

More than a 100 different types of arthritis affect 4.6 million Canadians.

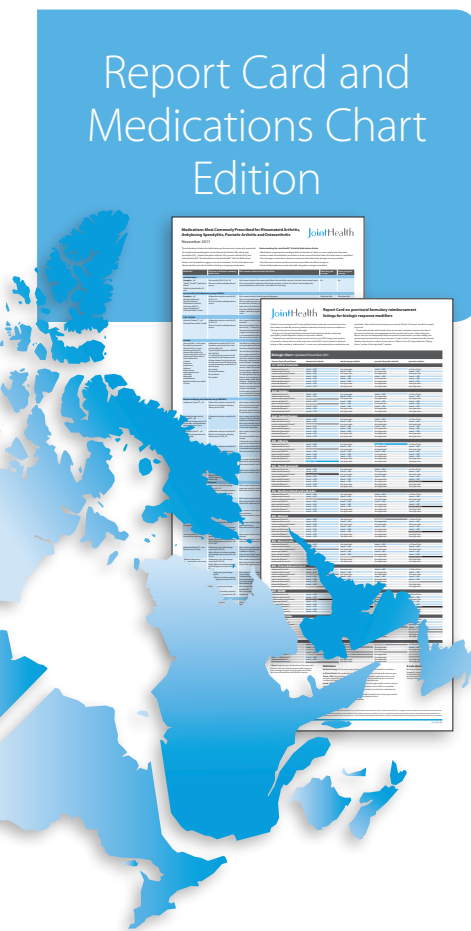
With so many people having arthritis, comes an immense burden on individuals and society. Besides causing an estimated \$33 billion cost to the economy due to the direct expense of healthcare and the indirect costs of lost productivity, arthritis is a host of conditions that can cause debilitating pain, lowers quality of life, and sometimes reduces life expectancy. Worse, it knows no age boundaries, and that is part of the reason arthritis costs society. People in the prime of their lives, if struck with arthritis come to rely on the healthcare system and are sometimes unable to work.

Arthritis can be either degenerative or inflammatory. Osteoarthritis, which affects 13% of adult Canadians, falls into the first category. Osteoarthritis can affect any joint, but most commonly the knees and hips. It occurs when cartilage breaks down, so that there is no longer a cushion to prevent the bones from rubbing together.

Inflammatory arthritis describes autoimmune forms of the disease. They are systemic, that is, whole-body, diseases in which the immune system attacks healthy joints and tissues, causing inflammation and damage. Around one percent of Canadians have rheumatoid arthritis (RA), which makes it the most common form, followed by ankylosing spondylitis (AS) and psoriatic arthritis (PsA). Juvenile idiopathic arthritis (JIA), also

known as juvenile rheumatoid arthritis is one of the most common chronic conditions in children.

Early and aggressive treatment is the key to slowing or preventing damage to joints and organs. How is that achieved? One way is to encourage policy makers to have health ministries provide coverage for all medically necessary arthritis medications, ideally within 6 weeks of a patient's diagnosis. Arthritis Consumer Experts (ACE) has worked toward that goal by writing letters to provincial and federal health ministers and by creating the *Report Card on provincial formulary reimbursement listings for biologic response modifiers ("biologics")*. The *Report Card* compares medication formularies from across



Canada, ranking each one based on how many biologics are covered, out of a possible eight, for the four most common forms of inflammatory arthritis.

In this issue of JointHealthTM monthly, ACE spotlights the four most common inflammatory arthritis types featured in the *Report Card* (provided with this issue as an easy-to-read pullout sheet). On the other side of the sheet, you will find the *JointHealthTM Arthritis Medications Guide*, a chart listing important information about the medications used to treat arthritis. Also provided in this issue is a section with information about the variability in medication coverage across Canada, a list of recent provincial and territorial elections, each jurisdiction's Premier and health minister, and suggestions for how you can advocate for equitable healthcare.



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Biologic response modifiers, also known as "biologics", are medications used to treat the underlying disease process of inflammatory arthritis types.

Spotlight on inflammatory arthritis

The following arthritis types have many things in common, including that they are all systemic autoimmune diseases, in which their effects are not confined to a single, localized area, but affect the entire body. With any of them, the body's immune system mistakenly attacks itself, causing inflammation and pain. Where and how it attacks, depend on the disease type.

Rheumatoid arthritis (RA) causes swelling and pain in and around joints, typically in hands and feet, but also in elbows, shoulders, neck, jaw, ankles, knees, and hips. It can also cause inflammation in organs, such as eyes, lungs, and heart. If the disease is moderate to severe, the average life expectancy of someone with RA is reduced by 10 years.

Rheumatoid arthritis occurs two to three times more often in women than in men. Though it can strike at any time, people of every age from toddlers to senior citizens have been diagnosed with the disease.

Red flags to watch for include:

- Morning stiffness lasting longer than 30 minutes
- Inflammation in the same joints on both sides of the body, often accompanied by pain
- Pain in three or more joints at the same time
- Loss of motion in the affected joints
- Severe fatigue

Your doctor will also watch for the following:

- Swelling of the wrists, knuckles and small joints of the fingers and toes, including the ball of the foot; AND
- A positive rheumatoid factor or anti-CCP (a negative test does not exclude RA); OR
- An elevated C-reactive protein or ESR

Ankylosing spondylitis (AS) mainly affects the spine, but can also involve hips, knees, shoulders, and rib cage. Many people with AS have family members with a history of AS, psoriatic arthritis, psoriasis, and inflammatory bowel disease.

Distinct from many other forms of arthritis, AS more often occurs in men — 3 out of 4 diagnosed with it are men. The disease strikes at any age, but usually between ages 15 and 40.

The most common symptom of AS is long-term back pain, along with spinal stiffness in the morning or after a long period of rest, and is the main reason AS is often misdiagnosed as ordinary low back pain, particularly in young men who are active at work or leisure.

Red flags to watch for include:

- Back complaints are the first sign in 75% of patients diagnosed with AS
- Slow or gradual onset of back pain and stiffness that lasts over weeks or months, rather than hours or days
- Back pain that alternates from buttock to buttock.
- Pain and stiffness that improve with physical activity
- Pain that awakens a person from sleep
- Pain in the ribs, shoulder blades, buttocks, hips, thighs, and heels

While it has no known cure, it is treatable. With the proper care, people who are diagnosed with AS can lead full, productive lives.

Psoriatic arthritis (PsA) causes swelling and pain in and around joints, and a scaly rash on the skin. Joints most commonly affected are wrists, knees, shoulders, elbows, ankles, and those in the fingers and toes. The disease can also cause swelling of the tendons and ligaments around the joints. Sometimes PsA affects the spine — this form is called psoriatic spondylitis. Children whose parents have PsA are up to three times more likely to develop the disease. People with psoriasis, a condition that causes a scaly rash, have a higher risk of developing PsA.

Psoriatic arthritis affects men and women in equal numbers. Like many forms of inflammatory arthritis, it tends to strike people in the prime of their lives. Most commonly, people are diagnosed between the ages of 20 and 50.

Red flags to watch for include:

- Pain and swelling in joints, tendons, ligaments, fingers, and toes, causing the appearance of “sausage fingers”
- Fingernails detaching from the nail bed or developing pinhole sized dents (called “pitting”) on the surface
- Reduced range of motion
- Morning stiffness lasting more than one hour

Juvenile idiopathic arthritis (JIA), once called juvenile rheumatoid arthritis, develops in those under the age of 16. In JIA, joints are attacked by inflammation and become stiff, painful, and swollen. Some children with JIA develop inflammation involving their eyes as well. There are seven subtypes of JIA, and in the most severe ones organs such as the heart or lungs can be involved.

Overall, JIA affects slightly more girls than boys.

The most common complaints children have when they develop JIA is joint pain, along with swelling or stiffness.

Red flags to watch for include:

- Change in the ability to keep up with normal activities, such as sports or school work because of joint pain
- Irritability, especially in a young child who is in pain
- Refusal to walk, limping, or a child who knows how to walk may return to crawling

While it has no known cure, there are effective treatments for JIA which can often lead to remission and prevent permanent joint damage and disability.

If any of these diseases is suspected, then a patient should be referred to a rheumatologist immediately. Rheumatologists have many years of extra training on top of their regular medical schooling and are experts at diagnosing and treating all types of arthritis, especially inflammatory forms. Those under the age of 16, should be referred to a pediatric rheumatologist because they have specialized training in pediatrics and pediatric rheumatology. In all cases, early diagnosis and treatment are keys to maintaining joint health and preventing disability and deformity — and in the case of JIA, could lead to remission.

For more information about all of these arthritis types and others, visit www.jointhehealth.org or download the *Arthritis is cured! (if you want it)* **National Arthritis Awareness Program** apps, **ArthritisID** and **ArthritisID PRO**.

Medication and treatment options

While we wait for a cure for arthritis, a combination of medications, usually a disease modifying anti-rheumatic drug (DMARD) and/or a biologic response modifier, is the gold standard in treatment for inflammatory arthritis. The *JointHealth™ Arthritis Medications Guide* included with this newsletter provides details on the medications used to treat the four inflammatory forms of arthritis, plus osteoarthritis, and lists the associated side effects.

Unfortunately, reimbursement access to medications is not equal across the country, which means some Canadians with arthritis have fewer options, or have to “jump through more hoops”, to treat their disease than other citizens. No one province provides coverage for all the biologics approved in Canada, though BC, Saskatchewan, and Alberta come close. However, Alberta has overly restrictive criteria (ORC) for certain medications. The Yukon and Manitoba formularies

have the lowest number of medications listed and in both jurisdictions, there is no coverage for medications to treat juvenile idiopathic arthritis. Worse still, the Yukon does not reimburse for any ankylosing spondylitis medications.

The inflammatory forms of arthritis, especially

Pronunciation Guide*:

Abatacept : a-BAT-a-sept

Adalimumab : a-da-li-MU-mab

Anakinra : a-na-KIN-ra

Certolizumab pegol : ser-toe-LIZ-u-mab PEG-ol

Etanercept : e-TAN-er-sept

Golimumab : go-LI-mu-mab

Infliximab : in-FLIX-i-mab

Rituximab : ri-TUX-i-mab

Tocilizumab : toe-si-LIZ-oo-mab

* For generic names

rheumatoid arthritis, move quickly and aggressively to damage joints and the tissues that surround them. Left untreated, they cause chronic pain and lost mobility and joint function. Finally, because they are diseases that can affect the entire body, they are potentially life threatening. Diagnosis must be made early, so that treatment can begin before damage takes place.

Furthermore, there have to be many medication options available to every Canadian equally. Each person living with arthritis responds differently to each medication and no single biologic therapy is effective in everyone with a particular condition. Because the criteria for reimbursement on formularies is different across Canada, some people lack the same choices as others. Every Canadian deserves the same right to consider their personal risk factors, and with the help of their physician, choose the best medication for their disease.

How does your province compare?

The *JointHealth™ Report Card on provincial formulary reimbursement listings for biologic response modifiers* was developed to address the problem of unequal or unfair access to medications. Since it was originally published in 2005, the number of biologics covered across the country has improved greatly.

Wrongly, some provinces still fall behind the rest of the country. People who depend on financial assistance from their province's medication benefit plan are still being denied the treatments they require. How does your province compare? You can find out by reading the Report Card included in this issue of *JointHealth™* monthly.

What's new in this year's Report Card?

Since *JointHealth™* produced last year's paper version of the Report Card, a lot changed. Three new medications still under review at the time of printing became available to treat rheumatoid arthritis (RA), psoriatic arthritis (PsA) and ankylosing spondylitis (AS). The new medications are golimumab (Simponi®), which is used to treat all three disease types, and certolizumab pegol (Cimzia®) and tocilizumab (Actemra®) for RA only. Now, instead of ranking publicly funded medication formularies based on the number of medications they cover out of five, we base them out of eight. The Report Card has a new look too. It was reformatted to accommodate the additional medications.

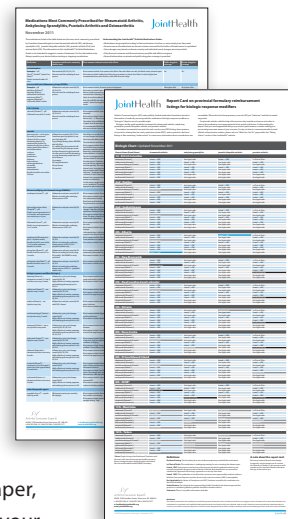
A few other changes involve each province's ranking. Last year, Québec was the best province, providing the most medications on its formulary. This year, it is in second place, along with Saskatchewan which did not move. Now BC takes first position, up from fourth place last year. Even though Alberta covers the same number of medications as Saskatchewan and Québec, which should put it in second place too, it lost points for having overly restrictive criteria for tocilizumab and abatacept. Ontario improved, moving up from seventh place to fifth. New Brunswick and Newfoundland and Labrador are also in fifth place, a drop one place from last year. Nova Scotia moved down one position from seventh, to eighth. Prince Edward Island and the NIHB (Non-Insured Health Benefits) joined Nova Scotia, from last year's ninth place spot. Manitoba (11th) and the Yukon remain in the same places, with Yukon last, not only because they cover the fewest medications, but also because they made no improvements whatsoever. Three new medications were approved last year, and their formularies are the only two not to include a single one.

Formularies change frequently, so ACE updates its online version of the Report Card each month. From there, you can also view the reimbursement criteria for each medication.

Fighting for your patient rights

Would you like to speak out about the need for

equal access to medications? You can do so by writing to the federal health minister or your province's health minister and the senior drug plan manager, writing a letter to the editor of your local paper or a national newspaper, or writing a letter to your elected provincial and federal representatives. For tips on how to compose a letter to an elected official or to a newspaper, please visit the “**What You Can Do**” section of the *JointHealth™* website.



Arthritis Consumer Experts is in the midst of a **large government letter writing campaign**, where we explain to the newly elected premiers and health ministers the burden of arthritis in Canada and ask them to fill out a questionnaire so they can let us know where they stand on the issue. Later this fall, we will publish the letters and the responses we receive at www.jointhealth.org. Please visit often to look for updates.

Getting to know your province or territory's governments

Six provinces or territories had elections in October this fall, and by the time you receive this November issue of JointHealth™ monthly, another one will have passed. Here, we provide the schedule of recent and upcoming elections. We also list the people to contact to let them know your concerns about access to arthritis medications: the Premier and the Health Minister of each province.

Province/Territory	Election date	Party and Premier	Health Minister
Alberta	Last: March 3, 2008 Next: No later than March 13, 2013	PC majority Alison Redford	Fred Horne
British Columbia	Last: May 12, 2009 Next: May 14, 2013	Liberal majority Christy Clark	Michael de Jong
Manitoba	Last: October 4, 2011	NDP majority Greg Selinger	Theresa Oswald
New Brunswick	Last: September 27, 2010 Next: 2014	PC majority David Alward	Madeleine Dubé
Newfoundland & Labrador	Last: October 11, 2011	PC majority Kathy Dunderdale	Susan Sullivan
Northwest Territories	Last: October 3, 2011	No political parties. Operates on basis of consensus government. The Premier, Bob McLeod, was chosen by and from the elected members.	Tom Beaulieu
Nova Scotia	Last: June 9, 2009 Next: 2013	NDP majority, Darrell Dexter	Maureen MacDonald
Nunavut	Last: October 27, 2008 Next: 2012	No political parties. Operates on basis of consensus government. The Premier, Eva Aariak, was chosen by and from the elected members.	Tagak Curley
Ontario	Last: October 6, 2011	Liberal minority Dalton McGuinty	Deb Matthews
Prince Edward Island	Last: October 3, 2011	Liberal majority Robert Ghiz	Doug W. Curry
Québec	Last: December 8, 2008 Next: 2012	Liberal majority Jean Charest	Dr. Yves Bolduc
Saskatchewan	Last: November 7, 2007 Next: November 7, 2011	Will have been determined by the time this arrives in mailboxes. (Sask Party majority in 2007)	Information not available at time of printing.
Yukon	Last: October 11, 2011	Yukon Party majority Darrell Pasloski	Doug Graham
Canada	Last: May 2, 2011 Next: 2015	Conservative Party majority Stephen Harper is Prime Minister	Leona Aglukkaq

Arthritis Consumer Experts

Who we are

Arthritis Consumer Experts (ACE) provides research-based education, advocacy training, advocacy leadership and information to Canadians with arthritis. We help empower people living with all forms of arthritis to take control of their disease and to take action in healthcare and research decision making. ACE activities are guided by its members and led by people with arthritis, leading medical professionals and the ACE Advisory Board. To learn more about ACE, visit www.jointhehealth.org

Guiding principles and acknowledgement

Guiding Principles

Healthcare is a human right. Those in healthcare, especially those who stand to gain from the ill health of others, have a moral responsibility to examine what they do, its long-term consequences and to ensure that all may benefit. The support of this should be shared by government, citizens, and non-profit and for-profit organizations. This is not only equitable, but is the best means to balance the influence of any specific constituency and a

practical necessity. Any profit from our activities is re-invested in our core programs for Canadians with arthritis.

To completely insulate the agenda, the activities, and the judgments of our organization from those of organizations supporting our work, we put forth our abiding principles:

- ACE only requests unrestricted grants from private and public organizations to support its core program.
- ACE employees do not receive equity interest or personal "in-kind" support of any kind from any health-related organization.
- ACE discloses all funding sources in all its activities.
- ACE identifies the source of all materials or documents used.
- ACE develops positions on health policy, products or services in collaboration with arthritis consumers, the academic community and healthcare providers and government free from concern or constraint of other organizations.
- ACE employees do not engage in any personal social activities with supporters.
- ACE does not promote any "brand", product or program on any of its materials or its web site, or during any of its educational programs or activities.

Thanks

ACE thanks the Arthritis Research Centre of Canada (ARC) for its scientific review of JointHealth™.



Acknowledgement

Over the past 12 months, ACE received unrestricted grants-in-aid from: Abbott Laboratories Ltd., Amgen Canada, Arthritis Research Centre of Canada, Bristol-Myers Squibb Canada, Canadian Institutes of Health Research, GlaxoSmithKline, Hoffman-La Roche Canada Ltd., Merck & Co. Canada, Novartis Canada, Pfizer Canada, Sanofi-aventis Canada Inc., Takeda Canada, Inc., and UCB Canada Inc. ACE also receives unsolicited donations from its community members (people with arthritis) across Canada.

ACE thanks these private and public organizations and individuals.

Disclaimer

The material contained in this newsletter is provided for general information only. It should not be relied on to suggest a course of treatment for a particular individual or as a substitute for consultation with qualified health professionals who are familiar with your individual medical needs. Should you have any healthcare related questions or concerns, you should contact your physician. You should never disregard medical advice or delay in seeking it because of something you have read in this or any newsletter.