



ACCELERATING IMPACT

RESEARCH STRATEGY

2020-2025



EXECUTIVE SUMMARY

Arthritis affects more Canadians than any other chronic health condition. As many as 6 million Canadians live with arthritis (that's 1 in 5 adults, plus 3 of every 1,000 children) and that number is expected to increase to 9 million by 2040.

You or someone you love lives with pain, fatigue and other symptoms of arthritis – and those symptoms can erode all aspects of life. Forty per cent of people with arthritis indicate that pain limits their activities, makes it harder to work, play sports, build relationships, pursue passions and even keep up with the simple daily routines of life. It gets worse. Without timely access to treatment, arthritis can cause permanent joint damage and loss of function, further compromising quality of life. And there is no cure at present, which means that for most people, there is no escaping the impacts of the disease.

The damage is real. The impact is vast. The challenges are serious. And half-measures are not enough. Tackling arthritis requires dedication and a coordinated, strategic effort.

Fueled by donors and volunteers, the Arthritis Society is Canada's preeminent national health charity working towards a world where people are free from the devastating effects that arthritis has on lives. We are Canada's largest charitable source of research funding and have invested over \$200 million in arthritis research since our inception in 1948.

Given the significant impact on patients, the healthcare system and society at large, strategic focus on arthritis research is critical to ensure that people receive the best possible care to improve their quality of lives, with a concerted focus on better understanding what causes these diseases, finding innovative treatments and discovering cures. Research that seeks opportunities for earlier and more accurate diagnoses will ensure that arthritis patients receive timely and effective care, leveraging technological advancements to pinpoint therapies will support personalized treatment, and an ongoing focus on fundamental discovery to understand the disease and innovations to improve peoples' everyday lives will advance the road to a cure. Through a re-designed research program, the Arthritis Society aims to spark new ideas and careers in arthritis research.

With a focus on ensuring that research is having a positive impact on health outcomes, the Arthritis Society's 2020-2025 Research Strategy: Accelerating Impact prioritizes two impact areas:

- ▼ **Innovative research informed by patient priorities**
- ▼ **Supporting a pipeline of strong researchers**

**OVER 5 YEARS
WE WILL:**

INVEST
\$30
million in
research

FUND
60
new innovative
research projects

LAUNCH
150
new research
careers in
arthritis

CONSULTATION PROCESS

The Arthritis Society engaged stakeholders using a variety of methods over a one-and-a-half-year process. Surveys, in-person meetings and workshops included diverse knowledge users – people from across the arthritis “ecosystem” who use research evidence to inform healthcare decisions, health policies, clinical practice and community programming, among other outputs. Consulted stakeholders included researchers, clinicians, consumers (i.e. people affected by arthritis, with an emphasis on patient perspectives), research funders, charities, government representatives and other partners, united by the common goal of identifying gaps and opportunities for the Arthritis Society’s research portfolio. The work was overseen by expert external advisors made up of the Arthritis Society’s Scientific Advisory Committee, Mission Committee and strategic consultants, along with strong support from the National Board of Directors. These groups will be critical to the implementation of the strategies and opportunities within the plan.

VALUES AND APPROACH

The Arthritis Society’s 2020-2025 Research Strategy: *Accelerating Impact*, is intended to guide the research portfolio based on patient priorities, outline principles of the approach and highlight current areas of focus. Themes and principles consistently arose through the consultation process, which are reflected in the outlined strategic approach. Underpinning this plan are the following five core values to guide the work:

▼ **Patient-focus**

As Canada’s leading national arthritis charity, the Arthritis Society is accountable to its donors, the public and specifically, people affected by arthritis. It is that focus that motivates the Arthritis Society to be a leader in research informed by patient priorities with a commitment to engage consumers at all stages of the research process from strategic planning, decision-making, within multidisciplinary teams, and as knowledge translation and exchange partners. Strong engagement of consumers will foster better partnerships and inspire research with the most potential to impact people affected by arthritis. To achieve success, a diversity of consumers and research questions will emerge through strong collaborations that define relevant needs and scientific strategies.

▼ **Excellence and innovation**

As the national champion for Canadians living with arthritis, the Arthritis Society invests in cutting-edge research that has the most potential to impact people affected by these diseases, while investing in prevention strategies and cures for the future. Through competitive, excellence-based selection processes supported by volunteer peers of researchers, clinicians and consumers, the Arthritis Society invests in the most promising research regardless of geography or institution. Based on this premise of excellence, the Arthritis Society supports the best research in the country – which is also showcased on the international stage.

▼ **Knowledge translation and exchange**

A focus on knowledge translation and exchange is critical to ensuring that research outcomes influence clinical practice, healthcare policy, programs and resources for people affected by arthritis. Equally important is the reciprocal relationship of lived experiences, policy and program needs to the direction of arthritis research. As a steward of donor funds, the Arthritis Society must work with researchers and partners to share the outcomes of research in ways that are meaningful to diverse audiences.

▼ **Evaluation and impact**

The Arthritis Society has adopted a comprehensive measurement and evaluation framework that focuses on short-, intermediate- and long-term outcomes. This framework articulates who is influenced and impacted by the knowledge generated through research, in what ways, and how research is promoting practice and behaviour change. These outcomes directly support the Arthritis Society's overall vision to live in a world where people are free from the devastating effects that arthritis has on lives. As a learning organization, this will help us assess our research programs and the impact of our research investments, which is foundational to effective knowledge translation and exchange.

▼ **Strong partnerships**

The challenges faced by arthritis patients are enormous and require coordinated action among arthritis organizations to leverage strengths and focus resources. The Arthritis Society is committed to supporting a collaborative arthritis community, which includes research partnerships with institutions, other charities and research funders. A component of the Arthritis Society's work will focus on leveraging funds to engage in larger-scale strategic partnerships that complement the organization's core research programs.

IMPACT AREAS

1. Innovative research informed by patient priorities

The scope and spectrum of arthritis research is broad and diversified. Moreover, in today's research world, discoveries in multiple, often unrelated areas, coalesce to generate new knowledge in a way that was not possible in the past. A range of national and international organizations address this through open and targeted funding strategies. The Arthritis Society has carefully and thoughtfully undertaken environmental scans and consulted widely to get an understanding of which part of the research spectrum is best suited for its mandate and vision.

As a leader in patient-informed research and consumer partnerships, the Arthritis Society believes that strong collaboration will inspire research with the most potential to impact people affected by arthritis. The Arthritis Society's 2020-2025 Research Strategy: *Accelerating Impact* aims to identify research avenues that focus on areas of highest priority to patients and achieve the highest levels of scientific excellence and rigour. These priorities will continue to be validated and refined through productive patient-clinician-researcher partnerships during the implementation of the plan.

Resulting from the patient-informed strategic planning process, the Arthritis Society has committed to focus on the following five areas:

▼ *A focus on pain*

Many Canadians are living with chronic pain due to a variety of conditions and, for people with arthritis, the physical and emotional burden of pain can be devastating. Whether intermittent or constant, pain has a serious impact on quality of life. Moderate or severe pain is reported by 39% of Canadians living with arthritis, with 40% of Canadians with arthritis (or 2.4 million people) indicating that pain limits their activities. Pain can affect each person with arthritis differently and is influenced by many factors, with existing pain medications working differently for different people. Supporting effective pain management is essential to overcoming the debilitating effects of chronic pain.

The challenge of chronic pain management is particularly pressing due to Canada's current opioid crisis, where rates of opioid use are second highest in the world. There is a significant need to find feasible and effective solutions for Canadians to manage their chronic pain, with the opioid crisis merely a symptom of the larger issue of the lack of viable alternatives. Building on a pain symposium held by the Arthritis Society in 2017 that brought together key stakeholder groups, consumers, experts and opinion leaders from across the healthcare spectrum, several urgent needs were identified including the following research priorities:

- Improving our understanding of the underlying mechanisms of pain
- Translating basic science discoveries into practice
- Improving techniques to measure pain
- Developing new and more personalized treatment approaches
- Alternative approaches to pain management including research on medical cannabis from basic science, clinical, health services and policy perspectives
- Improving self-management tools and technology enablers to help manage and communicate about pain

▼ **A focus on osteoarthritis**

Osteoarthritis (OA) is the most common type of arthritis by far. It is estimated that up to 5 million Canadians may be living with OA. OA has historically been considered a “wear and tear” form of arthritis. However, it has recently been redefined as the body’s failed attempt to repair damaged joint tissues. While joint damage can occur through deterioration associated with aging, it can also occur in response to injury or due to unusually formed joints. While lifestyle changes and medications can relieve symptoms, the underlying disease process of OA cannot currently be reversed. Treatment options are also limited for severe OA. Despite the high prevalence of OA, it is an emerging and evolving research focus in Canada. Current research priorities include:

- Improving our understanding of what causes different forms of OA, including the underlying biological mechanisms and how the disease progresses
- Understanding sex and gender differences in patients with OA
- Developing new and more personalized treatment approaches
- Developing more effective self-management tools
- Improving health services and systems
- Reducing health disparities in vulnerable and hard-to-reach populations

▼ **A focus on inflammatory arthritis**

Inflammatory arthritis (IA) occurs when the body’s immune system attacks joint tissues instead of germs, viruses and other foreign substances. It can affect the whole body – including organs outside of the joints – and its impact can be significant. Without effective treatment, IA can lead to irreversible damage and there is currently no cure. While genetics, age and lifestyle can all play a part in increasing the risk of developing IA, our understanding of what causes IA is limited. IA can lead to disabling pain and fatigue, impacting peoples’ ability to work and live well. Canada has historical strengths in IA-related research, with current research priorities including:

- Improving our understanding of what causes different forms of IA, including the underlying biological mechanisms and how the disease progresses
- Developing new and more personalized treatment approaches
- Improving strategies to manage symptoms
- Developing more effective methods to support patient-physician communications
- Improving health services and systems
- Reducing health disparities in vulnerable and hard-to-reach populations

▼ **A focus on childhood arthritis**

As many as 25,000 Canadian children and adolescents seek healthcare for arthritis, which makes it more common than most chronic childhood diseases, yet the causes of childhood arthritis are largely unknown. The course of childhood arthritis may also have periods of remissions and flares, and it's unclear when and how treatment can be stopped safely to minimize the risks of long-term treatment. Through a continued commitment to the Arthritis Society's *Stop Childhood Arthritis* initiative, research priorities include:

- Improving our understanding of what causes childhood arthritis, how to detect it earlier and diagnose it most effectively
- Developing new and more personalized therapies that are safe and effective
- Innovations to improve transitions in care as children navigate from pediatric to adult healthcare settings and improve unique quality of life issues through other life changes (e.g. education, employment)

▼ **A focus on work**

Millions of Canadians need to live and work while learning to cope with the debilitating effects of arthritis. The annual economic impact of treatment and lost productivity due to arthritis is estimated to be \$33 billion, or 2.7% of Canada's gross domestic product. While many people living with arthritis can work productively, episodic flares of symptoms will likely influence their capacity to work at some point in time. Proactive solutions are needed to support workers with arthritis before symptoms flare up or problems arise and ensure that employees and employers have the necessary tools to promote healthy work environments. Current research priorities include:

- Providing a strong evidence base to inform workplace policies and accommodations
- Ensuring that employees and employers have effective tools and resources to communicate about how to manage chronic conditions in the workplace
- The prevention of workplace disability and the most effective accommodations

2. Supporting a pipeline of strong researchers

Nurturing the next generation of scientists is critical to the future of arthritis research. With a focus on engaging scientists during the early stages of their careers, the Arthritis Society believes that trainees benefit from early exposure to arthritis research, meaningful engagement with consumers and other research disciplines, mentorship and networking opportunities. Through the design of targeted funding opportunities, the Arthritis Society aims to promote sustainable career paths that include partnerships with academic and clinical institutions. Project funding that promotes potentially high-risk, high-reward opportunities and funding to seed new ideas will be an important element of the Arthritis Society's early career investigator development program.

PROGRAM IMPACT AND ASSESSMENT

The Arthritis Society will focus on the areas described above through individual research awards coupled with strategic partnerships targeting large-scale programs and opportunities to achieve a larger collective. Impact will be evaluated based on a framework that recognizes short-, intermediate- and long-term outcomes. Investment in each of the areas of focus represents a critical input that will be carefully tracked. Traditional research metrics such as publications, academic citations and presentations will be used to assess the impacts of these investments complemented by markers that recognize objectives such as consumer engagement, knowledge translation and practice change. Examples of metrics that will be applied include influence on clinical practice, health policy and/or program delivery; multi-sector and consumer collaborations; and leveraged funding obtained.

The impact of the Arthritis Society's trainee and early career development program will be assessed based on an evaluation framework that assesses both quantitative and qualitative criteria. Progress and success will be tracked with metrics that include the number of early career investigators supported, research productivity, career growth, sustained engagement in research, the strength of collaborations and mentors involved in the program. The success of higher-risk endeavours will be assessed for their ability to spark new directions and attract additional funding to advance the research.

CONCLUDING REMARKS

As the most common chronic health condition in the country that impacts the daily lives of 1 in 5 Canadians, there is an urgent need to address the health and economic burden of arthritis. The growing prevalence of arthritic diseases underpins the need to understand what causes arthritis to develop, prevention and risk reduction strategies, as well as better detection, diagnosis and treatments. The population health impact begs for a better understanding of patient experiences and supportive care needs to improve the quality of life for people living with arthritis. With an integrated approach to address the needs of patients through research, advocacy and public policy, and information and support programs, the Arthritis Society looks to effect change through multidisciplinary approaches. The Arthritis Society's 2020-2025 Strategy: *Accelerating Impact* is intended to guide the research portfolio based on patient priorities, outline principles of the approach and highlight current areas of focus. It is through these focused approaches that the Arthritis Society aims to spark new ideas and careers in arthritis research to have the most potential impact for people affected by arthritis.

“Research presents me with hope for the future.”

**- David West,
living with arthritis**



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