simple tasks or responsibilities
- Getting frustrated at having to ask for help
- Having a hard time making decisions

What you can do

There are behaviours and personal actions patient can take to deal with their mental health. It's important, for example, for people to rest when they are feeling exhausted to avoid added stress and anxiety as well as trying to exercise or be active regularly. Another suggestion is to explore new passions or interests to replace what you have lost or to distract you like a new hobby or volunteering in the community. People may also try to find someone or something that inspires them and gives them strength – a role model or a book.

People with arthritis should also consider seeking help from their network around them. They can speak to their rheumatologist about their concerns and challenges they are having with mental health and determine the treatment plan best suited to their needs.

To learn more about communicating with your rheumatologist, go to ACE's **JointHealth™ Education** for tips on having better conversations with your health care team members.

Patients should also consider getting support from a counsellor, social worker or mental health professional. The Canadian Mental Health Association provides a useful **Support Service Directory** for resources across Canada.

We encourage you to share our Survey findings with your community. If you would like to get involved with ACE activities or have any mental health care tips to share with others, please email us at **feedback@jointhealth.org** or reach out to us on social media: **Facebook**, **Twitter**, **Instagram**, and **LinkedIn**.

References

1. Deb A, Dwibedi N, et al. Burden of Depression among Working-Age Adults with Rheumatoid Arthritis. *Arthritis*. June, 2018. DOI 10.1155/2018/8463632
2. Matcham F, Davis R, et al. The relationship between depression and biologic treatment response in rheumatoid arthritis: An analysis of the British Society for Rheumatology Biologics Register. *Rheumatology*. Volume 57, Issue 5, P835-843. May, 2018. DOI <https://www.ncbi.nlm.nih.gov/pubmed/29447376>



Arthritis Consumer Experts (ACE)

Who we are

Arthritis Consumer Experts (ACE) and its team members acknowledge that they gather and work on the traditional, ancestral and unceded territory of the Coast Salish peoples - x^wməθk^wəyəm (Musqueam), Skwx-wú7mesh (Squamish), and Səlílwəta?/ Selilwitulh (Tsleil-Waututh) Nations.

ACE operates as a non-profit and provides free research based education and information to Canadians with arthritis. We help (em)power people living with all forms of arthritis to take control of their disease and to take action in healthcare and research decision making. ACE activities are guided by its members and led by people with arthritis, scientific and medical experts on the ACE Advisory Board. To learn more about ACE, visit www.jointhehealth.org.

Guiding Principles

Healthcare is a human right. Those in healthcare, especially those who stand to gain from the ill health of others, have a moral responsibility to examine what they do, its long-term consequences and to ensure that all may benefit. The support of this should be shared by government, citizens, and non-profit and for-profit organizations. This is not only equitable, but is the best means to balance the influence of any specific constituency and a practical necessity. Any amount remaining from our annual budget at year end remains with ACE and is used to support the following year's core programs to continue helping Canadians living with arthritis.

For its past 20 years, ACE has consistently honored a commitment to its members and subscribers, academic and healthcare professional colleagues, collaborators, government and the public that its work is free from the influence of its funders.

To inform ACE employees and our stakeholders, members, subscribers that we will operate our organization with integrity and abide by the highest standards of lawful and ethical behaviour, ACE has adopted this strict set of guiding principles:

- ACE requests grants from private and public organizations to support its core program and plans and allocates those funds free from influence;
- ACE discloses all funding sources in all its activities;
- ACE does not promote any “brand”, product or program on any of its materials or its website, or during any of its educational programs or activities.
- ACE employees do not receive equity interest or personal “in-kind” support of any kind from any health-related organization;
- ACE identifies the source of all materials or documents used;
- ACE develops positions on health policy, products or services in collaboration with people living with arthritis, academic research community, health care providers and governments free from concern or constraint of its funders or other organizations; ACE employees do not engage in personal activities with its funders;
- Cheryl Koehn does not own stock or any financial interest in any of its private or public funders.

Thanks

ACE thanks Arthritis Research Canada (ARC) for its scientific review of all ACE and JointHealth™ materials.



Disclosures

Over the past 12 months, ACE received grants-in-aid from: Amgen Canada, Arthritis Research Canada, Canadian Biosimilars Forum, Canadian Rheumatology Association, Eli Lilly Canada, Fresenius Kabi Canada, Merck Canada, Novartis Canada, Organon Canada, Pfizer Canada, Sandoz Canada, Teva Canada, UCB Canada and the University of British Columbia.

Disclaimer

The material contained in this publication should not be relied on to suggest a course of treatment for a particular individual or as a substitute for consultation with qualified health professionals who are familiar with your individual medical needs. Please contact your physician for your own health care related questions.

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ACE does not promote any “brand”, product or program on any of its materials or its website, or during any of its educational programs or activities.

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