# A pan-Canadian Approach to **Inflammatory Arthritis Models of Care**





A pan-Canadian Approach to Inflammatory Arthritis Models of Care is available at www.arthritisalliance.ca.

## Acknowledgements

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## **Executive Summary**

## A pan-Canadian Approach to Inflammatory Arthritis Models of Care

#### I. Background

It is estimated that one million Canadians live with inflammatory types of arthritis (IA). Its most common forms include rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis and juvenile idiopathic arthritis. The current pattern of health care delivery to those living with IA is in crisis: the economic burden is expected to double within a generation, and the number of rheumatologists in Canada is already insufficient to provide timely care.

This report establishes high quality models of IA care that are evidence informed and reinforced by best practices.

A pan-Canadian Approach to Inflammatory Arthritis Models of Care has been prepared by the Arthritis Alliance of Canada (AAC) in response to these challenges, to improve the way health care is delivered to patients with IA.

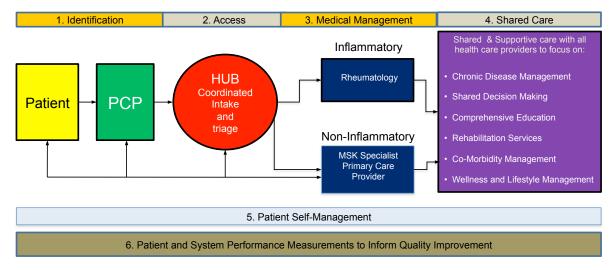
#### II. Introduction

The purpose of this report is to establish the framework for the development of high quality models of IA care that are evidence informed and reinforced by best practices.

A model of care is an overarching design for the provision of a particular type of health care service that is shaped by a theoretical basis, Evidence Based Practice and defined standards. It consists of defined core elements and principles and has a framework that provides the structure for the implementation and subsequent evaluation of care.<sup>1</sup>

#### III. The pan-Canadian Approach to Inflammatory Arthritis Models of Care

The pan-Canadian Approach to Inflammatory Arthritis Models of Care is comprised of six key elements (adapted from the Ontario Rheumatology Association Model of Care):



#### IV. Elements of the Model

**Patients recognize symptoms and seek care** – Patients must understand that this is not "just arthritis." **Access to specialist care** – Early identification, assessment and referral to appropriate specialists are essential steps in proper IA management.

**Medical management** – The management of IA is complex and requires constant monitoring with a specialist to ensure effectiveness.

**Shared care** – Treatment decisions must be made through agreement between the patient and the health care team, and there must be adherence to the treatment regime, including appropriate lifestyle changes.

**Patient self-management** – The patient must be fully educated about their medical conditions and the importance of adherence to the treatment regime.

**Patient and system performance measurements to inform quality improvement** –The framework can be used by healthcare decision makers to evaluate models of care and health system changes.

#### V. Next Steps

This document describes the framework for models of care for IA in Canada. AAC acknowledges that this is an important first step in improving the care of individuals with IA.

In addition, AAC has developed a "Care Path for Inflammatory Arthritis", a comprehensive map of a patient's journey through the health care system, along with a toolkit for each step along the way. This can be found on the AAC website (<a href="www.arthritisalliance.ca">www.arthritisalliance.ca</a>) and is meant to be a living document in the sense that the tools will be continually adapted and modified over time.

"Care Path for Inflammatory Arthritis" – a comprehensive map of a patient's journey through the health care system, along with a toolkit for each step.

Finally, the AAC has created a national network of provincial champions who will partner with key stakeholders to integrate this approach into the chronic disease management programs of each jurisdiction.

#### VI. Contact Us

For more information on the pan-Canadian Approach to Inflammatory Arthritis Models of Care please email us at info@arthritisalliance.ca or visit <a href="https://www.arthritisalliance.ca">www.arthritisalliance.ca</a>.

#### **About the Arthritis Alliance of Canada**

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 35 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.

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## Background

#### What is inflammatory arthritis?

It is estimated that one million Canadians live with inflammatory types of arthritis (IA).<sup>2</sup> IA results from synovitis, which is swelling and inflammation of the lining of the joints. Untreated, IA ultimately leads to joint destruction and consequent loss of the ability to participate in home, work and social activities. In addition, there is an increased risk for cardiovascular disease, osteoporosis and cancer.<sup>3,4</sup> However, IA can be managed effectively with a broad range of treatments if administered in an appropriate manner.<sup>5,6</sup> The critical factor to optimize the health of patients with IA is timely and ongoing access to specialty care, ideally delivered by a highly integrated, collaborative team of health care professionals knowledgeable in the diagnosis and management of IA.

This report will focus on the more common forms of IA, including rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis and juvenile idiopathic arthritis.

**Rheumatoid Arthritis** is the most common type of IA, affecting approximately 1% of the population. <sup>7</sup> In a

recent report, the prevalence of rheumatoid arthritis is projected to increase to 1.4% by 2040.<sup>8</sup> It is three times more common in women than in men and can occur at any age; however, the most frequent age of onset is between 30 and 50 years, affecting people

in the prime of their lives.

**Psoriatic Arthritis** occurs in roughly 0.5% of Canadians and 30% of patients with psoriasis, <sup>9,10</sup> a chronic

dermatologic condition. It may cause severe destruction to the peripheral joints as well

as the spine.

**Ankylosing Spondylitis** is a disease primarily affecting the spine but also peripheral joints and tendonous

insertions of the bone (enthesitis). Approximately 1% of the population suffers from axial and peripheral ankylosing spondylitis. It is three times more common in men than

women and commonly begins in teenage or early adult years of life. 11

Juvenile Idiopathic Arthritis affects roughly 24,000 children in Canada from birth to age 18 years. <sup>12</sup> It is important

for Canadians to recognize that children do get arthritis and that the disease results in

lifelong functional and social limitations that affect education, work and social

interactions.

## What are the risk factors for IA? Can it be prevented?

The causes of IA are multi-factorial and include complex genetics and environmental factors, not all of which are well defined in the scientific literature. <sup>13</sup>

Smoking is a definite risk factor for rheumatoid arthritis and there is evidence that in genetically susceptible individuals certain environmental factors can activate pathogenic immune reactions, including the formation of antibodies. <sup>14</sup> There is no question that as we gain a better understanding of the risk factors and causes of IA, we will be able to improve upon treatment and preventative strategies.

### What is the opportunity for control of the disease?

The evidence about disease control and remission is most robust in the case of rheumatoid arthritis. In treating rheumatoid arthritis, a delay of more than 12 weeks from symptom onset to therapy initiation results in a lower chance of attaining remission and an increased chance of progressive joint damage. The Two critical factors have been identified to achieve optimal health outcomes:

- 1. early access to diagnosis and treatment with tight control; and
- 2. a treat-to-target (T2T) approach to achieve low disease activity and remission. <sup>17,18,19</sup>

The Canadian Rheumatology Association (CRA) recommendations<sup>20,21</sup> for the management of rheumatoid arthritis are based on these two factors and provide guidance for their implementation. Canada is not alone in recommending this standard of care: in the Netherlands, providing both timely access and targeted care for rheumatoid arthritis has been shown to increase the likelihood of remission from 30% to 58% compared to usual care.<sup>22</sup> According to expert recommendations, the therapeutic approaches for juvenile idiopathic arthritis, ankylosing spondylitis are similar to those established for rheumatoid arthritis, with the goal of clinical remission or low disease activity.<sup>23,24</sup> Similar evidence is also now emerging for psoriatic arthritis where a delay in 6 months from onset of symptoms was associated with worse outcomes.<sup>25</sup> Tight control with a treat to target approach using minimal disease activity criteria as the target demonstrated better outcomes compared to standard of care.<sup>26</sup>

## Why are models of care needed?

There is a crisis in the current way health care is delivered to those living with IA. For rheumatoid arthritis, the direct economic burden of disease is estimated to be \$2.4 billion (2010) and will more than double within a generation.<sup>27</sup> This growing burden will continue to strain and potentially cripple the health system's ability to provide quality care for patients in a sustainable manner.

Furthermore, the number of rheumatologists in Canada is already insufficient to provide timely care to patients. There are approximately 420 rheumatologists in

This growing burden will continue to strain and potentially cripple the health system's ability to provide quality care for patients

Canada; however, with the growing percentage of the population with IA and the increasing complexity of the disease, the caseload is unmanageable and the system is not sustainable.<sup>28</sup> In addition, some provinces have noted gaps and inconsistencies in the provision of RA care compared to current treatment recommendations.<sup>29</sup>

... the number of rheumatologists in Canada is already insufficient to provide timely care To address these challenges, there is an urgent need to improve the way health care is delivered to patients with IA. In particular, in order to achieve the goals of timely access and targeted care, we need a patient-centred teambased approach to the management of IA that includes systems and processes to remove barriers and promote early referral and T2T management approaches. 30,31,32 Models of care are very important for chronic diseases such

as IA because they facilitate early efficient diagnosis and delivery of holistic health care services, help in the realignment of existing resources to optimize health system efficiencies, and identify the need for new resources.<sup>33,34,35</sup>

## Introduction

#### What is the purpose of this report?

The purpose of this report is to establish the framework for the development of high quality models of IA care that are evidence informed and reinforced by best practices. In addition, this report will outline how patient-centred team-based models of care that employ educational and self-management strategies are necessary to achieve the best health outcomes in a system sustainable manner. It is our goal to establish a common national approach to inflammatory arthritis models of care.

The target users of *A pan-Canadian Approach to Inflammatory Arthritis Models of Care* include health policy decision-makers and system planners; rheumatologists, allied health providers and other primary care providers; and people living with arthritis.

#### What is a model of care?

A model of care outlines the way health care services are organized and delivered for a patient population. A review of the literature by Davidson et al., <sup>36</sup> defines a model of care as follows:

A model of care is an overarching design for the provision of a particular type of health care service that is shaped by a theoretical basis, Evidence Based Practice and defined standards. It consists of defined core elements and principles and has a framework that provides the structure for the implementation and subsequent evaluation of care.

A complete model of care follows the patient's needs through the health care continuum as well as through the length of the disease process. For patients with a chronic disease such as IA, the model of care needs to ensure access to care on an ongoing basis as the patient's disease changes over time.

Each component of the model must be patient-focused; if possible, be evidence-based; be quality-driven; include valid and reliable outcome measures; and provide value relative to health care costs. To this end, the *Tool for Developing and Evaluating Models of Care* was created by the Arthritis Alliance of Canada (AAC) to help evaluate the completeness of currently implemented models of care as well as to evaluate models of care in the planning and development stages.<sup>37</sup> This tool is available at <a href="http://arthritisalliance.ca/en/initiativesen/moc-eval">http://arthritisalliance.ca/en/initiativesen/moc-eval</a>. It serves as a key document in developing the framework for the pan-Canadian Approach to Inflammatory Arthritis Models of Care.

#### What work has been done to date?

Through the leadership of the AAC, a coalition of arthritis organizations from across Canada, a national framework was established to focus on three main priorities:<sup>38</sup>

- a) advancing knowledge and awareness;
- b) improving prevention and care (access and delivery to care); and
- c) supporting ongoing stakeholder collaboration.

National steering committees have provided leadership to drive the successful execution of each of these specific priorities. In Ontario, a working committee was established in 2011, and has been dedicated to building a regional plan to improve prevention and care for arthritis patients. In every province, there are examples of best practices and innovative models of care, and this document is based on input from a broad range of leaders and stakeholders across the country. Other provincial efforts are also ongoing to drive regional implementation from the national models of care framework.

A significant amount of work has been completed within the rheumatology community to provide guidelines on clinical best practices in Canada. Published work includes the Canadian Recommendations for the Medication Management of Rheumatoid Arthritis, developed by the Canadian Rheumatology Association<sup>39,40</sup> and International Guidelines for Psoriatic Arthritis. <sup>41</sup> This approach to IA models of care is aligned with the early access to care recommended in these guidelines and treat to target. Adherence to guidelines or a decrease in variance of clinical practice has been shown to improve clinical outcomes.

### What principles have guided the development of this approach?

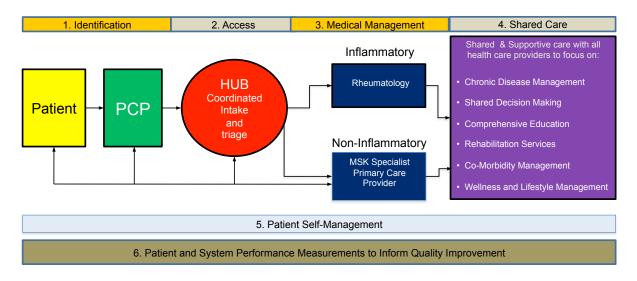
The following key principles of care have been developed for the assessment and management of rheumatoid arthritis and, for the purposes of this report, other IA conditions as well:

- 1. Patients with IA should be cared for by an adult or paediatric rheumatologist or by other healthcare professionals trained and experienced in the IA diagnosis, clinical assessment and appropriate prescription of drug therapies.
- 2. Every Canadian with IA should have timely and equitable access to appropriate rheumatologic care.
- 3. Treatment of patients with IA should be based on shared decision-making between patient and physician and/or other allied health professionals. This should include provision of appropriate education materials to patients and caregivers and clear discussion of the benefits and potential risks of treatment.
- 4. Team-based patient-centred models should be developed that integrate specialists, primary care providers and other allied health professionals trained in musculoskeletal (MSK) diseases, to enhance delivery of care for patients with IA.
- 5. Healthcare providers of patients with IA should consider opportunities for engaging patients in research both as participants and as potential research partners/consumer representatives to further the knowledge and understanding of their specific medical disease.
- 6. Based on a measurement framework, standardized metrics should be collected on all patients in order to evaluate and continuously improve care.

# A pan-Canadian Approach to Inflammatory Arthritis Models of Care

There is no single model of care for IA. This report describes the key elements of a model of care that must address the complex, long-term issues facing patients and include all points of contact across the health care system. It also considers the range of health care providers needed and their specialized scopes of practice. The proposed approach is meant to provide sufficient flexibility to be operational at a local or regional level.

Figure 1 **Six Key elements in the pan-Canadian Approach to IA Models or Care** (adapted from the Ontario Rheumatology Association Model of Care).



### Definitions of the six key elements

We included the following elements in the development of *A pan-Canadian Approach to Inflammatory Arthritis Models of Care*:

- 1. Identification of patients with IA
  - The patient has a key role in recognizing symptoms and accessing care.
  - Primary care engages with the patients to facilitate access to diagnosis and treatment.
- 2. Access to specialized care
  - Patients with symptoms of inflammatory disease require early identification and access to care. This is facilitated by a coordinated process of intake and triage.
- 3. Medical Management
  - Patients with inflammatory disease require access to a specialist who has the necessary training and expertise to diagnose and manage the clinical condition. This is typically provided by rheumatologists.
  - Patients require ongoing assessment of disease activity and wellness throughout the course of their disease.
  - Patients require effective pain management including assessment of the sources of pain and appropriate treatment.
- 4. Shared Care (Highly integrated team-based care)
  - Effective management of IA requires highly integrated team-based care based on the principles of chronic disease management.
  - To optimize patient outcomes, treatment decisions must be made through shared decision making between the patient and the health care team.
  - Comprehensive education and patient self-management are an important aspect of the shared care model.
  - Patients require access to allied health professionals especially rehabilitative services provided by physiotherapists, occupational therapists and foot specialists.
  - Patients may require coordinated access to other speciality care.
  - For patients to live well with their disease, they require access to resources on health and wellness and lifestyle management.
- 5. Patient self-management
  - Patients should be empowered to manage their disease and quality of life between health care interactions.
- 6. Patient and system performance measurements to inform quality improvement
  - Data on patient outcomes (e.g., function, disease activity) are needed to ensure that targets for low disease activity and reduced disability are met at an individual patient level.
  - Performance measures at a systems level are important to ensure that care is both efficient and effective (e.g., timely access).
  - Ongoing data collection provides feedback to health care professionals and decision-makers on the effectiveness of the IA model of care.
  - The appropriate accountability infrastructure is also required to ensure that quality improvements in infrastructure are maintained.

## Elements of the Model

The following sections provide further detail on each of the above elements of the model of care for patients with IA.

#### 1. Patients recognize symptoms and seek care

The effective treatment of inflammatory diseases has improved dramatically over the last 10 years with early access, T2T regimes and new treatments that can halt or reduce disease progression. 42 Therefore, awareness is important at both the public and primary care provider level. Patients must understand that this is not "just arthritis": early identification and assessment is essential for proper disease management.

- **Barriers** 1. The initial signs of the development of an IA may vary.
  - 2. Factors that determine whether a person will seek care may vary and could include geographic location, disease onset and presentation, the impact on functional ability, and cultural and health beliefs. 43

- Potential Facilitators 1. Public awareness campaigns
  - Social media 2.
  - 3. Screening tools

#### Primary care assessment

The first point of contact with the health care profession for patients experiencing symptoms or signs of IA is most frequently through primary care. This is usually a family physician, but patients may present to a nurse practitioner (NP), physiotherapist, chiropractor, occupational therapist or pharmacist. Referrals are sometimes received from other specialists. As only physicians and NPs (in some provinces) can make a referral to a specialist, this can pose a significant problem, given that many Canadians are without a family physician. For patients presenting with signs and symptoms consistent with IA, it is extremely important that primary care providers make an urgent referral to a rheumatologist or other trained specialist who can manage the disease to prevent joint damage or disease progression.

#### **Barriers**

- 1. For many Canadians, the lack of a primary care physician
- 2. Access to specialist care limited to physicians and NPs
- 3. Limited awareness of signs and symptoms of IA by primary care
- 4. Limited awareness of both the urgency and the benefits of treatment
- Real or perceived lack of access to a rheumatologist

#### **Potential Facilitators**

- 1. Increased exposure in medical/physiotherapy/occupational therapist/chiropractor and pharmacy schools to an MSK curriculum
- 2. Innovative continuing medical education programs
- 3. Screening tools and clinics for patients with suspected IA
- 4. Increased access to rheumatologist by primary care through telephone consultation or telemedicine

#### Referral process

Currently, a written request for consultation must be made by a physician or, in some provinces, an NP. In most parts of the country, there are very long waiting lists to see a rheumatologist who is, in turn, unable to see all patients in a timely manner. IA requires urgent assessment because the patient's outcome is dependent on timely diagnosis and treatment. Often, there is insufficient information on the written referral to assign prioritization.

#### Barrier

- 1. Lack of standardized referral criteria and forms
- 2. Lack of information to prioritize the assessment of patient with potential IA
- 3. No direct access from non-physicians to consultation
- 4. Lack of electronic referral processes

#### **Potential Facilitators**

- Standardized referral process
- 2. Referral tools that help identify early IA
- 3. Improved diagnostics that will aid in the process of identification of early disease
- 4. Standardized screening assessment forms for allied health professionals

## 2. Access to specialist care

People with IA present with a range of symptoms at various times during the course of their disease. Delays in diagnosis and referral to a specialist can occur for a number of reasons, including the fact that rheumatologists may no longer be accepting new referrals, and inadequate or non-existent triage.<sup>44</sup> Therefore, care must be streamlined in order to get the patient to the earliest appointment time available with an appropriate health care professional. Undefined processes can result in delays for patients that need to be seen urgently.

Triage is a process of prioritizing the treatment of patients based on the urgency of their disease. Establishment of a coordinated triage model is an effective way to determine urgency and prioritize patients within a determined time frame. A central triage model is the optimal way to manage this process by preventing duplication of referral and providing access to the first available rheumatologist. This process works well in rheumatology where priority is given to IA patients, who are often seen on an expedited basis to provide access to appropriate medications as soon as possible. With a shrinking number of an already limited supply of rheumatologists compared to the volume of referrals, triage is important to maximize system efficiencies. Triage also allows for timely intake of new patients while ensuring the ongoing management of long-term patients. 45,46

Wait times for inflammatory diseases fall into a number of categories, including time to access primary care, diagnostic testing, triage and follow-up care, as well as the time from primary care to a specialist. All of these transitions represent potential delays in care that can jeopardize optimal disease management. Ideally, a database linked to a centralized schedule and electronic medical records can facilitate tracking and provide accurate wait time data, which is useful in the

evaluation of a centralized triage model. The electronic referral system should also be able to provide all the relevant data on a patient.

Physical triage is another method of prioritizing patients for more rapid access to specialty care. In this model, a health care professional with advanced skills in MSK medicine will initially screen by physical exam and a standardized assessment form for inflammatory joint disease. Those screened positive for IA are then seen by a rheumatologist.

#### **Barriers**

- 1. Limited availability of appointments with rheumatologists
- 2. Multiple referrals of the same patient to different rheumatologists
- 3. Request for unnecessary second opinions
- 4. Different case loads and therefore availability amongst rheumatologists
- 5. Inappropriate referrals—chronic pain, orthopaedic problems, neurologic conditions

- Potential Facilitators 1. Central referral and triage
  - Physical triage

## 3. Medical management

For many IA conditions, guidelines have been developed on the use of medications as well as other factors relevant to the particular disease state, including rheumatoid arthritis, psoriatic arthritis, spondyloarthritis and juvenile inflammatory arthritis (JIA). 47,48,49,50,51 Specific information on medications and treatment options is therefore not provided in this report, instead it is referenced in the IA Toolkit.<sup>52</sup>

For all diseases, the management of IA is complex and requires constant monitoring with a specialist to ensure effectiveness and safety. The medical diagnosis and initial treatment, as well as any changes to treatment including medication, should be provided by a rheumatologist. If a patient's symptoms stabilize, they may receive ongoing care through a health care practitioner with advanced training.

Medical management includes the management of the inflammatory symptoms, function and long-term disability. IA is a chronic disease that changes over time and, as such, patients may experience periods of exacerbation and remission. The initial interaction ensures the patient, once diagnosed, receives intensive medical management to stabilize the disease. Over time, the patient needs to re-access services to determine the need, if any, for treatment modifications.

#### Initial assessment and diagnosis

IA is a chronic disease that can have devastating effects on the health and overall well-being of individuals diagnosed with the disease. Patients require a holistic approach to care that includes a number of health care disciplines over a period of time: nursing, physiotherapy, occupational therapy, pharmacy, social work, dietetics, kinesiology and psychology. Team-based care in a hospital or community setting requires an integrated network of allied health professionals working together with specialists in a coordinated fashion. This approach requires extensive training and ongoing communication as well as regular monitoring and evaluation.

Assessment needs to be undertaken to:

- confirm the diagnosis and establish prognosis;
- identify patient education needs on disease and medication;
- identify and start the treatment of the acute symptoms;
- identify contraindications to treatment including testing;
- assess for comorbidities such as depression and other complications; and

• assess for work disability or other functional issues.

#### Goal of treatment

The primary goal of treatment of IA is disease remission through the control of inflammation in the joints.<sup>53</sup> This goal needs to be set in collaboration with the patient because success depends on adherence to the treatment regime, including medications and lifestyle changes.

For some patients, the use of the medications results in clinical remission of the disease process. However, one of the major factors in achieving clinical remission is timely access to medication; therefore, clinical remission cannot be obtained in all patients.<sup>54</sup> For patients where clinical remission is not possible, the goal is the lowest disease activity state that is achievable and acceptable to the patients and that maintains maximum function.<sup>55,56,57</sup> This is completed through a T2T approach, which is outlined below.

#### Treat to target (T2T)

The philosophy in the management of patients with IA is to treat the patient to a pre-defined target.<sup>58</sup> The patient must be engaged in a process of shared decision-making and the target may well be different for different people presenting the same symptoms.<sup>59</sup> Developing a target for care needs to include:

- defining the clinical target by deciding the level of disease state acceptable to the patient in conjunction with the team;
- evaluating the patient's status on an ongoing basis;
- ensuring that the strategies follow the recommendations provided within the appropriate clinical guidelines;
- collecting data on all patients using a validated measurement system to track performance; and
- using Electronic Medical Record (EMR) functionality to support clinical data collection and to integrate clinical practice guidelines.

A number of considerations regarding care can influence the ability to provide early diagnosis and treatment including:

- Access to medications: Each province and insurer has its own approval process that can define the timelines on which patients can access their medications.
- Access to imaging: In some inflammatory diseases, patients may require imaging such as MRI for diagnosis and treatment
- Access to other specialties: Patients may require a consultation with another specialist.
- Treatment of complications: Patients may require a more comprehensive testing regimen and treatment schedule.
- Regional variations in care: Earlier population-based assessments have demonstrated that many Canadians are not provided optimal IA therapy and that gaps and inconsistencies in the provision of IA care exists compared to current treatment guidelines.<sup>60</sup>

As the disease is stabilized through appropriate medications, the timelines between visits can increase and many patients whose disease is deemed stable can be seen once per year.

#### 4. Shared care

#### Chronic disease management

Patients presenting with an inflammatory disease have complex medical needs that require access to care for the management of disease and complications, the management of co-morbidities, and education and lifestyle management (Figure 1). As adherence to a treatment regime is key to the effective management of this disease, patients consistently need to share changes in their symptoms with health care providers in order to access the appropriate health services.

#### Shared decision making

To optimize patient outcomes, treatment decisions must be made through agreement between the patient and the health care team. In addition, there must be adherence to the treatment regime including appropriate lifestyle changes.

An essential component of a shared decision-making model is effective communications. Communication between the specialists and the primary care provider as well as among team members is extremely important to ensure that the ongoing needs of the patient are being met. A formal mechanism is required

To optimize patient outcomes, treatment decisions must be made through agreement between the patient and the health care team.

to provide details on the status of patients following every change in health care management. Ongoing two-way communication between the specialist and the primary care provider is necessary to ensure consistent feedback to the patient on disease management and other treatment options.

Research has identified that the outcomes for patients are better when the care of the patient's inflammatory disease is shared <sup>61,62</sup> and under the direct supervision of the rheumatologist. <sup>63 64</sup>

#### Compliance and adherence

The management of IA requires ongoing compliance and adherence to the treatment plan. A regular monitoring strategy is therefore necessary to provide support and to ensure follow-up with the team if there are changes in a patient's disease activity or adverse events. Monitoring of adherence is particularly important for patients who are considered at risk for non-compliance with their medications.

#### Patient factors in a shared care model

#### Disease stability

With new medications and appropriate medical management using the T2T approach, IA can be stabilized to achieve low disease activity. The decision on disease stability needs to be made with the rheumatologist based on their clinical findings and needs to include input from the patient and any other health care providers involved with the care of the patient. Once stability is achieved, fewer visits with the rheumatologist are required.

#### **Social factors**

The management of inflammatory diseases is a lifelong requirement for which patients need ongoing access to specialist services. However, for many patients there are issues in accessing consultations, including geographic, cultural and socioeconomic factors.

#### Comprehensive education

The patient's assessment is often the first interaction with the health care team. As such, the role of the assessors is both to determine the medical condition as well as to provide education on the disease, typical disease progression, appropriate medications (including side effects) and self-management principles. Education is also important on an ongoing basis throughout the course of the disease to ensure that the patient remains current about treatment options and self-management care. Education should also cover topics associated with lifestyle, such as weight management, exercise and smoking cessation. This can be supported by a range of health professionals and through other resources such as The Arthritis Society.

#### Rehabilitative services

In many cases, patients require the assistance of rehabilitation specialists to manage the signs and symptoms common to many arthritis conditions—pain, swelling, loss of joint movement, muscle weakness and fatigue. Treatment interventions often take the form of range of motion and strengthening exercises, joint protection strategies, and consultation on optimizing functional home, work and personal care activities. In additional, the provision of splints, footwear, orthotics and assistive devices to minimize disability and functional limitation is often prescribed. Availability, access and funding of these services vary in communities, as do the skills, knowledge and expertise of providers in the delivery of best practice arthritis care. Effective coordination of these services can be assumed by any of these professionals, however some responsibility for system navigation often falls to the patient. As with pharmacological interventions, the success of rehabilitation is highly dependent on patient compliance with treatment regimes, and appropriate supports need to be incorporated into plans of care to accommodate those patients who are less able to manage their multiple/complex needs independently. Strong communication mechanisms among rehabilitation practitioners are needed to enhance interprofessional collaboration and help the patient realize the benefits and value of a shared approach to care.

#### Co-morbidity management

Some co-morbid diseases, such as cardiovascular disease and osteoporosis, are the result of the cumulative effective of unopposed inflammatory activity<sup>65</sup> or drug therapy. Therefore, management of these co-morbidities needs to be coordinated between the specialists and primary care teams.

#### Wellness and Lifestyle Management

There is no doubt that lifestyle issues can have a profound effect on the likelihood of individuals developing inflammatory arthritis. Smoking has been associated with an increased prevalence and severity in inflammatory arthritis as well as decreasing the response to medications. As with many chronic diseases, a healthy lifestyle including regular exercise and good nutrition are an important component of comprehensive disease management.

### 5. Patient self-management

Self-management requires the patient to be fully educated on an ongoing basis about their medical conditions and the importance of adherence to the treatment regime, including how to deal with adverse side effects of their medications and how to recognize symptoms associated with exacerbations of IA. Patients must also be educated on the services of other health care providers that they may need in order to live well with their disease and enhance their quality of life in terms of maximum functionality, lifestyle management and their psycho-social needs.

Self-management requires the patient to be fully educated about their medical conditions and the importance of adherence to the treatment regime.

# 6. Patient and system performance measurements to inform quality improvement

Measurement is an integral part of a model of care. An expert committee has been convened to define a quality measurement framework for IA. AAC is best positioned to define system level performance measures for inclusion in the framework. The framework can be used by healthcare decision-makers (administrative clinicians, managers and policy makers) to evaluate models of care and health system changes, with the goal of developing safe, cost-effective and efficient high quality care for patients with IA.

The AAC will focus on developing a minimum set of key standardized metrics that should be collected across Canada. In collaboration with our provincial governments, the AAC will ensure that these are feasible to implement in the context of the provincial settings.

## Implementing the model

The model that is developed needs to facilitate a coordinated approach to care. Consider the following:

- 1. **Location** Work can be undertaken in one location or through multiple locations where communication is facilitated on a virtual basis.
- 2. **Coordinated assessment system** Each assessment needs to be coordinated so that the appropriate health professionals see the patient.
- 3. **Medical record and charting** A shared medical record and charting system should be accessible to all those involved in the patient's care. EMRs are essential to facilitate this.
- 4. **Directs links to other specialty care** Direct links are needed for rheumatologists to refer patients that require additional management for co-morbid conditions
- 5. **Provider training** All members of the teams need core competencies in assessment and management of IA. Education should also be accessible for advanced practitioners. Certification will identify individuals competent in delivering quality IA care.
- 6. **Ongoing health care provider education** A coordinated education program would ensure ongoing competency.
- 7. **Comprehensive patient education programmes** Comprehensive patient education programs are important to facilitate patient empowerment and self-management. They help patients understand their disease, drug therapy and rehabilitation in order to improve compliance and adherence to treatment. They should be available at the time of diagnosis and at any time afterwards when the patient needs more information. These programmes lead to a stronger partnership between the patients and their treating physicians.
- 8. **Point of care data** Extraction from EMRs to research databases facilitates real world data analysis.
- 9. **Ongoing evaluation** All models should undergo continuous evaluation using a quality measurement framework for IA.
- 10. **Funding mechanisms** In order to ensure the sustainability of the model, all members must be appropriately compensated and sufficient funding must be available to support infrastructure, including space, technology, administration, research and evaluation.

## **Next Steps**

This document has described the framework for models of care for IA in Canada. We acknowledge that this is an important first step in improving the care of individuals with IA.

In addition, the AAC has developed a "Care Path for Inflammatory Arthritis", a comprehensive map of a patient's journey through the health care system, along with a toolkit for each step along the way. This can be found on the AAC website (www.arthritisalliance.ca) and is meant to be a living document in the sense that the tools will be continually adapted and modified over time.

Finally, the AAC has created a national network of provincial champions who will partner with key stakeholders to integrate this approach into the chronic disease management programs of each jurisdiction.

## Contact us

For more information on *A pan-Canadian Approach to Inflammatory Arthritis Models of Care* please email us at info@arthritisalliance.ca or visit www.arthritisalliance.ca.

#### **About the Arthritis Alliance of Canada**

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 35 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 AAC provides a central focus for national arthritis-related initiatives.

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