# JointHealthinsight

Arthritis research, education and advocacy news: February 2024

# Today's arthritis experience in Canada: The view from the street

This issue of JointHealth™ insight focusses on today's real-world experiences of Canadians living with arthritis. As we explore the current state of arthritis care, especially in northern, rural regions, it's clear that the journey to optimal treatment still has many challenges despite all the advances being made in treatment and care provided by rheumatologists, physio and occupational therapists and others with specialized arthritis training.

Arthritis is a daily reality for more than 6 million people in the country. It can affect every aspect of their lives. Because of a lack of government attention and funding, arthritis care from province to province to territory does not have an unified approach or national strategy like other major chronic diseases, including cancer, heart and stroke, diabetes, and mental health.

In this JointHealth™ insight issue, we examine the critical gaps in care, specifically for those living with inflammatory arthritis (IA), which requires timely culturally appropriate access to specialized arthritis doctors, swift diagnosis, and affordable, effective non-medication and medication treatments. These gaps are highlighted in our summary of a report from the Canadian arthritis community titled "The State of Arthritis Care in Canada Report Card."

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Unfortunately, for many living with IA in less accessible northern areas of Canada, these care necessities remain out of reach, worsening their struggles and deepening healthcare disparities. We also look at how this particularly affects Indigenous Peoples living in northern, rural Canada, and how they experience a higher prevalence of IA and face even steeper barriers to accessing care.

We also examine the innovative solutions being trialled in remote communities, from traveling specialists to virtual health platforms, and the expanding role of arthritis health professionals in bridging the care divide.

The theme of healthcare disparities continues in our preview of a research poster that ACE will be presenting at the upcoming *Canadian Rheumatology Association Annual Scientific Meeting* in Winnipeg on February 28 – March 2, 2024. The poster provides a deep analysis of the findings from ACE's National Survey on Arthritis and Health Literacy and compares the effects of age and ethnicity on health literacy between Black, Indigenous and Person of Colour (BIPOC) and white respondents.

Our issue concludes with a report on how the savings from biosimilars are being reinvested into treatment affordability and accessibility, with the potential to be applied into improving arthritis care for our arthritis "sisters and brothers" living in the north.

We hope you find this issue of JointHealth™ insight informative and helpful. Please let us know about the challenges you may be experiencing in your neighbourhood, city, province, or territory. Navigating these pressing challenges and sharing your ideas on how we can make arthritis care more equitable and effective in Canada is why we do what we do: We responsibly inform, educate and advocate for people like you, and ourselves.

Please **click here** to share your own "insight."

# The State of Arthritis in Canada Report Card

Arthritis Society Canada in collaboration with other leaders in the Canadian arthritis community – Arthritis Consumer Experts, Canadian Arthritis Patient Alliance, Canadian Rheumatology Association, Canadian Orthopaedic Association, Arthritis Health Professions Association, Canadian Spondyloarthritis Association, Arthritis Research Canada and Arthritis Community Research, Epidemiology Unit (ACREU) – has launched the *State of Arthritis in Canada Report Card*. The Report Card analyzes and evaluates provinces and territories on three main categories: access to arthritis care and treatment, wellness, and commitment to research and innovation.

The Report gave low grades to all provinces and territories, reflecting the urgent need for collaboration and innovation in arthritis care. Key findings included:

- Canada needs better arthritis data: Data across the country is inconsistent, insufficient, and too siloed to show a clear picture of the problem and its potential solutions.
- Getting access to care is the challenge: Too many Canadians cannot access arthritis care and demands outweigh system capacity.
- Arthritis research is underfunded: Relative to the burden of disease, including the number of Canadians impacted, more investment is needed in arthritis research.
- Provincial/territorial findings and opportunities for action: The highest grade among all jurisdictions in Canada was a "C," indicating significant room for improvement and that much work needs to be done.

The next steps for the arthritis community are to work with different levels of government – federal, provincial, and territorial – to address the gaps in care, the need for arthritis data and the underfunding of arthritis research. The time to address models of care in arthritis across Canada is now after years of being at the back of line of health care planning and delivery.

This acutely affects residents living with inflammatory arthritis, like rheumatoid arthritis, psoriatic arthritis, and ankylosing

# THE STATE OF ARTHRITIS IN CANADA

Report Card October 2023



# FINDINGS: PROVINCIAL AND TERRITORIAL RANKING - OVERALL GRADES



The following provides a comprehensive breakdown of the points awarded to each jurisdiction within the three categories, culminating in a final score out of 100 points, and accompanied by corresponding letter grades.

| JURISDICTION              | Access<br>Category<br>Points /50 | Wellness<br>Category<br>Points /30 | Research &<br>Innovation<br>Category<br>Points /20 | Total Score<br>/100 | LETTER<br>GRADE |
|---------------------------|----------------------------------|------------------------------------|--|---------------------|-----------------|
| British Columbia          | 34                               | 21                                 | 9  | 64                  | С               |
| Alberta                   | 33                               | 16                                 | 13   | 62                  | С               |
| Saskatchewan              | 28                               | 12                                 | 6  | 46                  | D               |
| Manitoba                  | 24                               | 11                                 | 12   | 47                  | D               |
| Ontario                   | 38                               | 14                                 | 12   | 64                  | С               |
| Quebec                    | 35                               | 16                                 | 8  | 59                  | С               |
| New Brunswick             | 32                               | 5                                  | 9  | 46                  | D               |
| Nova Scotia               | 33                               | 9                                  | 10   | 52                  | D               |
| Prince Edward<br>Island   | 23                               | 9                                  | 3  | 35                  | F               |
| Newfoundland and Labrador | 33                               | 8                                  | 5  | 46                  | D               |
| Northwest<br>Territories  | 10                               | 18                                 | 0  | 28                  | F               |
| Yukon                     | 16                               | 20                                 | 0  | 36                  | F               |
| Nunavut                   | 2                                | 14                                 | 0  | 16                  | F               |

GRADES: 85-100 A | 70-84 B | 55-69 C | 40-54 D | 0-39 F



spondylitis, who depend on getting a timely and accurate diagnosis, fast access to rheumatologists, appropriate public reimbursement for needed disease-controlling medications, among other critical elements of an arthritis model of care. These are serious diseases that, when untreated or undertreated, affect a person's mobility, preventing them from doing their regular day to day activities, such as dressing and looking after their families or continuing to work.

With timely diagnosis and access to treatments and care, the majority of people with these diseases will live a full life with minimal disability or long-term consequences. Without it, 50% of patients go on to develop some form of disability within 10 years, require expensive joint replacement surgery, have a three times increased risk for cardiovascular disease along with higher risks of developing cancers and uveitis, which causes blindness.

For more information, read the *State of Arthritis in Canada Report Card* here: https://bit.ly/StateofArthritisReportCardEN.

# Arthritis care in Northern Canada: When will it get better and how?

People living with inflammatory arthritis (IA) – like rheumatoid arthritis, psoriatic arthritis, lupus, or ankylosing spondylitis – are at greater health risk as their lives depend on getting a timely diagnosis, treatment, and appropriate public reimbursement for medications.

This gap is particularly felt by people living with IA in the northern, rural regions of Canada. Where you live can be more important in determining arthritis care and treatment than how sick or disabled you are. The disparity in arthritis care leads to frustration and disappointment for tens of thousands of patients whose very lives depend on an IA model of care that meets their unique needs.

The Canadian Rheumatology Association – the national professional association for Canadian rheumatologists – recommends one rheumatologist for every 75,000 people in Canada to ensure everyone can get the best care possible. However, in the northern, rural regions in Canada, there are far fewer rheumatologists than needed. This shortage means people can wait 6 to 12 months to see a specialist (compared to 60-90 days in southern Canada)¹.

For people living with arthritis in the north where there is a higher need for rheumatologic care, that means it's much harder for them to get the care they need. Optimally, that high quality care is close-to-home as many people with arthritis have serious mobility issues. Some people travel to cities in the south for treatment, using travel grants provided by provincial governments to help with the costs. Unfortunately, when it's too difficult to access a referral to an arthritis centre in the urban south, some people may not seek or get the treatment they need at all.

## What's the fix?

There are several established models of care in northern, rural communities to address serious gaps in arthritis care communities, including:

- a travelling rheumatologist model where a rheumatologist, based in an urban, south location, visits patients in the north on a regular basis to provide assessment and management of patients at a local clinic
- virtual health that provides a connection between
  the patient in a remote location with a care provider
  (however, a person living with IA would still need inperson physical examination for accurate diagnosis and
  to receive appropriate treatment plan)
- conventional local rheumatologist located in a patient's home community

There is also an increasing call to expand the role of arthritis health professionals to fill the gaps in arthritis care in the north. Arthritis health professionals (AHPs) are a diverse group who provide healthcare to people with arthritis across different settings and stages of disease and include physiotherapists, occupational therapists, registered nurses and nurse practitioners.

Arthritis health professionals can:

- improve patient access by reducing wait times for new referrals, enabling earlier treatment decisions, and allowing follow-up patients to be seen more promptly when needed
- help patients to remain current about treatment options and self-management care
- improve management of the signs and symptoms of many types of arthritis – pain, swelling, loss of joint movement, muscle weakness and fatigue
- promote adherence to treatment regimes





In British Columbia, the government provides funds for physician extenders in rheumatology practice, such as rheumatology nurses, physiotherapists, and other health care providers who can help with initial assessments and patient education. This enables the rheumatologist to focus on patients who need specific medical care and for the practice to have better and more comprehensive care to more people. B.C. Drs. Tommy Gerschman and Michelle Teo also continue to lead the way with their impactful project in specialist team care. Ten sites and eight different specialties have transformed their practices based on learnings primarily gathered from the rheumatology nursing experience over the past decade.

In Ontario, models of care using non-physician extended role practitioners (ERPs) in arthritis care have been successfully adopted in the co-management of patients with arthritis. These ERPs receive comprehensive training from the Advanced Clinician Practitioner in Arthritis Care (ACPAC) - an academic and clinical training program developed to prepare experienced physical therapists, occupational therapists, chiropractors and nurses in the assessment and management of arthritis.

The Ontario Rheumatology Association (ORA) is working with the provincial government to address disparities and inequities in arthritis care in Northern Ontario by using ACPAC trained ERPs to help bridge the gap in Northern Ontario. The ORA is proposing to create a program to train local ACPAC ERPs in northern communities, who would work with rheumatologists virtually in southern urban centers in a "hub-and-spoke" model that will help address many of the gaps in Northern Ontario.

The Northern Ontario Committee of the ORA, chaired by Dr. Sahil Koppikar, has made great strides in making this proposal into a reality by setting up a structure to enhance rheumatological care in this underserved area of the province. The ORA, together with the Ontario government, is implementing a model of rheumatological care in Thunder Bay and continues to work on identifying candidates for ACPAC training in all northern hubs.

# State of care for Indigenous Peoples living with arthritis

Northern, rural communities have a higher prevalence of arthritis and are disproportionately affected. This is particularly acute for Indigenous Peoples who represent a high proportion of the population in northern, rural Canada and who also have a higher prevalence of arthritis compared to the rest of the Canadian population. "Prevalence" refers to the total number of individuals in a population who have a disease at a specific period of time, usually expressed as a percentage of the population.

The higher prevalence of arthritis, combined with poor access to equitable care, results in Indigenous Peoples in Canada having some of the highest rates of serious or life-threatening arthritis in the world and are at greater risk for becoming disabled by arthritis. The foundational driver for these higher rates of arthritis and risk of disability are the results of intergenerational trauma from Indian Residential Schools, 140-plus years of racism and the inability of Indigenous Peoples to freely practice their traditional ways of knowing and being on their land.

Research has shown that Indigenous Peoples experience fewer visits to specialists than the non-Indigenous population as well as significantly more hospitalizations due to arthritis complications.<sup>2</sup> Another care gap for Indigenous Peoples is the lower rates of evidence-based inflammatory arthritis therapies being used among Indigenous people despite the disease being more severe.<sup>3</sup>

Indigenous Peoples also face significant challenges accessing health care related to racism, economic status, geographical distance, and difficulties in navigating the healthcare system. Additionally, issues surrounding medication access for Indigenous Peoples include trust concerns, stigma related to medication use, challenges in the supply chain, and financial burdens associated with reimbursement coverage for arthritis medications.

ACE is working with the arthritis community to advocate to provincial and territory governments for new and innovative ways to deliver Indigenous health care in culturally appropriate ways to address these health disparities:





- First, our community is recommending improving the relationship between patients and health care providers by adopting trauma-informed care. This approach aims to create a safer and more supportive environment for individuals who have experienced trauma.
- Another key recommendation is enhancing access and coordination through navigation models, making it easier for Indigenous Peoples living with arthritis to navigate the complex healthcare systems across Canada.
- Finally, we are encouraging governments to introduce culturally appropriate, patient-centered policies, such as a patient care facilitator or "arthritis liaison," to enhance the delivery of care to Indigenous communities and optimize health outcomes.

Arthritis Consumer Experts and its Indigenous advisors have developed specific recommendations for policymakers focused on expanding the role of Indigenous community-based patient care facilitators to help serve as a bridge between clinicians and patients, helping patients receive coordinated, continuous, culturally appropriate care within their community. These recommendations include:

- 1. In consultation with the arthritis community, uncover barriers to IA diagnosis, treatment and care, including a specific focus on the care gaps Indigenous Peoples with arthritis and other comorbidities face.
- Promote culturally appropriate IA patient support, education, case management and system navigation delivered by trained arthritis professionals and personnel who are trusted community-based members as an effective approach in inflammatory arthritis management, especially in underserved, vulnerable communities.
- 3. Ensure IA models of care are informed by Indigenous community members to ensure care facilitation is included in the model based on a culturally appropriate patient-centred approach dictated by their needs.<sup>4</sup>

## Reinvesting biosimilar savings: Enhancing patient care in Canada

When the patent of an originator biologic expires, other manufacturers are allowed to make a biosimilar version of the medicine. Over the past five years, Canadian public drug plans have expanded the reimbursement coverage for safe, effective, lower-cost biosimilar biologics to treat autoimmune diseases, including inflammatory arthritis, cancer, inflammatory bowel disease, diabetes, multiple sclerosis, psoriasis, and retinal vascular disorders.

Biosimilars have the potential to improve patient access to biologics and save public and private healthcare systems billions of dollars now and over the coming years. A study commissioned by the Canadian Government's Patented Medicine Prices Review Board (PMPRB) has estimated that private and public drug plans across Canada could save from \$332 million CDN to \$1.81 billion CDN in the third year following biosimilar entry across a portfolio of products.<sup>5</sup>

This fiscal breathing room has enabled provinces and territories to reinvest biosimilars savings into critical areas of healthcare, enhancing the overall quality of patient care. For example, the Ontario Ministry of Health stated savings generated from its biosimilar transition policy will allow Ontario to fund more new drug therapies, continue to grow the roster of publicly funded life-saving drugs, bring innovation to the healthcare system, and continue to deliver better, connected patient care.

Many Canadian provinces have demonstrated effective use of savings from the adoption of biosimilars, channeling these funds into enhancing patient care and expanding access to medications that treat inflammatory arthritis, cancer, and inflammatory bowel disease (IBD).

In British Columbia, the government reinvested the savings from biosimilar transitions into covering several long-requested drugs, diagnostic tests, and additional nursing support for patients with rheumatoid arthritis and IBD. Saskatchewan





implemented a biosimilar switching policy that resulted in significant savings, estimated at \$20 million once the transition period is complete. These savings are being used to support patient access to public drug coverage and new drug benefits. In Nova Scotia, a similar biosimilar switching policy was implemented. In B.C., the savings have helped improve the sustainability of healthcare services and add new therapies for public drug plan beneficiaries.

As the use of biosimilars continue to expand in Canada so does the significant amount of savings for federal, provincial, and territorial drug plans. Arthritis Consumer Experts will continue to meet with the public drug plans to ensure the savings are reinvested not only back into drug plan budgets but also used to modernize "special access criteria" where patients must try and fail treatment on older, less expensive medications and into non-medication elements of care that patients need, such as specialized nursing, counselling, and physio- and occupational therapy.

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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>əyʻəm (Musqueam), Skwx-wú7mesh (Squamish), and Səlilwəta?/ 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.jointhealth.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 longterm consequences and to ensure that all may benefit. The support of this should be shared by government, citizens, and non-profit and forprofit 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 "inkind" 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**

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#### 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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