

## ACE's Focus for 2022: Patient-driven education and advocacy

With more than 50,000 members and subscribers across Canada, ACE continues to meet the challenges of leading patient education and advocacy programming during the ongoing COVID-19 pandemic. In this special issue of JointHealth<sup>TM</sup> insight, we go behind the scenes to look at some of the initiatives ACE is planning for 2022.

A key part of the planning process for ACE education and advocacy programs in 2022 was to consider the changes underway in a Canadian health system that is rapidly transforming coming out of the pandemic.

As the direct and indirect impact of COVID-19 on the Canadian health care system continues, the federal, provincial and territorial governments are preparing for recovery phases in 2022, confronting the challenges of severe pandemic budget deficits. ACE understands that governments are narrowing their search for solutions that make financial sense and is advocating that creating a health care system that provides the best possible treatment and care to people living with arthritis makes sense, socially and economically.

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## **Who is guiding ACE's 2022 programming? Patients like you.**

To capture the arthritis patient perspective on these changes and challenges, ACE relied on its four 2021 national survey findings on the most critical issues facing the arthritis community. Several interesting themes emerged from these ACE national surveys. There is a significant ongoing demand from people living with arthritis for education and advice on understanding their disease, treatment options and self-care. ACE's national surveys also uncovered a strong need for more information on the latest arthritis research, particularly as it relates to medication advances and clinical practice.

***“If a patient doesn't know how they should be treated, they are far less likely to receive optimal or equitable care.”***

***“Patient-centred care and patient engagement can only really happen when some of the power is transferred to patients themselves.”***

***“Taking charge of our disease is essential. We spend a tiny percentage of our lives in the doctor's office – we are the ones in charge of our own care on a daily basis.”***

***“The patient perspective is the most important. No one knows arthritis better than me and others who live with it every day.”***

### **Focus into action**

Based on our learnings from our national surveys, ACE's 2022 focus is on providing education and leading advocacy efforts to ensure the arthritis patient voice is amplified and heard during patient-healthcare provider conversations and healthcare policy-making discussions in Canada. Our underlying goal is to ensure the health care system and providers recognize and treat arthritis effectively through improved models of care.

Specifically, in 2022, ACE is planning initiatives in five key education and advocacy programming areas:

- Models of care
- Health inequities
- Virtual care
- Access to medications
- Self-advocacy

## Models of Care

### Why it's important

Arthritis affects more than 6 million Canadians, yet no standardized model of arthritis care (MoC) is available. Inequitable models of care exist from province to province.

For example, the way people living with inflammatory arthritis (IA), such as rheumatoid arthritis, psoriatic arthritis, juvenile idiopathic arthritis, lupus or ankylosing spondylitis, access and receive healthcare varies significantly. This disparity leads to frustration and disappointment for tens of thousands of patients whose very lives depend on getting a timely and accurate diagnosis, timely access to rheumatologists, adequate reimbursement for medications, among other critical elements of a robust IA MoC.

A consistent theme in ACE's national survey findings is the considerable challenges Canadians living with arthritis still face with access to diagnosis and treatment. Survey results also revealed there is no "one size fits all" solution for IA, and in the end, the most appropriate model is determined by patient needs, the rheumatologist's style of practice, availability of arthritis health professionals and resources to support the MoC.<sup>1</sup>

In 2022, ACE will continue to focus on models of care advocacy and impactful healthcare community initiatives that improve arthritis patient experience and outcomes.







## What patients told us

***“If a patient doesn’t know how they should be treated, they are far less likely to receive optimal care.”***

***“Patient-centred care and patient engagement can only really happen when some of the power is transferred to patients themselves.”***

***“Taking charge of our disease is essential with RA. We spend a tiny percentage of our lives in the doctor’s office – we are the ones in charge of our own care on a daily basis.”***

## What ACE is doing:

- Helping models of care policymakers understand what is fundamentally important to patients, who know inflammatory arthritis and osteoarthritis intimately, is a key first step to shaping their decision-making.
- Ensuring those responsible for the delivery of models of care understand arthritis patient priorities to address gaps in arthritis treatment strategies.
- Raising awareness of gaps in care and treatment and improve models of care for arthritis patients, based on the current scientific evidence, with external stakeholders such as elected officials, key bureaucrats, pharmacy leaders, employers and private insurers.

## Health Inequities

### Why it’s important

ACE intends to continue to demonstrate leadership in 2022 to promote health equity for patients in underserved communities that impact social and economic disparities in access.

Race is an important social determinant of health because it is closely tied to other factors such as income, employment, education, housing, and experiences accessing healthcare resources. In other words, *systemic racism* can impact many areas of a person’s life and thus their health. In addition, life-long experiences of racism and discrimination can affect a person’s health by causing them high levels of stress in their daily life.



The largest racial health inequalities in Canada are faced by Indigenous peoples who have some of the highest rates of serious or life-threatening arthritis in the world, are at greater risk for becoming disabled by arthritis and a high rate of co-morbidities like heart disease, hypertension, asthma, arthritis and cancer. There is strong evidence that these health gaps are not the outcome of genetic differences but are instead the result of social and economic conditions shaped by a long history of colonialism, racism, destruction of land and food resources, and the trauma that comes with these experiences.

A key issue for Indigenous people with arthritis in Canada are the barriers they encounter on their care journeys; for example, the delay to diagnosis and referral to a specialist. In some cases, patients wait more than 10 years after their disease started because the health system has not been able to get them through the door to the specialist. Another care gap identified by Arthritis Research Canada is the lower rates of evidence-based inflammatory arthritis therapies being used among Indigenous people despite the disease being more severe.<sup>2</sup>

## What patients told us

In each of its national surveys in 2021, ACE conducted a sub-analysis of survey results to understand how the experiences of **black, Indigenous, or a person of colour (BIPOC)** differ from their white counterparts. These differences in respondents' experiences helped identify areas of arthritis services that are unjust and helped to focus ACE's 2022 education and advocacy programming.

For example, people living with arthritis who identified as black, Indigenous or a person of colour were:

- significantly more likely to experience factors that made it difficult to use virtual care services (*highly statistically significant finding*)
- more likely to report having no access to virtual care services (*borderline statistically significant finding*)
- less likely to be very satisfied with their virtual care experiences (*highly statistically significant finding*)





Respondents who identified as BIPOC were also 3 times more likely to report the forms they needed to fill out for medication reimbursement were confusing. Specifically, 29% (3 in 10) of BIPOC respondents reported that the forms they needed to fill out for reimbursement were confusing compared to 9% (1 in 10) white respondents. In addition, there were 4 times more BIPOC respondents who indicated there were too many forms to fill out with 24% of BIPOC respondents compared to 6% of white respondents. These findings underscore that the reimbursement forms may be too complicated to understand for Canadians who do not speak English or French as a first language and the possibility of a lack of available translation services at various stages of the application process for medications reimbursement.

### **What ACE is doing:**

- Raise awareness of social and economic factors affecting arthritis care for Indigenous peoples and other people of colour who face bias, racism and prejudice in Canadian healthcare systems.
- Work with the arthritis research community to push towards more inclusive participation as key informants in research prioritization, design, implementation, participation and knowledge translation.
- In the coming months, ACE will unveil new programming based on its leadership efforts to build trust and collaboration with Indigenous communities and advance the work of Truth and Reconciliation by specifically working on Call to Action #22: “We call upon those who can effect change within the Canadian health-care system to recognize the value of Aboriginal healing practices and use them in the treatment of Aboriginal patients in collaboration with Aboriginal healers and Elders where requested by Aboriginal patients.” – Truth and Reconciliation Commission of Canada: Calls to Action, p.3

## **Virtual Care**

### **Why it’s important**

The Canadian health system is rapidly transforming in response to the pandemic. In meetings with the provinces and territories over the past two years, ACE has discussed and

consulted with elected officials and senior bureaucrats about the innovative digital and data initiatives they are developing to improve the sustainability of health systems and improve models of care for patients.

Virtual care — the delivery of health care services and information via electronic methods - allows more patients with arthritis to see their specialists and helps conserve costs. For the diagnosis and treatment of complex types of inflammatory arthritis, it's important that people see a rheumatologist — a specialist specifically trained to treat IA. However, many people with IA live in locations where specialists are scarce and/or have difficulty traveling (due to symptoms like decreased mobility, imbalance or walking issues)— can address some of these challenges by bringing doctors into patients' homes or nearby clinics.

ACE conducted a National Survey on Virtual Care for People Living with Arthritis in 2021 and shared the results with provincial governments across Canada who are all at some stage of integrating virtual care into their health care **systems**.

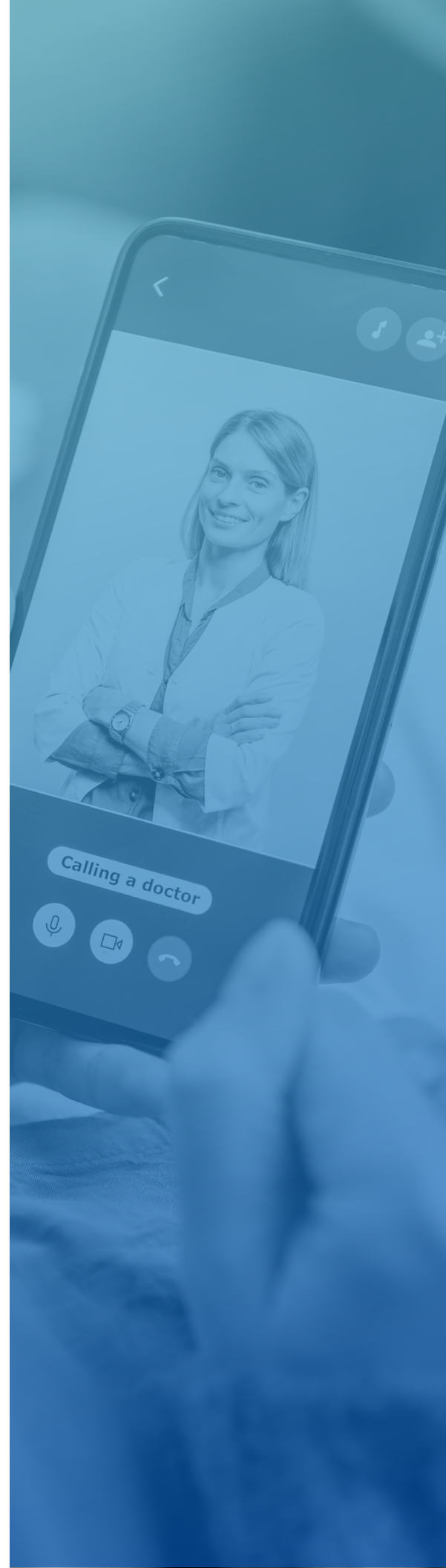
## What patients told us

***“Video conference with my rheumatologist is good as long as I am well. It is less tiring than going to the office and more comfortable.”***

***“I live on my own and do not know how to use electronics. I rely on family members to be at my resident and on the telephone visit with me.”***

***“I would like a combo of in-person and telephone, video, text. It's very convenient to simply call my GP and have a video meeting with my rheumatologists.”***

***“I don't have reliable access to the internet and that has made it really difficult to connect with my arthritis specialists.”***







As seen in the comments above, many respondents to ACE's Survey reported their preference for a mix of in-person and virtual care services, with a preference of in-person for more complex examinations such as joint counts, and virtual consults to augment care (e.g., in between visits or to support patient self-care).

Although the level of satisfaction was generally high with virtual care, arthritis patients did identify several difficulties that they are experiencing when it comes to accessing virtual care. These challenges include access to the internet, cost of electronics and lack of translation services and collectively act as barriers to meaningfully access and benefit from virtual care.

More disturbingly, survey respondents living with arthritis who identified as black, Indigenous or a person of colour were:

- significantly more likely to experience factors that made it difficult to use virtual care services
- more likely to report having no access to virtual care services
- less likely to be very satisfied with their virtual care experiences

### **What ACE is doing:**

- Work with policymakers to improve the IA MoC by integrating virtual care in the healthcare system to ensure people living with IA in urban, rural and Indigenous communities receive the right care in the right place at the right time to optimize their outcomes.
- Working closely with arthritis patient organizations, researchers and clinicians, ACE will lead and participate on virtual care initiatives across Canada, during and after pandemic, and advocate for their adoption by provincial governments.
- Address inequities built into virtual care services use, chief among them access to required electronic devices that can support a video call and lack of digital skills to operate a video call and navigate through difficult user interfaces.

## Access to Medications

### Why it's important

For government regulators and public drug plans to effectively review and approve new therapies and provide reimbursement access to treatment options, it is important for them to be aware of the unmet needs of arthritis patients; while at the same time, ensuring patients can afford the medicines they need.

Although many Canadians have access to public or private drug insurance, the patchwork of drug plans in Canada creates inequities in access to medications that can lead to reduced treatment and treatment delays, exposes households and businesses to considerable financial burden, and isolates the management of prescription drugs from other key components of the Canadian healthcare system.

The **findings** from ACE's National Survey on Arthritis Medications Reimbursement for People Living with Arthritis show that reimbursement coverage accessibility and affordability for prescribed arthritis medications are causing hardship and forcing a significant percentage of respondents to make difficult choices to obtain and stay on their life-changing medications. For many, the reimbursement process itself is too challenging and complex. Nearly 20% of ACE's survey respondents reported they "strongly disagree" or "disagree" that they have the information and support needed to understand reimbursement options and easily navigate the reimbursement process.

Another disturbing survey finding was that 32% of respondents "do not know" or "am not sure" what biologic medication(s) they are on. This is a red flag finding as it reveals a fundamental lack of patient understanding of their medication treatment. Ideally, when a patient and their healthcare specialist discuss whether to start, continue or stop taking a biologic therapy, the patient should be able to assess treatment (or no treatment) risk against benefit and have tools to enable them to discuss the pros and cons of the treatment with their healthcare team and the reimbursement access options.





## What patients told us

*“I have no idea who when and how my new medication is going to get paid for. I have no idea if my old medication is good to be continued to pay for. One agency points the finger to the next. So, I am left in the dark. Why can't there be one agency to help me figure out my costs, help me with paperwork in a timely manner and send me regular (at least once a year) communication (either by phone, email or mail) regarding how my coverage is setup and if there's any changes.”*

*“The approval process for my medication can be somewhat confusing as several parties are involved - my rheumatologist, the provincial Medicare program, the provincial Seniors Pharmacare program, the drug company and of course the pharmacy. So, it can be hard to keep track of who does what in the processes.”*

*“The extent of support I've received is the flyers that come with various biologic injections explaining whom to contact for manufacturers' support programs. The nurses who have provided these have, generally, not explaining any of the particulars, which vary by manufacturer. The ability to work with a specific pharmacist or nurse across medications (I'm sure I'm not the only arthritis patient who has tried many medications and often must switch prescriptions) who has extensive and up-to-date training in seeking reimbursements would be very helpful. “*

### What ACE is doing:

- Ensure government regulators and public and private drug plans are aware of the unmet needs of inflammatory arthritis patients when they review and approve new therapies and provide reimbursement



access to treatment options; while at the same time, ensuring patients can afford the medicines they need to improve their lives.

- Monitor monthly federal and provincial formulary reimbursement access for inflammatory arthritis medications and provide analysis and measurement through ACE's Arthritis Medications **Report Card**.
- Engage with public and private drug plans on biosimilar biologic policies and initiatives and provide most current biosimilars **news and research to patients**.

## Self-Advocacy

### Why it's important

No one knows arthritis better than those who live with it every day. When patients share their story and experiences with family, healthcare providers, work colleagues, community leaders and elected officials, they help them understand how their actions impact patients.

ACE's national surveys uncovered 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. 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.

### What patients told us

***“I want to learn more about coexisting conditions and who to see to treat those symptoms. What is available for disease treatment and pain relievers. Discussion on quality of life and needing to go on disability.”***

***“I would like to know more about what may trigger flare-ups, and more general details about psoriatic arthritis, since I was young when I was diagnosed and don't remember a lot of the information that my rheumatologist gave me at the time.”***



*“I don’t see research on living long term with arthritis, aging with RA, the effect on the body of RA medications over decades, coping with joint damage, association of RA and OA, association of RA and osteoporosis.”*

*“I’d like more information about my OA to help me communicate with my doctors and become partners in the management of my OA.”*

*“Literally as much as I can possibly learn. Possible causes, assistance, more about current and upcoming research, most importantly I have lots to learn about the supports I am eligible to receive in Canada and should seek out.”*

### What ACE is doing:

- Providing education to patients, self-care, and self-advocacy tools, and encouraging them to share their story and experience with their specialist, with the media, with their employer or with a policy maker helps patients communicate compellingly how arthritis and arthritis policies impact patients, families, and care partners.
- In 2022, ACE will continue to provide updates to its patient education and advocacy offerings on its **JointHealth.org** and **Arthritis Broadcast Network** websites.
- ACE will add to its course offerings on its **online learning program** and research and develop a new course in 2022 - **JointHealth™ Education: Osteoarthritis** - with a focus on educating and powering people with osteoarthritis.

ACE is interested in your feedback to our 2022 patient education and advocacy programming. Tell us what you think by contacting us at: [feedback@jointhealth.org](mailto:feedback@jointhealth.org)

## Stay informed.

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## References

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<https://www.jrheum.org/content/43/3/530>
2. Arthritis Research Canada: Indigenous Patient Preferences for Rheumatoid Arthritis Pharmacotherapy, 2017  
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## 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<sup>w</sup>məθk<sup>w</sup>əyəm (Musqueam), Skwx-wú7mesh (Squamish), and Səlilwətaʔ 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](http://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: Arthritis Research Canada, Amgen Canada, Canadian Biosimilars Forum, Canadian Institutes of Health Research, Canadian Rheumatology Association, Eli Lilly Canada, Fresenius Kabi Canada, Gilead Sciences Canada, Hoffman-La Roche Canada Ltd., Knowledge Translation Canada, Merck Canada, Novartis Canada, Pfizer Canada, Sandoz Canada, Sanofi Canada, St. Paul's Hospital (Vancouver), 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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