# JointHealthinsight

Arthritis research, education and advocacy news: September 2024

Arthritis Consumer Experts National Survey Report on Private Health Insurance Part One: Understanding the Private Health Insurance Experience for Canadians with Arthritis

Private health insurance is a cornerstone of healthcare access for millions of Canadians, providing coverage for medications, physical therapy, and other essential services. According to the Canadian Life and Health Insurance Association (CLHIA), approximately 60% of Canadians are covered by private health insurance, largely through employer provided health insurance, which often supplements public healthcare by covering services that may not be included in publicly provided health care systems. However, the experiences of individuals with chronic diseases like inflammatory arthritis or osteoarthritis can vary widely, particularly in areas such as medication reimbursement, affordability, and access to support services.



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Arthritis Consumer Experts (ACE) recently conducted a National Survey to explore the experiences of people living with arthritis in Canada who are covered through additional private health insurance and identify both successes and critical gaps in coverage. The findings of the National Survey on Private Health Insurance are critical for understanding how well private health insurance plans meet the needs of people with arthritis and identifying areas for improvement. In this special edition of JointHealth™ insight, ACE breaks down the Survey findings into key sections, each addressing an essential aspect of the insurance experience for arthritis patients.



By sharing the findings from this Survey, we hope to inform and influence decision-making among health care providers, insurance companies, and policymakers to better support the arthritis community.

In the next JointHealth™ insight, ACE will present a Part 2 summary of the ACE National Survey on Private Health Insurance where we take a deeper look at the experience of respondents who have been prescribed biosimilars.

## **Survey demographics**

Who participated:

- **Gender distribution:** 114 (66%) identified as women, 56 (32%) as men.
- Age range: Participants were well-distributed across different birth decades:
  - between 1950-1969: 83 [41%]
  - between 1970-1989: 50 [25%]
  - between 1990-2009: 14 [7%]
  - between 1930-1949: 8 [4%]
  - betweeen 1910-1929: 1 [<1%]</li>
  - between 1910: 1 [<1%]
- Ethnocultural identity: Indigenous 16 [9%], Person of Colour 12 [8%], Black 4 [3%]
- Geographical distribution: Most respondents, 97 (48%) reside in large urban centers, 32 (16%) in small-medium sized communities, 27 (13%) in rural or remote communities, and 2 (1%) reside on a First Nations, Metis, or Inuit reserve/settlement.

# How did Survey respondents obtain their current private health insurance?

| Method of obtaining insurance                                    | Percentage |
|--|------------|
| Through your current employer                                    | 42%        |
| Other (please specify)   | 16%        |
| Through a professional, union, or alumni association             | 13%        |
| Individually purchased   | 13%        |
| Through a spouse or life partner's private health insurance plan | 12%        |
| Student care plan  | 3%         |
| Through a parent's care plan                                     | 1%         |

# How long have Survey respondents had their current private health insurance plan?

| Duration           | Percentage |
|--------------------|------------|
| 1-5 years          | 29%        |
| More than 20 years | 25%        |
| 6-10 years         | 18%        |
| 11-20 years        | 18%        |
| Less than 1 year   | 9%         |

For more demographic information including type of arthritis, source of diagnosis, time since diagnosis, education, income and geographic location (province or territory), please refer to the Appendix at the end of this report.

# Key survey findings Ease of reimbursement

Reimbursement for medications is a vital function of any health insurance plan, particularly for individuals with chronic diseases like inflammatory arthritis, where long-term and consistent medication use is often necessary. The ease with which plan members can navigate the reimbursement process directly impacts their access to essential treatments and, consequently, their overall health outcomes. According to Arthritis Research Canada, delays or difficulties in medication reimbursement can lead to non-adherence, which is associated with worsened disease progression and increased healthcare costs.

Navigating the reimbursement process for arthritis medications can be complex and stressful. Survey participants were asked about the ease of obtaining reimbursement through their current private health insurance plans and provided a wide range of responses:

Very easy and straightforward: 29%

• Easy and straightforward: 27%

Extremely easy and straightforward: 22%
Somewhat easy and straightforward: 14%

Somewhat difficult: 13%

Difficult: 8%Unsure: 5%

• Very difficult: 3%

Extremely difficult: 1%





The findings show that while most respondents find the reimbursement process relatively straightforward, a significant portion experiences varying degrees of difficulty. These challenges can lead to delays in accessing necessary medications, thereby affecting the effectiveness of treatment and overall quality of life.

#### Confidence in reimbursement coverage

Confidence in one's insurance coverage is crucial for managing arthritis. Patients who are uncertain about their coverage may delay seeking treatment or avoid filling prescriptions due to fears of out-of-pocket costs. Consistent and reliable access to medication is essential for preventing flare-ups and maintaining a good quality of life for people with arthritis.

Participants were asked about their confidence in their insurance plan's ability to pay for their arthritis medications and responded:

Somewhat confident: 34%

Very confident: 26%

Extremely confident: 19%Somewhat unconfident: 11%

Not very confident: 11%
Not confident at all: 6%

Unsure: 6%

These responses indicate that while a substantial number of individuals are confident in their coverage, many are uncertain or lack confidence. This uncertainty can lead to stress and anxiety, which may worsen the symptoms of arthritis. Clear communication and reassurance from insurers are essential to maintaining plan member confidence and ensuring adherence to treatment plans.

# Satisfaction and affordability with insurance plans

Affordability is a significant concern for many Canadians, particularly those with chronic diseases and conditions that require ongoing treatment. According to a report by the CLHIA, rising costs of medications and healthcare services have made affordability a critical issue for many insured Canadians. For people living with arthritis, adequate coverage that is also affordable is key to managing their condition without financial strain.

When asked if their current health insurance adequately covers their arthritis-specific medications, most respondents (73%) responded positively. However, affordability remains a concern: 71% of respondents stated their monthly premium is affordable; 16% stated their monthly premium is not affordable.

These results underscore the financial burden that some individuals face, even when covered by insurance. The affordability of premiums and out-of-pocket costs directly influences a plan member's ability to maintain their arthritis treatment regimen, which is critical for managing their disease effectively.

### Cost impact on arthritis care

The extent to which insurance coverage impacts arthritis care is a significant concern. Limited or insufficient coverage can force patients to make difficult choices, such as skipping doses or not filling prescriptions, which can lead to worsening symptoms, increased disability, and higher long-term healthcare costs.

The survey explored the impact of insurance coverage on arthritis care with 125 out of a total of 186 respondents describing how limited or insufficient coverage negatively affected arthritis care.

Survey participants responded their insurance plan's lack of adequate reimbursement led to the following actions (respondents were allowed to select more than one):

- Seek reimbursement from a pharmaceutical company: 15%
- Stop taking prescribed medication: 12%
- Take less of the prescribed medication: 11%
- Not fill a new prescription: 9%
- Not renew a prescription: 6%
- Start taking a different medication: 6%
- Fill some prescriptions over others: 6%
- Borrow money to pay for medications: 6%
- Take medications prescribed for someone else: 2%

These findings reveal the significant impact that insufficient coverage can have on the health and well-being of individuals with arthritis. Such coverage gaps can lead to non-adherence to treatment, potentially worsening the patient's condition and increasing the overall burden on the healthcare system.







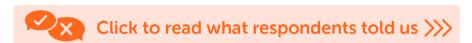


#### **Delay and declines**

In ACE's Survey, **28%** respondents experienced delays in receiving approval for arthritis medication coverage from their current private health insurance. The delay most commonly ranged from 1-4 weeks; however, **26%** of respondents reported delays over 5 weeks in duration. Thirty-four per cent experienced moderate impacts, while **15%** experienced severe impacts.

Thirty-one per cent of respondents also reported their current private health insurance plan had declined coverage for a medication prescribed for their arthritis. Of the 51 respondents who were declined, 34 respondents were provided with a reason, while 17 respondents were not.

Experiencing delays in receiving approval for arthritis medication coverage or facing declined coverage for prescribed medications can have a profound impact on the health and quality of life for a person living with arthritis. Arthritis is a chronic disease that often requires timely and consistent access to specific medications to manage symptoms, prevent disease progression, and maintain mobility. Delays in approval can lead to prolonged periods of untreated symptoms, exacerbating pain, inflammation, and joint damage, which may ultimately result in a diminished quality of life and increased healthcare costs. Additionally, when coverage for a prescribed medication is declined, patients may be forced to either switch to less effective alternatives, endure out-of-pocket expenses, or go without the necessary treatment altogether.



#### **Prior authorization**

Prior authorization is a common requirement in private health insurance plans, intended to control costs by ensuring that prescribed medications are necessary and follow a specific clinical guideline. However, this process can be a significant hurdle for patients needing timely access to medications. The Canadian Health Policy Institute has noted that prior authorization can lead to delays in treatment, particularly for patients with chronic diseases like inflammatory arthritis.

Survey results reveal a wide range of experiences with prior authorization, with respondents reporting varying degrees of ease or difficulty in navigating the process:

Easy: 33%Very easy: 18%

Do not know/have not had to do this: 13%

Difficult: 11%Very difficult: 5%

The mixed experiences with prior authorization suggest that while it is manageable for some, others face significant challenges. These hurdles can delay treatment, increase the chance of worsening symptoms and increase disease activity.



## Click to read what respondents told us >>>

### Access to additional support services

Beyond medication coverage, the Survey investigated the availability of additional services provided by insurance plans to support reimbursement and arthritis care, such as disease management programs, educational resources, and virtual care, which are critical for comprehensive arthritis care. According to a study by the Canadian Health Services Research Foundation, integrated support services can significantly improve health outcomes and quality of life for individuals with chronic diseases.

Respondents reported accessing the following services from their insurance plans:

Prior approval requirement: 32%
Limitations or exclusions: 30%
Medication management: 29%
Health and wellness plans: 29%
Generic substitutions: 23%

Educational and counseling services: 20%

Care coordination: 17%
Digital health tools: 16%
Disease management: 13%
Virtual care services: 13%
Biosimilar transitioning: 10%

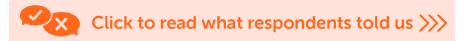
Appeals process for declined reimbursement: 9%

The access to these additional support services from private health insurance plans are crucial for helping people manage their arthritis effectively. However, the Survey results indicate





inconsistent access, which may leave some patients without the comprehensive care they need. Expanding access to these services could significantly improve health outcomes for people with arthritis



#### **Patient support program**

Patient support programs can provide critical support for people with inflammatory arthritis facing a variety of barriers to accessing their medication. Patient support program services can help a person who has been prescribed an advanced therapy navigate the reimbursement coverage process from a public or private insurer as well as provide educational resources, nursing support (for things like self-injection training) and even financial assistance in dire emergencies. Ensuring that all patients have access to these resources is essential for effective arthritis management.

When asked if the medications they take are supported by patient assistance programs, 72% of respondents confirmed participation, and using the following services:

- pre-authorization assistance for prescription medications and financial support: 57%
- Financial assistance: 41%

Respondents who answered "Yes" were also asked about the availability of additional services provided by patient support programs to support their arthritis care and they reported varying levels of access to the following services:

Pre-authorization requirements: 57%

Financial assistance: 41%

• Limitations or exclusions: 39%

• Medication management: 25%

• Care coordination: 23%

• Generic substitution: 14%

Appeals process: 11%

• Disease management: 10%

• Digital health tools: 10%

Virtual care services: 6%

• Biosimilar transitioning: 5%

• Health and wellness plans: 5%



Click to read what respondents told us >>>

# **Experience of Black, Indigenous, and People of Colour (BIPOC) vs. White Respondents**

The ACE National Survey on Private Health Insurance Plans reveals significant disparities in the experiences of Black, Indigenous, and people of colour (BIPOC) respondents compared to white respondents. These differences highlight inequities in access to and satisfaction with private health insurance coverage for arthritis care.

#### Affordability of coverage

A stark contrast emerged in the affordability of health insurance premiums between BIPOC and white respondents. While 33% of BIPOC respondents found their private health insurance coverage unaffordable, only 12% of white respondents reported the same. This gap underscores the greater financial strain that BIPOC communities experience when managing their arthritis. High costs can lead to delayed or forgone treatments, worsening health outcomes and increasing long-term healthcare expenses.

#### Reimbursement denials

BIPOC respondents were also significantly more likely to face denials in reimbursement for arthritis medications. 50% of BIPOC respondents reported having reimbursement requests declined, compared to 27% of white respondents. This discrepancy raises concerns about barriers in the private health insurance system that may disproportionately impact BIPOC individuals, potentially limiting their access to necessary medications and exacerbating health inequities.

#### Plan limitations or exclusions

Interestingly, fewer BIPOC respondents (19%) reported encountering limitations or exclusions in their health insurance plans compared to white respondents (41%). While this may appear positive at first glance, it could also reflect a lack of awareness or understanding of their plan details among BIPOC respondents, suggesting the need for more comprehensive education and support to help them navigate their coverage effectively.





#### Knowledge of patient support programs

Awareness of patient support programs, which can provide crucial assistance with reimbursement and other aspects of arthritis care, was notably lower among BIPOC respondents. Only 52% of BIPOC respondents knew about these programs, compared to 77% of white respondents. This gap in knowledge may result in BIPOC individuals missing out on essential financial or additional health service support, further widening health disparities.

# Access to supplemental help with reimbursement – Preauthorization

Access to supplemental help, particularly around preauthorization requirements, was another area where BIPOC respondents faced challenges. Only 17% of BIPOC respondents received assistance with preauthorization, in stark contrast to 63% of white respondents. Preauthorization is often a critical step in ensuring timely access to medications, and without adequate support, BIPOC patients may face longer delays or barriers in receiving their prescribed treatments.

#### Conclusions and recommendations

The ACE National Survey on Private Health Insurance Plans highlights both the strengths and shortcomings of current private insurance coverage for people with arthritis in Canada. While some patients experience satisfactory coverage, a substantial number of them face serious obstacles, including cumbersome reimbursement processes, unaffordable premiums, delayed medication approvals, and even declined coverage of essential treatments. These are barriers that can lead to worsened health outcomes, increased pain and disability, and a diminished quality of life for millions of Canadians.

## **Key recommendations:**

## Comprehensive coverage for arthritis medications

Insurance providers should consider expanding coverage for all necessary arthritis medications. This is a matter of health equity and human dignity. Patients should not have to fight for the treatments they need to maintain their health and quality of life.

#### Eliminate reimbursement hurdles

The reimbursement process should be simplified and standardized across the industry to ensure that patients can access their medications without unnecessary delays. Insurers must streamline their processes and remove bureaucratic barriers that prevent timely treatment, which is essential for managing chronic diseases like arthritis.

# **Enforce fair and transparent prior authorization practices**

Prior authorization requirements should be transparent, with clear guidelines and timelines. Insurance providers must be held accountable for any delays that compromise patient care. Prior authorization should not serve as a cost-containment strategy at the expense of patient health.

#### Improve access to affordability programs

Insurers should offer comprehensive affordability programs, including full premium coverage where necessary, to ensure that no patient is forced to choose between their health and financial stability.

#### **Expand support services**

Beyond medication coverage, insurance plans should provide robust support services, including disease management programs, mental health resources, and digital health tools. These services are critical for helping patients manage their condition holistically and maintain a high quality of life.

#### **Enhance communication and education**

Patients need clear, accessible information about their insurance plans, including how to navigate prior authorization and other processes.

## **Address health inequities**

The Survey findings highlight clear disparities in the experiences of BIPOC versus white respondents in navigating private health insurance for arthritis care. BIPOC respondents consistently reported facing greater financial burdens, higher rates of reimbursement denials, and lower awareness of available support services. These disparities point to the urgent need for private health insurers and advisors to address these inequities by ensuring more accessible, equitable, and transparent healthcare coverage and support systems for all Canadians.





# **Next steps**

Arthritis Consumer Experts will continue to advocate for better private health insurance coverage for people with arthritis. The findings from this survey will be shared with key stakeholders, including health care providers, insurers, and policymakers, to drive meaningful change in the system.

The findings from this Survey will serve as a powerful tool in our campaign to ensure that every Canadian with arthritis receives the comprehensive, affordable, and timely care they deserve.

# **Appendix**

# **Survey sociodemographic information**

Type(s) of arthritis, as diagnosed by a health care provider

| Disease                                  | Percentage |
|--|------------|
| Adult-onset Still's disease              | 1%         |
| Ankylosing spondylitis                   | 6%         |
| Fibromyalgia                             | 13%        |
| Gout                                     | 7%         |
| Juvenile idiopathic arthritis            | 2%         |
| Lupus                                    | 5%         |
| Non-radiographic axial spondyloarthritis | 1%         |
| Osteoarthritis                           | 45%        |
| Polymyalgia rheumatica                   | 2%         |
| Psoriatic arthritis                      | 10%        |
| Rheumatoid arthritis                     | 39%        |
| Scleroderma                              | 1%         |
| Sjogren's syndrome                       | 3%         |
| Vasculitis                               | 1%         |
| Crohn's and Colitis                      | 6%         |
| Diabetes                                 | 9%         |
| Inflammatory bowel disease               | 6%         |
| Multiple sclerosis                       | 0%         |
| Do not know                              | 18%        |

### Health care provider who provided the diagnosis

| Health care provider   | # of Participants | Percentage |
|------------------------|-------------------|------------|
| Rheumatologist         | 81                | 46%        |
| Family doctor          | 62                | 35%        |
| Other (please specify) | 10                | 6%         |
| Pain specialist        | 10                | 6%         |
| Chiropractor           | 3                 | 2%         |
| Pharmacist             | 2                 | 1%         |
| Radiologist            | 2                 | 1%         |
| Elder                  | 1                 | 1%         |
| Massage therapist      | 1                 | 1%         |
| Naturopath             | 1                 | 1%         |
| Occupational therapist | 1                 | 1%         |
| Physiotherapist        | 1                 | 1%         |





|                       | Response<br>Option        | # of<br>Participants | Percent |
|-----------------------|---------------------------|----------------------|---------|
| Arthritis<br>duration | 0-10 years ago            | 77                   | 38%     |
|                       | 11-20 years ago           | 40                   | 20%     |
|                       | 31-40 years ago           | 31                   | 15%     |
|                       | 21-30 years ago           | 21                   | 10%     |
|                       | No diagnosis              | 4                    | 2%      |
|                       | 41 or more years ago      | 2                    | 1%      |
|                       | Alberta                   | 19                   | 9%      |
|                       | British Columbia          | 33                   | 16%     |
|                       | Ontario                   | 66                   | 33%     |
|                       | Quebec                    | 15                   | 7%      |
|                       | Manitoba                  | 7                    | 3%      |
| Province              | Saskatchewan              | 3                    | 1%      |
|                       | Nova Scotia               | 4                    | 2%      |
|                       | New Brunswick             | 8                    | 4%      |
|                       | Newfoundland and Labrador | 1                    | <1%     |
|                       | Prince Edward Isaland     | 1                    | <1%     |
|                       | Large urban center        | 97                   | 48%     |
| Area                  | Small-medium              | 60                   | 30%     |
|                       | Other                     | 27                   | 13%     |
|                       | 0-10km                    | 62                   | 31%     |
|                       | 11-25km                   | 48                   | 24%     |
| Distance to provider  | 26-50km                   | 18                   | 9%      |
|                       | 51-100km                  | 16                   | 8%      |
|                       | 101-250km                 | 9                    | 4%      |
|                       | 251-500km                 | 3                    | 1%      |
| Education level       | University graduate       | 122                  | 61%     |
|                       | Some college              | 21                   | 10%     |
|                       | High school graduate      | 10                   | 5%      |
|                       | Less than high school     | 2                    | 1%      |
| Anual                 | Above \$80K               | 78                   | 39%     |
| income                | \$40K-80K                 | 44                   | 22%     |
|                       | Below \$40K               | 20                   | 10%     |

## Call to action

Stay informed by subscribing to JointHealth™ insight, share these findings with your community, and advocate for better private health insurance coverage. Together, we can create a future where every person living with arthritis has the support and resources they need to live a full and healthy life.

# Thank you

Our deepest gratitude goes to the Survey respondents. Your contributions are invaluable in helping us understand and address the challenges faced by the arthritis community in Canada.

If you have any questions or would like to learn more about our advocacy efforts, please visit our website at <a href="https://www.jointhealth.org">www.jointhealth.org</a> or contact us at <a href="mailto:feedback@jointhealth.org">feedback@jointhealth.org</a>



# **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\*məθk\*əyəm (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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Canada, Sandoz 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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