Joint Action on Arthritis

A Framework to Improve Arthritis Prevention and Care in Canada

- A growing and costly burden.
- Solutions are available.
- A response is required.

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Arthritis Alliance of Canada
Alliance de l'arthrite du Canada

Fall, 2012

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List of Abbreviations

AAC	Arthritis Alliance of Canada
ACE	Arthritis Consumer Experts
ARC	Arthritis Research Center of Canada
CAN	Canadian Arthritis Network
CAPRI	Canadian Alliance of Pediatric Rheumatology Investigators
CIHR	Canadian Institutes of Health Research
DMARDs	Disease modifying anti-rheumatic drugs
JIA	Juvenile idiopathic arthritis
OA	Osteoarthritis
RA	Rheumatoid arthritis
SLE	Systemic lupus erythematosus
TJR	Total joint replacement

Executive Summary

Joint Action on Arthritis: A Framework to Improve Arthritis Prevention and Care in Canada

ARTHRITIS is a chronic disease that has devastating and debilitating effects on the lives of more than 4.6 million Canadians. In addition to the burden of pain and disability faced every day by individuals living with arthritis, it is the most common cause of disability in Canada. As a result, it is a significant cost to the public health care system and negatively affects workplace productivity and the Canadian economy. Arthritis knows no limits with respect to age or gender. Unfortunately, many Canadians living with the disease are told that it is "just arthritis". Indeed, joint pain is often seen as simply a normal part of aging. The significance of arthritis, and the importance of doing something about it, are discounted.

How will Canada remain globally competitive when, by 2040, 1 in 3 workers (almost 30% of the employed labour force) will suffer hip or knee pain, disability and mobility difficulties?

A Growing and Costly Burden

Due to increased longevity, reduced physical activity, increasing obesity and lack of access to timely health care, the burden of arthritis is increasing. Within a generation, more than 10 million (one in four) Canadians are expected to have either osteoarthritis (OA) or rheumatoid arthritis (RA), the two most common forms of arthritis. The total economic burden of OA and RA in Canada, including direct health care costs and productivity losses to the economy, will grow from $33.2 billion in 2010 (2.7% of the value of Canada's Gross Domestic Product) to over $68 billion in 2040 (2010 values).

Solutions are Available

The Arthritis Alliance has created ***Joint Action on Arthritis: A Framework to Improve Arthritis Prevention and Care in Canada*** with three primary goals:

- Communicate the arthritis community's vision of the actions and interventions required to improve the lives of people living with arthritis.
- Galvanize action around long-term strategies to improve arthritis prevention, and quality and efficiency of care.
- Facilitate and focus collaboration among governments and arthritis stakeholders in awareness, models of care and research.

Joint Action on Arthritis presents evidence-based strategic directions and solutions, organized into six objectives under three strategic pillars, to achieve the desired goal of improving the lives of Canadians.

Pillar I - Advancing knowledge and awareness

Effective arthritis prevention and care are inhibited by a lack of knowledge, poor understanding and limited training about this chronic disease among the public, researchers, providers, governments and others. As a result, widely held myths about arthritis suggest that nothing can be done and that it is merely a natural part of aging. This is not true and under ***Joint Action on Arthritis***, the Arthritis Alliance will:

Objective 1: Raise Awareness of Arthritis

Objective 2: Align and Strengthen Research in Arthritis

Objective 3: Enhance Professional Education with Respect to Arthritis

Pillar II - Improving prevention and care

Today, it is essential that prevention and care strategies are improved in order to ensure a sustainable health care system for the future. Greater efficiencies and improved quality care can be achieved through prevention and self-management strategies and evidence-based models of care delivery. Under ***Joint Action on Arthritis***, the Arthritis Alliance has the tools and expertise to:

Objective 4: Improve Prevention of Arthritis

Objective 5: Improve Access to and Delivery of the Best Care Possible (Models of Care)

Pillar III - Supporting ongoing stakeholder collaboration

The arthritis community has rallied and is focused toward addressing this underserved, chronic disease. However, key government and other stakeholders are needed at the table in order to successfully implement the Framework. Under ***Joint Action on Arthritis***, the Arthritis Alliance will:

Objective 6: Broaden Stakeholder Participation in the Alliance

A RESPONSE IS REQUIRED

The time has come to improve not only the quality of life of millions of Canadians, but also the sustainability of our health care system and the productivity of our workforce. The Alliance and its members have taken a leadership role in developing this Framework and will be approaching governments and other arthritis stakeholder organizations with specific requests for support and participation in implementing its initial priorities and actions.

The time has come to improve not only the quality of life of millions of Canadians, but also the sustainability of our health care system and the productivity of our workforce.

Initial Priorities and Actions

Following the launch, the Arthritis Alliance will focus its efforts on the following initial priorities in order to begin implementing the Framework:

Raise Awareness of Arthritis – The arthritis community is aligned and has begun coordinating messages and promotional activities to improve awareness of arthritis among Canadians. To achieve the desired outcomes, the Arthritis Alliance must join with workplace, government and other stakeholders to launch a pan-Canadian strategy to raise awareness of key risk factors, consequences and prevention strategies for arthritis.

Improve Access to and Delivery of the Best Possible Arthritis Care – It is hard to believe that many Canadians do not receive timely and effective arthritis care. Members of the Arthritis Alliance have demonstrated expertise and have a proven track record in improving health care quality and efficiency. These local successes need to be expanded to cover other arthritis and related musculoskeletal disorders and implemented across Canada.

Align and Strengthen Research – Canada has a strong track record as an international leader in arthritis research. The Arthritis Alliance has established an expert Research Working Group to partner and work with governments and other arthritis research stakeholders to enhance and focus resources on research that will improve prevention and the delivery of arthritis care to Canadians.

Build Ongoing Stakeholder Collaboration – Since 2002, the Arthritis Alliance has unified the community to address challenges that could not be done alone. Now, with our major stakeholders focused and aligned, we must engage policy and decision makers (governments, etc.) to implement our vision.

Contact Us

Send us your feedback on ***Joint Action for Arthritis: A Framework to Improve Arthritis Prevention and Care in Canada*** to info@arthritisalliance.ca or visit www.arthritisalliance.ca.

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Introduction

It's Not "Just Arthritis"!

Arthritis is a chronic disease that has a devastating and debilitating effect on the lives of more than 4.6 million Canadians.[1] In addition to the burden of pain and disability faced every day by individuals living with arthritis, arthritis is the most common cause of disability in Canada. As a result, it exacts significant costs from the public health care system, from workplace productivity and from the Canadian economy.[2,3,4]

Arthritis is a chronic disease that has a devastating and debilitating effect on the lives of more than 4.6 million Canadians.

Many Canadians living with the disease are told that it is "just arthritis". Indeed, joint pain is often seen as simply a normal part of aging. The significance of arthritis, and the possibility and importance of doing something about it, are discounted. The health care system and providers often fail to recognize and treat arthritis effectively. Health strategies, public policy and workplace policies treat arthritis lightly or say nothing at all.

There are solutions to this situation: solutions that are backed by solid research evidence and supported by individuals living with arthritis and the professionals and organizations working with them across Canada. The Arthritis Alliance of Canada, a coalition of arthritis organizations from across the country, has developed *Joint Action on Arthritis: A Framework to Improve Arthritis Prevention and Care in Canada* to facilitate collaboration on effective solutions and to secure the collective leadership commitments to make change happen.

About the Arthritis Alliance of Canada

The Arthritis Alliance of Canada was formed in 2002 with a commitment to improve the lives of Canadians with arthritis. With 36 member organizations, the Alliance brings together individuals living with arthritis; health care providers; researchers; and funding agencies, governments, voluntary sector agencies and industry to discuss, share and develop strategies to alleviate the burden of arthritis. The following is a list of current Alliance members and their websites.

There are solutions backed by solid research evidence and supported by individuals living with arthritis and the professionals and organizations working with them across Canada.

Arthritis Alliance of Canada

Member Organizations

Arthritis & Autoimmunity Research Centre (www.uhnresearch.ca/programs/aarc/programs.php)

Alberta Bone and Joint Health Institute (www.albertaboneandjoint.com)

Arthritis Community Research & Evaluation Unit (www.acreu.ca)

Arthritis Consumer Experts (www.jointhealth.org)

Arthritis Health Professions Association (www.ahpa.ca)

Arthritis Research Centre of Canada (www.arthritisresearch.ca)

Arthritis Research Foundation (www.beatarthritis.ca)

Bone and Joint Canada (www.boneandjointcanada.com)

Canadian Alliance of Pediatric Rheumatology Investigators

Canadian Arthritis Network (www.arthritisnetwork.ca)

Canadian Arthritis Patient Alliance (www.arthritispatient.ca)

Canadian Academy of Sports and Exercise Medicine (www.casem-acmse.org)

Canadian Association of Occupational Therapists (www.caot.ca)

Canadian Chiropractic Association (www.chiropraticcanada.ca)

Canadian Obesity Network (www.obesitynetwork.ca)

Canadian Orthopaedic Association (www.coa-aco.org)

Canadian Orthopaedic Foundation (www.canorth.org)

Canadian Physiotherapy Association (www.physiotherapy.ca)

Canadian Rheumatology Association (www.rheum.ca)

Canadian Society for Exercise Physiology (www.csep.ca)

Canadian Spondylitis Association (www.spondylitis.ca)

Cochrane Collaboration (www.cochrane.org)

Consumer Advisory Board of the Arthritis Research Centre of Canada (www.arthritisresearch.ca)

Consumer Advisory Council of the Canadian Arthritis Network (www.arthritisnetwork.ca/consumers)

Institute for Work and Health (www.iwh.on.ca)

McCaig Institute for Bone and Joint Health (www.mccaiginstitute.com)

Patient Partners (www.arthritis.ca)

The Arthritis Society (www.arthritis.ca)

Government Affiliates

CIHR Institute of Musculoskeletal Health and Arthritis (www.cihr-irsc.gc.ca)

Public Health Agency of Canada (www.phac-aspc.gc.ca)

Member Companies

Abbott Laboratories Limited (abbott.ca)

Amgen Canada Inc. (www.amgen.ca)

Hoffmann-La Roche Limited (www.rochecanada.com)

Janssen Inc. (www.janssen.ca)

Pfizer Canada Inc. (www.pfizer.ca)

UCB Canada Inc. (www.ucbcanada.com)

Members of the Alliance bring a wide range of expertise, capabilities and networks from across Canada to the work of improving the lives of individuals with arthritis. Their ongoing work both as individual organizations and in collaboration with other arthritis stakeholders is essential to achieving the overall goals of the arthritis community. Examples of collaborative initiatives that are already being led by individual organizations are highlighted throughout this document.

While each member organization continues its own work, the Alliance provides a central focus and facilitating forum for broader collaborative initiatives such as the development of this Framework.

Purpose of the Framework

The Alliance has created *Joint Action on Arthritis: A Framework to Improve Arthritis Prevention and Care in Canada* with three primary goals:

- To communicate the arthritis community's vision of the actions and interventions required to improve the lives of people living with arthritis;
- To galvanize action around long-term strategies and initial priorities to improve the prevention, quality and efficiency of arthritis care; and
- To facilitate and focus collaboration among governments and arthritis stakeholders in awareness, models of care and research.

Joint Action on Arthritis (the Framework) looks at arthritis prevention and care from a systemic point of view, with the experience of individuals living with arthritis as its central focus.

Joint Action on Arthritis (the Framework) looks at arthritis prevention and care from a systemic point of view, with the experience of individuals living with arthritis as its central focus.

The Framework is intended to engage individuals living with arthritis, educators, employers, insurers, government policy makers, health care providers, researchers and other arthritis stakeholders in the implementation of strategies to optimize resources for more effective prevention, detection and management of arthritis. With a mandate to create collaborative and constructive change, the Framework focuses on activities and initiatives that will directly affect the lives of people living with arthritis.

Framework Development Process

Joint Action on Arthritis was developed by the Alliance between January and September 2012 in consultation with over 100 stakeholders from 60 different organizations across Canada, who contributed as workshop participants or provided expert advice during the process (see Appendix A). The stakeholders included member organizations of the Alliance, individuals living with arthritis, researchers and clinicians, as well as representatives from other national organizations with an interest in arthritis, such as Bone and Joint Canada, the Canadian Academy of Sport and Exercise Medicine, the Canadian Chiropractic Association, the Canadian Obesity Network, the Canadian Occupational Therapy Association, the Canadian Pain Society and the Canadian Physiotherapy Association.

Joint Action on Arthritis builds on past reports of the Alliance, including the report of the 2005 Summit on Standards for Arthritis Prevention and Care, the 2011 *Canadian Arthritis*

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Funding Landscape Review (published in partnership with The Arthritis Society, the Canadian Arthritis Network and Canadian Institutes of Health Research) and *the Impact of Arthritis in Canada: Today and Over the Next 30 Years* (see http://www.arthritisalliance.ca). *Joint Action on Arthritis* is to serve as the mechanism for implementing the 2005 standards and turning the findings of these other key reports into action.

Why Arthritis Must Be Addressed

Arthritis and related musculoskeletal conditions are the most common chronic health conditions in Canada today, affecting over 4.6 million Canadians. Arthritis is the leading cause of limited function and long-term disability,[5,6,7,8] and as such, must be addressed to prevent unnecessary disability, productivity loss and maintain our global competiveness.

Arthritis knows no limits with respect to age or gender. Although it is one of the major reasons why people over 65 years of age visit their family physicians,[9] arthritis can strike children and adults of all ages. About 1 in every 1,000 children in Canada are affected by juvenile idiopathic arthritis (JIA), the most common form of childhood arthritis.[10] While both men and women get arthritis, two thirds of those affected in Canada are women.[2,11]

Nikolas Harris

At 18, Nikolas Harris has never known a day without pain or obstacle. Diagnosed at 22 months old with juvenile arthritis, Nikolas has lived with constant aching and immobility in his left hand and wrist, both knees and ankles. Simple tasks such as putting on shoes, showering and carrying his backpack pose daily challenges for this young adult. Nikolas is an advocate for raising awareness of juvenile arthritis in Canada, a disease that affects 1 in every 1,000 Canadians under the age of 16.

About Arthritis

Arthritis encompasses over 100 different conditions that produce joint and musculoskeletal pain, often the result of inflammation of the joint lining.[12] The most common form of arthritis is osteoarthritis (OA), and the most common form of inflammatory arthritis is rheumatoid arthritis (RA). However, there are many other arthritis and musculoskeletal conditions, ranging from milder forms to more disabling systemic forms, including systemic lupus erythematosus (SLE) (a connective tissue disorder), ankylosing spondylitis (an inflammatory arthritis of the spine) and gout.[2]

OA affects approximately one in eight Canadians[1]. OA is a progressive joint disease that occurs when damaged joint tissues lose their normal ability to repair themselves, resulting in a breakdown of cartilage and bone.[13] The most commonly affected joints include the hands and weight-bearing joints (hips, knees, feet and spine).[14] While OA is more common with age, *it is not a normal part of aging.*[4] Key risk factors for OA are obesity and joint injuries.[15]

RA affects over 272,000 Canadian adults. RA causes significant disability: within ten years of the onset of disease, up to 50% of people with RA become work disabled if left untreated. While RA affects all ages, more than one half of all new cases are diagnosed between the ages of 40 and 70 years.[1] RA is associated with chronic systemic inflammation resulting in an increased risk of mortality, in particular mortality due to cardiovascular disease.[16] On average, the life expectancy of someone with RA is 10 years shorter than that of the general population.[1]

While RA is the most common type of inflammatory arthritis in Canada, other types of inflammatory arthritis, such as ankylosing spondylitis, lupus, gout and psoriatic arthritis, have similar consequences with disabling pain and fatigue, limiting people's ability to lead productive and satisfying lives.[12]

Juvenile idiopathic arthritis (JIA), the most common form of childhood arthritis, is chronic inflammatory arthritis developing in children. JIA can affect children of any age, from infancy to 16 years.[17] In JIA, joints are attacked by inflammation and become stiff, painful and swollen.[18]

A Debilitating and Devastating Disease

Arthritis's greatest burden is on both the personal lives of Canadians living with arthritic conditions and the lives of their families. For example, of the 4.4 million Canadians with OA, for approximately 600,000, pain is severe enough to significantly limit their ability to perform daily activities.[1]

The simplest daily activities can be a challenge to those living with arthritis, including getting out of bed, dressing, walking up and down stairs, tying shoes, eating and using the toilet. They often face the inability to work and/or to live independently, and must rely on their families and friends for support or make use of public or private home-based or institutional care.

> The simplest daily activities can be a challenge to those living with arthritis, including getting out of bed, dressing, walking up and down stairs.

Adults with arthritis can experience significant disruption through loss of valuable roles and reduced participation in important activities. Middle-aged and older adults with OA report that their condition has a particularly devastating impact on employment, community mobility, heavy housework, leisure activities, social activities and close relationships.[4]

Adults living with arthritis are twice as likely as those without it to have at least one other chronic health condition.[11] For OA, the presence of other chronic conditions is a major barrier to receiving appropriate care[19] and leads to worse outcomes.[20,21] Given that diabetes mellitus and cardiovascular disease (including angina, congestive heart failure and hypertension) are high on the agenda for chronic disease management in Canada, better understanding of the impact of arthritis on the management or outcomes of these chronic conditions is needed.

Individuals living with painful arthritis face a lifetime of chronic pain and associated disability, fatigue,[22] and poor sleep.[23] The stresses of living with pain, compounded with disappointment of lost opportunities to participate fully in society—particularly in the workforce—put individuals living with painful arthritis at a higher risk for depression and anxiety.[24,25,26]

Nearly one half of all adolescents and young adults with arthritis report suffering from chronic pain.[27] Children and adolescents afflicted with arthritis carry the burden of the disease even longer than adults. Having arthritis as a child can have a significant impact on one's lifelong potential for achievement as a result of absences from school, work and social activities. Unique support needs must be addressed in order to integrate children appropriately at home, in school and in the community

> Having arthritis as a child can have a significant impact on one's lifelong potential for achievement as a result of absences from school, work and social activities.

A Growing Burden

The Arthritis Alliance of Canada's 2011 report, *The Impact of Arthritis in Canada: Today and Over the Next 30 Years*, documented the extent of the growth and burden of arthritis.[1]

Due to increased longevity, reduced physical activity, increasing obesity and lack of access to timely health care, the burden of arthritis in the population is increasing. Within a generation (by 2040), more than 10 million (or one in four) Canadians are expected to have OA. There will be a new diagnosis of OA every 60 seconds, resulting in almost 30% of the employed labour force, or one in three workers, having difficulty working due to OA. In addition, approximately 500,000 Canadians will be suffering moderate to severe disability due to OA.[1]

Over the next 30 years, the proportion of the Canadian adult population living with RA will increase from 0.9% to 1.3%. Approximately 0.74% of the employed labour force, or 1 in 136 workers is currently suffering from RA. Within a generation, this will increase to 1.5%, or 1 in 68 workers.[1]

Arthritis is also particularly prevalent among Aboriginal people. According to the Public Health Agency of Canada's latest arthritis surveillance report, the prevalence estimate for First Nations adults living both on- and off-reserve and for Metis adults is 1.3–1.6 times higher than the national estimate in the Canadian adult population.[4]

A Costly Disease

The Impact of Arthritis in Canada: Today and Over the Next 30 Years identified the cumulative economic burden of OA and RA. This was measured both in terms of direct costs to the health care system and in indirect costs to the economy.

In 2010, the total economic burden of OA in Canada was $27.5 billion, while the cost of RA was $5.7 billion. When combined, the economic burden of arthritis in 2010 was equivalent to 2.7% of the value of Canada's Gross Domestic Product. These costs will increase at an alarming rate, as rising rates of OA and RA and the aging population exert an increasing burden on the health care system and workforce productivity.

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Anne Fouillard

Anne, 60, lost seven years of her career (and one-half million dollars in earnings) as an international development consultant because of osteoarthritis. The disease began in her knees when she was about 30, then moved into her hips and back. Pain and stiffness in her joints and extreme fatigue forced Anne into a wheelchair for two years before she had both hips replaced at the age of 51, followed by spine-fusion surgery four years ago. Since her back surgery, Anne has returned full-time to an international consulting practice.

AAC
Arthritis Alliance of Canada
Alliance de l'arthrite du Canada

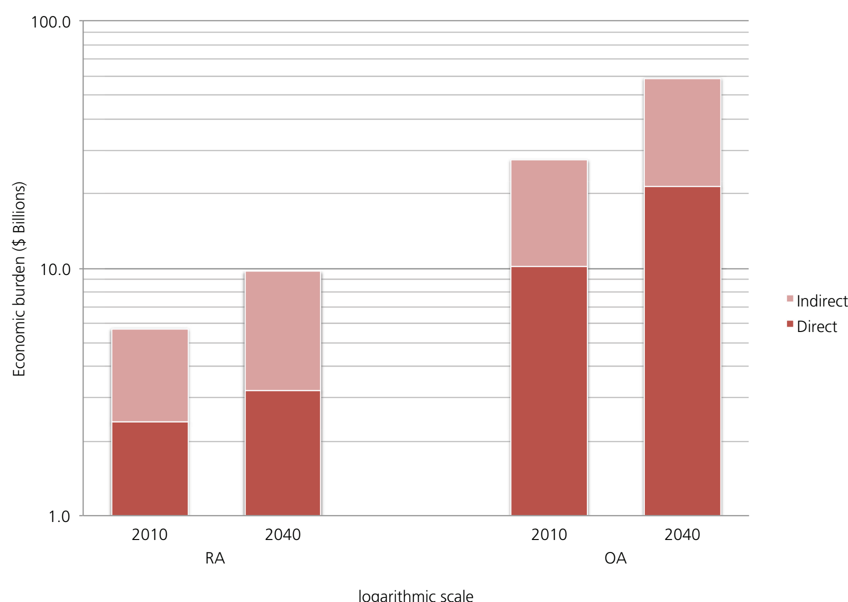

Figure 1 - Economic Burden of Rheumatoid Arthritis (RA) and Osteoarthritis (OA) in Canada, 2010

Source: *The Impact of Arthritis in Canada: Today and Over the Next 30 Years*, Arthritis Alliance of Canada, 2011.

Table 1 - Economic Burden of Rheumatoid Arthritis (RA) and Osteoarthritis (OA) in Canada, 2010*

	2010	2040 (2010 Present Value)
RA Direct	$ 2.4 B	$ 3.2 B
RA Indirect	$ 3.3 B	$ 6.5 B
OA Direct	$ 10.2 B	$ 21.4 B
OA Indirect	$ 17.3 B	$ 37.2 B
	$ 33.2 B	**$ 68.3 B**

* B = Billion

Catherine Hofstetter

Catherine Hofstetter was diagnosed with rheumatoid arthritis in 1993 and with fibromyalgia in 1998. She is the president of McGowan Fence & Supply Ltd., a Toronto-based family-owned business. Catherine is actively involved with the Canadian Arthritis Patient Alliance and The Arthritis Society, volunteering to advance the arthritis agenda. Her personal experience and involvement in the arthritis community have given her unique insight into the financial burden that arthritis exerts on employers and the stigma that the workplace environment can hold about the disease.

A Concerted, Collaborative Response Is Required

The growing burden of arthritis, with its impact on the lives of Canadians and the cost to governments, employers and the economy, puts the sustainability of the health care system at risk. A concerted, collaborative response by government, health care providers, employers, researchers, educators, consumers/patients and the general public is required.

Many things can be done. The next section of this report will identify the overall framework of needs and opportunities from which initial priorities for implementation have been identified. The results will improve the quality of life of millions of Canadians, the sustainability of our health care system and the productivity of our workforce.

Objectives and Strategies

Joint Action on Arthritis: A Framework to Improve Arthritis Prevention and Care in Canada (the Framework) outlines the objectives that must be realized and the strategies for implementation in order to improve the lives of Canadians living with arthritis and reduce the burden of arthritis in the future.

Overview of the Framework

The Framework includes a long-term vision of the overall change that is required to improve the lives of all Canadians—children, adolescents and adults—living with arthritis. It sets out a series of objectives organized under three strategic pillars:

- Advancing knowledge and awareness,
- Improving prevention and care, and
- Supporting ongoing stakeholder collaboration.

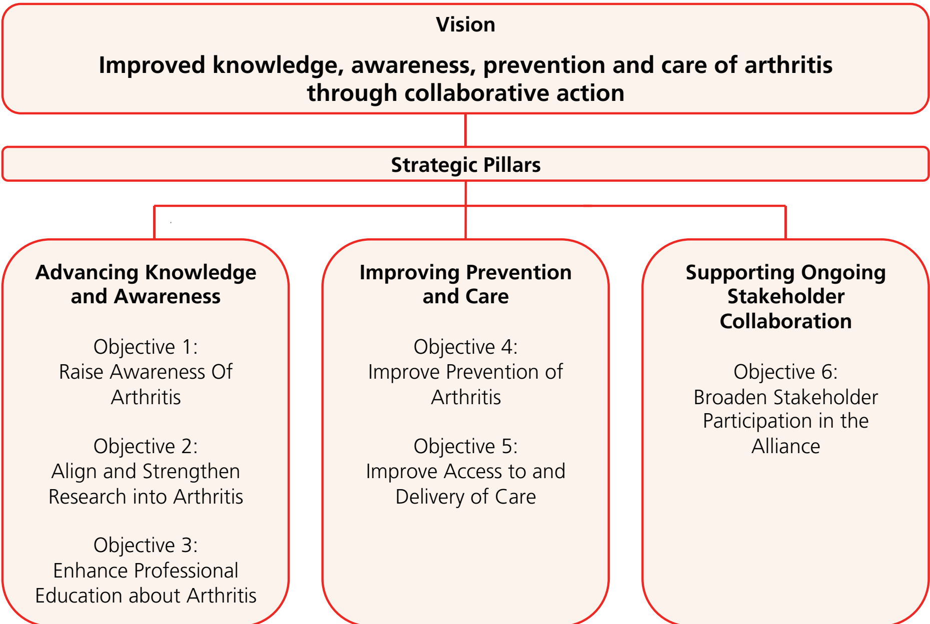

Figure 2 - Overview of Framework

Advancing Knowledge and Awareness

The first pillar in the way ahead is the enhancement of public, research and professional knowledge and awareness of arthritis.

Objective 1: Raise Awareness of Arthritis

The level of awareness of and understanding about arthritis and its consequences is low among the general public. Effective prevention and care are inhibited by widely held myths that nothing can be done to reduce the onset, progression and consequences of the disease, and that it is part of the natural course of aging. At the same time, the challenges in accessing reliable and effective information about it on the internet lead many people to seek relief through non-evidence-based interventions.

While many organizations have appropriate, evidence-based messages about arthritis prevention and care, dissemination efforts need to be escalated and coordinated. Governments, the private sector and other stakeholders all have key roles to play in ensuring that key messages are disseminated across the country in order to motivate people into taking appropriate action.

Desired Outcomes

The following outcomes will be achieved through raising public awareness of arthritis:

- Every Canadian is aware of arthritis and its consequences.*
- Every Canadian with arthritis has access to accurate arthritis information and education that meets a defined set of criteria and is appropriate to their age and the type and stage of their disease.*
- Arthritis is incorporated into all chronic disease prevention, injury prevention and obesity reduction strategies.
- Participation in social, leisure, education, community and work activities is used as an integral measure to evaluate outcomes.*
- Employers and insurers understand the productivity costs associated with under-addressing arthritis.

*2005 Summit on Standards for Arthritis Prevention and Care, Arthritis Alliance of Canada

Using Multi-Media to Raise Awareness

In partnership with the Arthritis Research Center of Canada (ARC), Arthritis Consumer Experts (ACE) leads the National Arthritis Awareness Program, including the creation of the Arthritis Broadcast Network to broaden the conversation on arthritis across Canada.

As part of this program, ACE and ARC created ArthritisID and ArthritisID PRO, Canada's top medical apps delivering evidence-based information on the most common types of arthritis.

Collaborative efforts such as these need to be enhanced to raise awareness of arthritis.

Strategies

To achieve these outcomes, government and arthritis stakeholders must focus their efforts and collaborate on the following strategies.

1.1 Implement a harmonized, pan-Canadian strategy to raise awareness of arthritis.

1.2 Engage employers' participation and support in raising awareness to manage arthritis in the workplace.

1.3 Support the use of continuing medical/professional education credits and other incentives to encourage health practitioner participation in strategies to raise awareness about arthritis.

1.4 Implement ongoing measurement of levels of awareness and attitudes about arthritis among Canadians.

Objective 2: Align and Strengthen Research into Arthritis

There are many opportunities for aligning and strengthening research into arthritis**.**

a) Research Funding

Canada's strong track record as an international leader in arthritis research needs to be sustained and enhanced. The 2011 *Canadian Arthritis Funding Landscape Review* found, however, that arthritis research funding has plateaued since 2005 and continues to be underfunded relative to its economic and social burden, compared to other chronic diseases. When compared to the total number of people affected by disease, Canadian Institutes of Health Research (CIHR) invested only $4.30 for every person with arthritis, compared with $12.83 per person with diabetes and $138.60 per person with cancer.[28]

In addition, as the Canadian Arthritis Network completes its full 14-year term as a research network funded under the federal Networks of Centres of Excellence program, $4.1 million dollars in annual arthritis research investment will be lost.

The current and increasing prevalence of OA and the high economic and social burden associated with all forms of arthritis warrant higher investment in research in order to develop and implement more effective prevention and care strategies for the future. All four pillars of health research (biomedical; clinical; health systems and services; and the social, cultural and environmental factors that affect the health of populations) must each be supported in order to more fully understand the causes, progression, prevention and treatment of arthritis.

It is also important that the efforts of research funders be integrated in order to encompass different perspectives and maximize the use of resources in order to realize full benefits from research investment.

b) Research Infrastructure and Networking

The infrastructure to support arthritis research needs to be strengthened to promote integration of research efforts. For example, key research data sets must be maintained and investigator access to and linkages between databases must be facilitated in order to advance arthritis research. The need for new data sets must also be considered.

Networking and partnership opportunities are an important catalyst to the discovery and innovation processes. The need for resources to support ongoing collaboration among basic and applied arthritis researchers and research stakeholders in Canada is critical.

It is also particularly important to both continue and enhance the involvement of individuals living with arthritis in all aspects of research. Their input, through participation in peer review panels and as integral partners on research teams, is critical in determining research priorities.

c) Research Capacity Building

The arthritis community has been very successful in building and retaining research capacity among research personnel to support ongoing work and advancements in research. Currently, much of this investment nationally is made through the Canadian Institutes of Health Research and The Arthritis Society/Canadian Arthritis Network training programs.[28] However, the strengths and gaps in the current state of research capacity in Canada need to be reviewed to align training investments with the research priorities set out in this Framework. The success of a national Framework rests in large part on the coordination and appropriate distribution of training investments in different areas of research and across the career development lifecycle.

d) Knowledge Translation and Exchange

Finally—and crucially—there is a significant ongoing need to ensure that research is supported by effective knowledge translation and exchange so that research findings are implemented, leading to improved health outcomes and health system efficiencies.

The Canadian Arthritis Network (CAN)

The Canadian Arthritis Network (CAN), a research network funded under the Federal Networks of Centres of Excellence program, unified the arthritis research community to tackle the larger problems of arthritis. Through targeted strategic funding, CAN created collaborative multi-disciplinary teams to work on improving the care of Canadians living with arthritis and the Canadian economy. At the end of its highly successful 14-year term, CAN's departure will leave a significant gap in arthritis research in Canada.

Desired Outcomes

Strengthening research will lead to the following outcomes.

- The annual levels of investment in research support provided by the Canadian Arthritis Network are replaced, with ongoing adjustments for inflation.
- Overall investment in arthritis research in Canada is increased across all four pillars of health research over the longer term.
- Research efforts are integrated through sustainable research platforms of expertise, improved data access and linkages, researcher development and stakeholder collaboration.
- Knowledge translation of integrated research efforts leading to improved prevention and care of arthritis are enhanced.
- Reports of the arthritis research funding landscape (including unmet research needs and new strategic opportunities) and Canadian arthritis research priorities are produced biannually.

Strategies

To achieve these outcomes, government and arthritis stakeholders must focus their efforts and collaborate on the following strategies:

2.1 Increase investment in arthritis research.

- o Develop a long-term plan to increase research investment across all four pillars of research to levels adequate to better address the economic and social burden of the disease; and
- o Concerted effort to assist current funders in increasing funds raised for arthritis research, as well as engage new funders

2.2 Research funders to partner and offer coordinated funding opportunities focused on knowledge gaps related to:

- o Understanding of disease mechanisms and progression;
- o Personalized medicine (detection of risk and development of therapeutic strategies based on the individual's clinical presentation (phenotype) as well as molecular and genomic diagnostics);
- o Interactions among lifestyle, behaviour and the environment in relation to arthritis;
- o Comorbidities and their interaction with arthritis as a person ages;
- o Monitoring and surveillance of arthritis disease and care in the population; and
- o Systems of care and their delivery to both prevent and treat arthritis.

2.3 Create, develop and sustain the necessary infrastructure to contribute to research in identified strategic areas (e.g., access and linkage to administrative datasets, development of longitudinal datasets).

2.4 Promote greater networking, collaboration and stakeholder engagement in research, including meaningful participation by individuals living with arthritis.

2.5 Implement targeted strategies to develop and sustain future researchers.

2.6 Enhance research, knowledge translation and exchange efforts about arthritis prevention, self-management and the effectiveness and efficiency of arthritis care.

2.7 Identify research needs and monitor for successes and challenges; develop strategies to address unmet research needs on an on-going basis.

Objective 3: Enhance Professional Education with Respect to Arthritis

Musculoskeletal issues are routinely presented in the practices of primary care physicians and are a significant element of the practices of physiotherapists, occupational therapists, nurses, chiropractors, pharmacists and other health professionals.[29,30,31,32]

Primary care physicians report less confidence and ability in completing a musculoskeletal assessment, compared with other clinical encounters.[33,34,35] Arthritis history and physical assessment skills have been found to be limited among entry-level physiotherapists and occupational therapy students.[36,37,38]

Across all health professions, strengthening training and continuing education in musculoskeletal disorders would effectively develop and maintain the professional knowledge and skills necessary to effectively identify, assess, monitor and care for individuals with arthritis. As well, professional education needs to position arthritis in the context of chronic disease prevention and management and to the health care needs associated with various comorbidities.

Desired Outcomes

The following outcomes will be achieved through enhancing professional education.

- All relevant health professionals are able to perform a valid, standardized, age- and health-appropriate musculoskeletal screening assessment.*
- Health professionals recognize and treat arthritis as an interrelated component of chronic disease prevention and management.

*2005 Summit on Standards for Arthritis Prevention and Care, Arthritis Alliance of Canada

Consumer Collaboration in Research

Consumers have been actively involved in all aspects of arthritis research including planning and priority setting, research project design and implementation, and knowledge translation and dissemination. These collaborations have been facilitated by consumer groups such as Arthritis Consumer Experts, the Consumer Advisory Council of the Canadian Arthritis Network, Canadian Arthritis Patient Alliance, Consumer Advisory Board of the Arthritis Research Centre of Canada, Patient Partners, and The Arthritis Society's many consumer support groups.

Continued consumer involvement in arthritis research is essential, but the resources and infrastructure required to sustain, let alone enhance, consumer involvement are being eroded.

Investments in training and education will help support the changes currently taking place in primary care delivery and in the roles of various health professionals who provide care for individuals with arthritis. For example, the roles of occupational physiotherapists[39] and physiotherapists[40] have changed in Ontario, and in British Columbia, legislative changes have expanded the role of pharmacists.[41]

Strategies

To achieve these desired outcomes, government, professional colleges and regulatory agencies, and arthritis stakeholders must focus their efforts and collaborate on the following strategies:

3.1 Strengthen the undergraduate/professional entry-level curricula related to arthritis as part of chronic disease prevention and management for all health care providers.

3.2 Promote consumer/patient and other stakeholder participation in health professional education related to arthritis.

3.3 Incorporate arthritis-related curriculum into post-graduate and specialty programs that address the needs of vulnerable groups.

3.4 Develop and implement a strategy to incorporate arthritis-related information and new research knowledge into continuing health professional education.

Across all health professions, strengthening training and continuing education in musculoskeletal disorders would effectively develop and maintain the professional knowledge and skills necessary to effectively identify, assess, monitor and care for individuals with arthritis.

Improving Prevention and Care

The second pillar of the Framework is promoting prevention strategies and improving care for individuals with arthritis.

Objective 4: Improve Prevention of Arthritis

A number of factors can predispose people to getting arthritis.

Obesity is a primary risk factor for both the development and progression of OA.[42,43,44,45,46] Attaining and maintaining a healthy weight, and weight reduction where appropriate, are important prevention strategies for OA[47,48,49] as well as many other chronic diseases. Arthritis is considered to be a comorbidity in the Canadian Obesity Network's Edmonton Obesity Staging System and a major barrier to weight management.[50] Among people with arthritis, physical activity has a beneficial effect on bone and joint health.[51,52,53]

Injuries are a leading cause of OA.[54] At high levels of physical activity, as in organized sports like soccer and basketball, the potential for injury must be considered and preventive measures taken. Lower extremity injuries account for more than 60% of all sport injuries in adolescents, the most common being knee and ankle injuries.[55, 56,57] For adults, many injuries occur in the workplace.[58,59,60,61,62]

Risk factors for inflammatory arthritis are not as well understood. It is thought that specific genes are associated with a higher risk of certain types of arthritis, such as RA, systemic lupus erythematous (SLE) and ankylosing spondylitis. Environmental factors are also thought to play a role.[63]

Andrew Milne

In 2008, at only 31 years of age, Andrew was diagnosed with Psoriatic Arthritis. Within months, the disease spread from one to over 20 affected joints. Andrew was obviously quite worried about how arthritis was going to affect his active lifestyle.

Fortunately, through diligent treatment, he is now symptom free and very active, having just completed the 210-km Ride to Conquer Cancer and winning a silver medal at the 2012 Canadian Ultimate Championships.

Desired Outcomes

The following outcomes will be realized through implementation of strategies to prevent arthritis and its consequences.

- Every Canadian is informed about the importance of achieving and maintaining a healthy body weight and actively encouraged to engage in physical activity to prevent the onset or progression of arthritis.*
- Every Canadian understands and implements strategies to reduce sport and recreation injuries that lead to arthritis.*
- Employers, insurers and government agencies recognize arthritis as a major source of workplace disability and invest in injury prevention strategies and workplace policies that support diagnosis, appropriate treatments and accommodation of episodic disability of employees living with arthritis.
- Chronic disease prevention, injury prevention and obesity reduction strategies are implemented across Canada and recognize the link to arthritis.

*2005 Summit on Standards for Arthritis Prevention and Care, Arthritis Alliance of Canada

Strategies

To achieve the desired outcomes, federal and provincial/territorial governments, and arthritis stakeholders must focus their efforts and collaborate on the following strategies:

4.1 Integrate arthritis awareness into existing obesity, diabetes, heart disease, mental health and overall chronic disease strategies across Canada.

4.2 Integrate arthritis awareness into efforts to encourage Canadians to engage in physical activity, to prevent the onset and progression of arthritis and to improve the condition of those with arthritis.

4.3 Integrate arthritis awareness into existing strategies to prevent sport and recreational injuries that lead to arthritis, particularly among children and youth.

4.4 Integrate arthritis awareness into workplace policies and programs that help to prevent injuries leading to arthritis and support episodic disability related to arthritis.

Objective 5: Improve Access to and Delivery of the Best Possible Care (Models of Care)

The phrase "models of care" describes how health care services and resources are delivered to a community. There are many needs and opportunities for improving access to and delivery of arthritis care.

a) Standards and Quality Measurement

While many guidelines are available, there are few validated quality indicators and tools to evaluate quality of care, and none are in systematic use in Canada.[64] The only area of care that has made substantial progress is the evaluation of wait times for hip and knee replacement surgery.[65] As well, there is no nation-wide process for evaluating, improving and disseminating effective models of care.

Addressing these needs would ensure that arthritis care functions as part of a system of care designed to improve the experience and health outcomes of individuals living with arthritis.

b) Access to Effective Care

For many, gaining access to the right care and the right provider is a challenge. This is particularly true for people living in rural and remote areas, especially Aboriginal populations,[66] where distance and transportation costs are additional barriers. For people living with arthritis, access to appropriate chronic pain care by way of multidisciplinary pain treatment facilities is severely limited, and reported wait times in Canada and Australia approach, and in some case can exceed, one year.[67,68]

Access to appropriate care is also very difficult for children. According to the Canadian Alliance of Pediatric Rheumatology Investigators (CAPRI), most children will see at least three health practitioners and wait four to five months following the onset of symptoms before being seen in the optimal place of care, a multi-disciplinary childhood arthritis centre.[69,70]

Arthritis care is not always effectively integrated into chronic disease management models and primary health care reform strategies. Through the redesign of the roles of health care professionals and referral processes, physiotherapists, occupational therapists and nurses who work in advanced or extended practice roles within an inter-professional team have the potential to facilitate timely and appropriate access to the right provider at the right time.

Effective care begins with early identification and assessment of disease. While guidelines for the treatment of RA and OA have been developed, translating these guidelines into consistent, effective practice through current models of care is a challenge due to such issues as lack of awareness of, and difficulty in implementing, the guidelines.[71,72,73,74] The guidelines for RA care recommend early consultation with an arthritis specialist, but many RA patients (as well as those with other forms of inflammatory arthritis), do not get referred to the proper care pathway in a timely manner. Often, this is due to a lack of continuity of care and ineffective screening and referral.[75,76,77]

Improving Models of Care Across the Country

Through Health Canada funding, Bone and Joint Canada has developed a national network that has successfully implemented models of care for hip and knee replacements and hip fractures in all provinces across Canada. The network is an example of how new models of care can be effectively developed and disseminated on a province-by-province basis. This approach should serve as the basis for similar initiatives to disseminate models of care for other forms of arthritis, including inflammatory conditions.

Clinical management of OA considers the use of both pharmacological and non-pharmacological therapies to alleviate joint pain and improve joint mobility. For patients who do not respond to these therapies, total joint replacement (TJR) surgery is recommended.[1] This cost-effective therapy is under-utilized among patients who are appropriate surgical candidates, however.[78]

Due to a lack of understanding of the disease and its treatment,[79] many patients pursue ineffective treatments or do not adhere to effective management strategies, effectively worsening both their condition and the associated consequences.

Treatment for children and adolescents must recognize the unique needs of these populations. The goal of treatment for children and adolescents with arthritis should be inactive disease and remission. Treatment strategies should optimize outcomes, including normal growth and development, as well as quality of life.

c) Health Human Resources

At a time when arthritis is on the rise, there are significant constraints on the available health human resources. Many families do not have a family physician and may go to walk-in clinics instead, where continuity of care is less certain. Family physicians play a key role in helping individuals living with arthritis access specialized arthritis care, in treating arthritis and in assisting in the navigation of the health care system.[80]

In 2011, there were only 345 rheumatologists in Canada (Canadian Rheumatology Association).[81] And despite the rising demand for joint surgery, many orthopaedic surgeons cannot get access to operating room time. In addition, newly graduated orthopaedic surgeons are having difficulty finding jobs.[82]

There is a growing need and a lack of funding for advanced-practice trained nurses and therapists to provide integrated multi-disciplinary care for individuals with arthritis in Canada.[83]

There is a growing need and a lack of funding for advanced-practice trained nurses and therapists to provide integrated multi-disciplinary care for individuals with arthritis in Canada.

d) Access to Therapies

Among the various provinces/territories and regions of Canada, there is unacceptable inequity in access to proven, cost-effective therapies, including drug therapies.[1,75,76,78] Provincial formularies, which dictate access to drug therapies, are inconsistent across provinces. Getting access to some arthritis medications can be more difficult for children than for adults.

It is critical that post-approval evaluation of arthritis medications be part of the drug approval process and that return to work/work productivity, along with other aspects of participation, be used as a criterion for assessing new arthritis therapies.

Many gains have been made in wait times for hip and knee replacement surgeries as a result of a coordinated inter-provincial strategy led by Bone and Joint Canada. Significant issues with access to shoulder or ankle and foot surgery remain.

e) Self- Management

There are opportunities for improving self-management, such as improved coordination of the development and dissemination of on-line and hard copy educational materials for individuals living with arthritis and health care providers. The needs vary by province, with definite gaps in some areas and opportunities to reduce duplication and coordinate on development in others.

Desired Outcomes

The following outcomes will be the result of improving access to and delivery of care.

- Comprehensive quality standards for arthritis care are developed, implemented and monitored.
- Multi-disciplinary models of arthritis care are implemented, formally evaluated and continuously improved through effective knowledge transfer strategies.
- Develop a pan-Canadian reporting system for measuring improvements in models of care.
- Health care professionals recognize osteoarthritis as a significant health issue and treat it consistent with current best practice.*
- Assessment for arthritis and chronic pain become standard practice in the assessment of individuals presenting with excess weight.
- Inflammatory arthritis (e.g., rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis) is identified and treated according to current evidenced-based guidelines within four weeks of seeing a health care professional.*
- Every Canadian with arthritis has timely and equitable access to effective and appropriate self-management medical and surgical therapies to preserve function, prevent disability and associated morbidities, and control pain.
- Post approval evaluation of arthritis medications must be part of drug approval.*
- Patient preferences, including risk-benefit trade-offs, must be incorporated into regulatory decision making and prescribing of arthritis medications.*

*2005 Summit on Standards for Arthritis Prevention and Care, Arthritis Alliance of Canada

Strategies

To achieve these desired outcomes, governments and arthritis stakeholders must focus their efforts and collaborate on the following strategies:

5.1 Adopt and implement national standards and a quality measurement and reporting system for arthritis care in Canada.

5.2 Champion the development, evaluation, improvement and dissemination of effective models of arthritis care.

5.3 Support the increased involvement of allied health professionals in the identification, referral and treatment of arthritis, including, chiropractors, community pharmacists, kinesiologists, nurses, occupational therapists and physiotherapists.

5.4 Improve access to effective and appropriate therapies for the care of inflammatory arthritis across the country.

5.5 Improve access to hip, knee, shoulder, spine and foot surgery, with adequate pre- and post-operative rehabilitation where required.

5.6 Continue to enhance the use of networks of individuals living with arthritis in support of effective models of care.

5.7 Work with the providers of educational materials to ensure that there are evidence-based electronic and print materials to support self-management for all conditions.

Supporting Ongoing Stakeholder Collaboration

Effective collaboration among arthritis stakeholders will be the key to successful implementation of the Framework.

Objective 6: Broaden Stakeholder Participation in the Alliance

The Arthritis Alliance of Canada provides a forum for collaboration among arthritis stakeholders. In order to move the Framework forward and to significantly improve the lives of people living with arthritis in Canada, it is important that additional, key stakeholders join with existing members of the Alliance in championing implementation of the Framework.

Desired Outcomes

The following outcomes will be achieved through broadened stakeholder participation.

- The federal, provincial/territorial and municipal governments support the arthritis community in implementing Framework initiatives.
- A broadened range of health professional and injury prevention organizations participate in the implementation of Framework initiatives.
- Employers, workers and insurers participate in the implementation of Framework initiatives.

Strategies

To achieve these desired outcomes, governments and arthritis stakeholders must focus their efforts and collaborate on the following strategies:

6.1 Engage the participation of the federal, provincial/territorial and municipal governments to work with and support the arthritis community in implementing the Framework.

6.2 Engage the participation of health professions and organizations involved in the prevention of chronic disease in implementing the Framework.

6.3 Engage the participation of professions and organizations involved in sport and workplace injury prevention to participate with the arthritis community in implementing the Framework.

6.4 Engage employers and insurers to participate with the arthritis community in implementing the Framework.

Initial Priorities for Implementation

The Framework encompasses a wide range of objectives and strategies that need to be addressed over time. This section of the report outlines initial priorities for implementation and related opportunities for the contributions of various stakeholders.

Initial Priorities

The Arthritis Alliance of Canada will focus on facilitating the implementation of four initial priorities.

1. Implement a harmonized, pan-Canadian strategy to raise awareness of arthritis.

Joint action on arthritis must begin with raising awareness in order to change behaviours. The mandates of several organizations in the Alliance include raising awareness of arthritis through information and education. The support and involvement of governments, the private sector and health professional organizations is required to expand and build on these efforts through a harmonized, pan-Canadian awareness-building strategy that will change the understanding and behaviour of the public, health professionals, policy makers, employers, educators and others.

The goals of this initial priority are:

- Increased public awareness of key risk factors, consequences and prevention strategies for arthritis and directions to the appropriate resources for action;
- Increased recognition of arthritis as a chronic disease in chronic disease prevention and management strategies and obesity reduction strategies;
- Increased awareness and ability to effectively screen for arthritis; and
- Increased recognition among employers, insurers and government agencies of arthritis as a major source of workplace disability:
    - The need to invest in injury prevention as injury leads to arthritis; and
    - The importance of workplace policies to accommodate episodic disabilities of employees living with arthritis.

Requirements to achieve these goals include:

Awareness Through Resources, Research and Relationships

Working with its network of dedicated volunteers, health-care professionals and employees, The Arthritis Society provides leadership and funding for research, advocacy and solutions. To date, the Society's investment in research and education projects has led to breakthroughs in the diagnosis, treatment and care of people with arthritis.

Increased knowledge and awareness is critical so Canadians will consider joint pain as a health priority, eliminating risk to themselves and the far-reaching socio-economic implications for all Canadians.

- Engaging all stakeholders in the awareness raising effort;
- Developing common, compelling, evidence-based messages aimed at dispelling myths about arthritis;
- Targeting relevant messages to specific audiences in order to change behaviour;
- Delivering these messages through a communication strategy with a consistent look and feel;
- Coordinating delivery of these messages through existing arthritis-related organizations and vehicles, and through government chronic disease, injury prevention and obesity reduction strategies; and
- Using the strategy to direct people to take action and access appropriate resources.

The Alliance has established a leadership structure and working group to lead the development and implementation of this strategy.

2. Champion improvements in models of arthritis care.

The goal of this priority is to facilitate implementation and continuous improvement in models of care for individuals living with arthritis in Canada.

The Alliance has established an expert Models of Care Working Group that has developed evidence-based criteria that can enhance efficient and effective diagnosis and care of arthritis in different care environments. Based on this work, the Alliance will collaborate with interested stakeholders to:

- Seek the support of governments and health-related associations to champion improvement in models of arthritis care across the country;
- Develop new and build on existing quality indicators to demonstrate the effectiveness of arthritis care and report provincial outcomes on a regular basis;
- Develop and implement a communication strategy to share information on the best models of care across Canada; and
- Work with key providers of educational materials to ensure there are evidence-based electronic and print educational materials to support self-management in arthritis care.

3. Promote research into arthritis prevention, self-management, and the effectiveness and efficiency of arthritis care.

The third priority for initial implementation focuses on resources and efforts toward improving prevention and the delivery of care for arthritis. This priority aligns with and

coalesces ongoing initiatives across the country designed to deliver high quality patient-centred care in a sustainable publically funded health care system.

The goal of this priority is to promote research into the organization and delivery of health care services. This includes studies of arthritis prevention, self-management, and comparative effectiveness and efficiency of models of care with a focus on the patient. This is critical to ensuring not only that improvements in models of care are evidence based and patient focused, but also that they demonstrate measurable benefits.

The Alliance has established a Research Working Group to implement this initial priority and to guide longer-term efforts to align and strengthen research into arthritis. In the short term, the Research Working Group will collaborate with interested stakeholders to:

- Develop targeted research funding opportunities that focus on arthritis prevention, self-management and care delivery models and the measurement of their benefits to patients and the health care system;
- Enable the Canadian arthritis community to synthesize and exchange new knowledge and best practices in order to drive measurable improvements in the health of people living with arthritis;
- Facilitate the formation of multi-disciplinary research groups to address knowledge gaps in arthritis prevention, management and models of care; and
- Promote the application of knowledge transfer principles in order to engage health care decision makers and providers to facilitate the uptake and implementation of research results related to innovative models of care and their application in different settings.

4. Support ongoing stakeholder collaboration.

None of this work on these initial priorities or other Framework initiatives will happen without the ability to support ongoing stakeholder collaboration. The arthritis community must continue to collaborate, and new stakeholders need to participate in these initiatives. A stable, funded organization is required in order to support stakeholder collaboration and to facilitate implementation of Framework initiatives.

The Alliance will move this priority forward by broadening the range of stakeholders participating as Alliance members and contributors to the implementation of Framework initiatives.

What Stakeholders Can Do

The Alliance and its members have taken the lead in facilitating the development of this Framework and will be approaching governments and other arthritis stakeholder organizations with specific requests for both support and participation in order to implement its initial priorities.

To date, collaboration has been the hallmark of the Alliance's success. Improving the lives of individuals with arthritis and mitigating the increasing burden of arthritis will require the support and participation of all stakeholders.

Stakeholders will be encouraged to contribute to the implementation of the initial priorities in a variety of ways.

Stakeholders

- Consumer organizations
- Employers and business organizations
- Federal and provincial/territorial governments
- Educators
- Health care providers and associations
- Injury prevention organizations
- Insurers
- Researchers
- Research funding agencies
- Sports medicine and coaching organizations

How Stakeholders Can Contribute

- Support and participate in the awareness building strategy.
- Participate in evaluation and knowledge transfer strategies to improve models of arthritis care.
- Provide research funding and support to evaluate models of care.
- Become a member of the Arthritis Alliance of Canada.
- Provide financial support for the work of the Alliance in supporting ongoing stakeholder collaboration and implementation of the Framework.

Contact Us

We would like to hear from you. Send us your feedback on *Joint Action for Arthritis: A Framework to Improve Arthritis Prevention and Care in Canada* or contact us to discuss how your organization could help to make the Framework's vision a reality. Email us at info@arthritisalliance.ca or visit www.arthritisalliance.ca.

Appendix A

Summary of Supporting Evidence

1. Raising Awareness of Arthritis

- The level of awareness about arthritis as a specific health issue and the impact of arthritis on the workforce is low among the general public, health care providers, and employers.[33,34,79,84]
- Even among those living with arthritis, many do not know the type of arthritis that they are living with.[85]
- In addition, the quality of health information on the web is inadequate and the ability of patients to navigate the web for high quality arthritis information and resources is poor.[86,87,88,89,90]
- Although arthritis conditions are common problems seen in primary care, arthritis awareness and provision of arthritis care by primary care physicians is suboptimal.[33,34,35]
- Patient educational interventions are effective in improving knowledge levels about arthritis[91,92,93] and can promote behaviour change in people with arthritis.[94,95]

2. Align and Strengthen Research into Arthritis

- Most research over the last five years has focused on understanding mechanisms of disease, treatment, and disease management/quality of life: research focused on prevention and diagnosis or screening has been limited.[28]
- Arthritis funding has plateaued since 2005 and although arthritis is more prevalent, it continues to receive significantly less funding than diabetes and cancer ($ 4.30 for every person of arthritis, compared with $12.83 per person with diabetes and $138. 60 per person with cancer).[28]
- Furthermore, while osteoarthritis (OA) is more prevalent (>10% of the population) than rheumatoid arthritis (RA) (<1% of the population), and has an increasing burden,[1,4] research funding directed towards OA has been comparable to levels of funding in RA highlighting the need for ongoing research investment in OA.[28]
- It is recognized that there is high variability in disease activity and progression within and between patients with inflammatory arthritis (e.g. rheumatoid arthritis, psoriatic

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arthritis).[96] To improve disease prevention and develop better therapies for arthritis, it is important to understand underlying disease mechanisms (e.g. dysregulation of immune response) and progression.[97]

- Identification of biomarkers that can predict patients at risk for active and progressive disease has significant implications in preventing disease progression and maintaining function by targeting the right therapies to the right patient.[98] Although some progress has been made in advancing personalized and precision medicine in rheumatology, more research is needed.[99,100]
- Little is known about the interactions among lifestyle, behaviour, environment and genes on the development of arthritis conditions. Understanding these interactions and the etiology of disease is essential to control and prevent disease onset.[101,102,103]
- People living with arthritis have a higher likelihood of developing and living with other cormorbid conditions, especially as a person ages.[1,11,104,105,106] However, there is little information on best practices for the management of arthritis conditions such as OA in the setting of other common chronic conditions.[19] Furthermore, the presence of other chronic conditions has been shown to be a major barrier to receiving appropriate care and to lead to worse outcomes in OA.[20,21,107]
- Coordinated and integrated surveillance systems at multiple levels of the health care systems can promote and enhance quality of care delivered for people living with arthritis.[108,109]
- In order for health systems to provide effective and timely care for arthritis, valid and reliable information is needed to support decision-making by all health care stakeholders. Quality indicators are tools that can be used to measure the performance of systems of care, identify care gaps, and facilitate quality improvement initiatives to deliver the right care to the right patient at the right time.[64,110]
- There is evidence to support the effectiveness and, in some cases, cost-effectiveness of emerging models of care, such as the use of specialized nurses or rehabilitation therapists working in extended clinical roles.[111,112,113,114,115,116,117,118]
- While some studies have shown that models designed to improve knowledge of primary care physicians in screening and referrals resulted in positive outcomes, such as reduced wait times for rheumatologists,[91,119, 120,121] further research is needed to determine and evaluate optimal models and systems of care for arthritis in Canada.

3. Enhance Professional Education with Respect to Arthritis

- Musculoskeletal conditions make up the largest area of practice for Canadian physiotherapists, occupational therapists, nurses, chiropractors, pharmacists, and other health care professionals.[29,30,31,32]
- However, primary care physicians report less confidence and fewer abilities completing musculoskeletal assessments compared with other clinical encounters.[33,34,35]
- Additionally, arthritis history and physical assessment skills have been found to be limited among entry-level physiotherapists and occupational therapy students.[36,38] It is also important to note that the recent transition from a four-year baccalaureate program to a two-year master's program in most Canadian universities has resulted in a reduction in the average rheumatology instructional time in undergraduate physiotherapy programs.[37]
- Education programs focused on health care providers have been shown to enhance provision of arthritis care specifically by improving patient knowledge about their type of arthritis, their treatments and associated side effects, and available community services and resources to help manage their disease.[122]
- There is a need for health care professionals to improve aboriginal health in Canada by providing holistic care that considers aboriginal history, traditional beliefs and healing practices, and that acknowledges and addresses the needs of this vulnerable population.[123]

4. Improve Prevention of Arthritis

- Obesity is a recognized risk factor for OA of the knee, the hip and the hand.[42,43,44,45] There is some agreement that increased load on the joint is one mechanism contributing to the development of OA.[124,125,126] Weight loss has been identified as an important prevention strategy for OA.[29,48,49]
- Physical activity is necessary to achieve and maintain healthy body weight,[127] which can be a preventative measure for the development of certain types of arthritis, such as OA.[49, 2]
- Physical activity can have a beneficial effect on bone and joint health, as well as physical and psychosocial functioning of individuals with joint disease.[128,129] Certain types of recreational physical activity are appropriate for persons with rheumatoid arthritis and osteoarthritis.[52,53,130]
- Therapeutic exercises, including functional strengthening, general physical activity and whole body, low-intensity exercises, are effective in managing arthritis.[131]
- Injuries such as fractures or injuries of the knee can lead to increased risk of development of osteoarthritis later in life.[54] Recent findings showed that > 50% of people who have a knee injury will develop OA within 12–20 years.[132]
- Sport is a leading cause of injuries in adolescents requiring medical attention and emergency department visits.[55,56,57] Injuries of the lower extremity, primarily knee

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and ankle, are most common, making up greater than 60% of sporting injuries.[55,56,133,134]

- Researchers have determined occupational risk factors and affected occupations for knee injuries,[58,59,60,61] which can allow employers to design and implement workplace policies and modifications to support episodic disability related to arthritis.[62]

5. Improve Access to and Delivery of Care

- Quality indicators can measure health care system performance across providers, system levels and regions.[64,110,135]
- The rheumatology community has made significant efforts to develop quality indicators that are focused on examining processes of care for arthritis, which are evidence-based and measurable for use in routine rheumatology practices.[64,110,136,137,138,139.]
- In rheumatology, continued collaborative efforts among rheumatology stakeholders, including policy makers and payers, are needed to develop quality measures that assess the impact of health system structures and processes of care on improving health outcomes. In addition, efforts are needed to validate the use of existing quality measures in routine data collection systems, such as electronic health records to facilitate ongoing quality and performance measurement across rheumatology practices.[64,110]
- Research has shown the timely access to total joint replacement for patients who are eligible for surgery is a cost saving both to the health care system and to patients and their caregivers.[140] There is significant suffering and significant loss in quality of life, possibility of joint damage, and reduced mobility for patients who wait greater than six months for surgery.[141]
- Guidelines recommend early consultation with an arthritis specialist to confirm diagnosis and treatment.[142,143,144,145,146]
- Many guidelines also support early referral to a rheumatologist and treatment with DMARDs (disease modifying anti-rheumatic drugs) for patients with RA.[147,148,149,150,151,152 153] Early DMARD intervention slows the progression of structural joint damage and improves long-term outcomes, as well as overall patient quality of life. Delays of three months or more in instituting DMARDs can lead to worse physical disability and joint damage.[154 155,156,157]
- Despite recommendations around early access to care for patients with RA, studies have found that less than 50% of patients receive DMARDs treatment within six months to a year of symptoms onset.[75,76,77]
- There are recommended guidelines that support the management of OA using both pharmacologic therapy and non-pharmacologic interventions, such as exercise, education, joint protection and assistive devices.[138,158,159,160,161,162,163] Strategies for guideline dissemination result in modest to moderate improvements.[71,72,73,74]

- In spite of the guidelines and recommendations that exist for the management of arthritis, inappropriate or ineffective medication use has been reported among arthritis patients.[21,164]
- To enhance quality and delivery of effective and efficient arthritis care, research has identified the need to develop models that are integrated across the continuum of care with linkages to primary and community care. The need for integration with other chronic disease models has also been noted for the sustainable management of arthritis as a chronic condition.[165]
- There is supporting evidence for the effectiveness of multidisciplinary team care for arthritis.[166,167]

Appendix B

Links to Related Reports

The list below provides links to key arthritis reports developed by the Alliance. All reports are available at www.arthritisalliance.ca.

Report Name*	Description
Summit on Standards for Arthritis Prevention and Care (2005)	Describes the process of national consultation conducted in 2005 and the resulting 12 standards for arthritis prevention and care. These standards have been incorporated as desired outcomes in *Joint Action on Arthritis: A Framework to Improve Arthritis Prevention and Care in Canada*.
*Canadian Arthritis Funding Landscape Review***	Describes the arthritis funding landscape related to research and summarizes Canada's strengths, needs and challenges in the global context of the disease.
The Impact of Arthritis in Canada: Today and Over the Next 30 Years	Documents the burden of arthritis in Canada, focusing on osteoarthritis and rheumatoid arthritis, and investigates the potential impact of targeted investigations to mitigate the burden.

*Some reports are under the Alliance's former name, the Alliance for a Canadian Arthritis Program (ACAP).

** Commissioned by the Canadian Arthritis Network (CAN), The Arthritis Society (TAS), the Institute of Musculoskeletal Health and Arthritis (IMHA) at the Canadian Institutes of Health Research (CIHR), and the Alliance for the Canadian Arthritis Program (ACAP).

Appendix C

Standards for Arthritis Prevention and Care

The following standards for arthritis prevention and care were developed in 2005 by the Alliance, then named the Alliance for a Canadian Arthritis Program.

Definitive Standards fro Arthritis Prevention and Care[1]

1. Every Canadian must be aware of arthritis.
2. Every Canadian with arthritis must have access to accurate information and education on arthritis that meet a defined set of criteria and are appropriate to their age and stage of disease.
3. Participation in social, leisure, education, community and work activities must be an integral measure used to evaluate outcomes by health professionals, educators, policy makers and researchers.
4. Every Canadian must be informed about the importance of achieving and maintaining a healthy body weight, and actively encouraged to engage in physical activity, to prevent the onset and worsening of arthritis.
5. All relevant health professionals must be able to perform a valid, standardized, age appropriate musculoskeletal screening assessment.
6. Inflammatory arthritis must be identified and treated appropriately within four weeks of seeing a health care professional.
7. Health care professionals must recognize osteoarthritis as a significant health issue and treat it according to current treatment guidelines (Jordan 2003).
8. Bone mineral density testing must be offered free to all women > 65 years, all men and women with low trauma fracture after age 40, and every Canadian of any age with risk factors for osteoporosis, according to current prevention and treatment guidelines (Brown 2002).
9. Every Canadian with arthritis must have timely and equal access to appropriate medications.
10. Post–approval evaluation of arthritis medications must be part of drug approval.

11. Patient preferences, including risk–benefit trade–offs, must be incorporated into regulatory decision making and prescribing of arthritis medications.

12. Every Canadian with arthritis requiring joint surgery must wait no longer than six months from the time the decision to have surgery is made by the patient and physician.

Provisional Standards Requiring Additional Research

13. To prevent arthritis, every Canadian must understand and implement prevention strategies to reduce sport and recreation injuries.

14. Every Canadian with arthritis must have timely access to appropriate integrated health care appropriate to their age and disease stage.

15. Every Canadian with arthritis will be enabled to participate in life roles that are important to them.

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NOTES:

In loving memory of Dr. Bernie Novokowsky.

The Arthritis Alliance of Canada, formerly the Alliance for the Canadian Arthritis Program (ACAP), was formed in 2002. Its goal is to improve the lives of Canadians with arthritis.

With more than 30 member organizations, the Alliance brings together arthritis health care professionals, researchers, funding agencies, governments, voluntary sector agencies, industry and, most importantly, representatives from arthritis consumer organizations from across Canada. While each member organization continues its own work, the Alliance provides a central focus for national arthritis-related initiatives.

http://www.arthritisalliance.ca