

Patient Group Input to Drugs for Management of Rheumatoid Arthritis

Name of patient group	The Arthritis Society
Patient group's website	www.arthritis.ca
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Section 1 — General Information

1. Submitting Organization

The Arthritis Society has been setting lives in motion for over 65 years. Dedicated to a vision of living well while creating a future without arthritis, The Society is Canada's principal health charity providing education, programs and support to the over 4.6 million Canadians living with arthritis. Since its founding in 1948, The Society has been the largest non-government funder of arthritis research in Canada, investing more than \$190 million in projects that have led to breakthroughs in the diagnosis, treatment and care of people with arthritis. The Arthritis Society is accredited under Imagine Canada's Standards Program. The website www.arthritis.ca provides more detailed information.

2. Conflict of Interest Declarations

The Arthritis Society does not believe that it or those individuals playing a significant role in compiling this submission have a conflict of interest that influences the information provided in this patient group submission. The Arthritis Society accepts funding from many pharmaceutical companies in order to work towards fulfilling its mission of enabling Canadians with arthritis to live well and be effective self managers and to lead and support arthritis research and care. In order to be fully transparent and meet the request to disclose pharmaceutical manufacturers who have provided support to the organization please be aware that over the past 12 months The Arthritis Society has accepted funding from the following members of the pharmaceutical industry: Abbvie, Amgen, Bayer, Bristol Myers Squibb, Celgene, Eli Lilly, Hospira, Janssen, Merck, Novartis, Pfizer, Purdue, Roche, UCB. The vast majority of The Arthritis Society's funding comes from individual donors as personal charitable giving.

The Society abides by all Canada Revenue Agency and Imagine Canada requirements, and has specific guidelines on advocacy relating to pharmaceuticals that are available upon request.

We have the following **declaration(s) of conflict of interest** with regard to those playing a significant role in compiling this submission: N/A

3. Information-Gathering

A survey questionnaire (August 2016) was promoted via The Society's social media channels to people living with RA. A total of 149 survey responses were received. The vast majority of people who responded to our survey have experienced more than one treatment option. Here is the breakdown from our survey:

- Methotrexate - 93.66% (133)
- Hydroxychloroquine - 69.72% (99)
- Sulfasalazine - 39.44% (56)
- Leflunomide - 28.87% (41)
- Adalimumab - 23.94% (34)
- Etanercept - 23.94% (34)
- Rituximab - 11.27% (16)
- Abatacept - 9.86% (14)

- Tocilizumab - 9.15% (13)
- Infliximab - 8.45% (12)
- Golimumab - 7.04% (10)
- Tofacitinib - 6.34% (9)
- Certolizumab pegol - 4.93% (7)
- Anakinra - 3.52% (5)

Section 2 — Treatment Outcomes

1. What would adult patients, their families, and caregivers like drug therapies for moderate to severe rheumatoid arthritis to achieve?

One of the outcomes for RA drug therapies respondents identified was remission:

- “Remission, improvement to fatigue, reduced inflammation, being able to sleep soundly through an entire night, lessened joint damage.”
- “Remission, but I’m not keeping my hopes up as I know that’s not always how it works out. But I would like to have decreased pain, increased mobility, less stiffness etc. I would like my treatment to make my condition manageable and easier to live with.”
- “Go into remission, and stop the progression of the RA.”
- “Remission and a good quality of life to be able to continue my normal activities.”
- “Remission to halt the joint damage and to enable me to be independent, working and to function without pain.”
- “Ideally I would like complete remission, but with the difficulty of my case I would be happy to just have some improvement that is reliable.”
- “Ideally, I would like to be free of RA. That’s not going to happen. Being kept on an even keel is the next best thing. To have no fatigue would be lovely.”

Respondents identified pain and fatigue management as desired outcomes for RA drug therapies:

- “Minimize fatigue, inflammation, pain and increase cognitive functions.”
- “I truly wish that I could have a few days a week that the pain would be controlled, without a lot of side effects from the drugs.”
- “Mostly pain free, able to do most things. Hopefully not harmful in the long term.”
- “I would love to not be in pain every day and for the fatigue to lessen.”
- “Pain free ...stop my hair from falling out ...”
- “Pain and side effect free to be able to continue an active lifestyle.”
- “Reduction in pain without increased fatigue.”
- “I’d love to have one pain free day. I’ve had increased mobility since beginning the Humira. I am happy with this outcome. However, I still wish for more days where I can function as a normal person. Many times I need to reschedule my plans due to flare ups and/or side effects of meds. Less pain and inflammation.”
- “Something to address the extreme exhaustion, brain fog and depression would be nice.”
- “To relieve all the pain and stiffness and not cause weight gain.”
- “Pain free, able to work and take care of family and self.”
- “Relatively pain free day with little or no side effects. With the ability to do things without suffering later on for your efforts. Plus not to be so tired all the time.”
- “Better quality of life. Efficient pain control. We need better doctor/ patient communication.”
- “To deal with the fatigue and depression.”

Respondents identified less inflammation and stiffness as desired outcomes for RA drug therapies:

- “Less swelling and pain. More function in my joints.”
- “I would like to have decreased inflammation and stiffness. Ideally, I would like to be able to live pain free.”

- “Relief from pain, swelling and stiffness as well as less fatigue.”
- “Able to get through days with less pain and stiffness.”
- “Allow pain free use of my hands. Stop the swelling of joints.”
- “Ideally I want my treatment to ease the pain and inflammation associated with having RA. Treatment would lessen the frequency of major flares.”
- “To experience a full range of motion in my joints and to live pain free.”

Respondents identified preventing joint damage as a desired outcome for RA drug therapies:

- “Prevent future joint damage and keep inflammation and pain to a minimum.”
- “To avoid erosion and pain.”
- “To keep my arthritis under control and hopefully offer some pain relief. I don't want to endure any more permanent joint damage.”
- “To live an active, healthy lifestyle. No degeneration of joints. A cure would be nice.”
- “Just to make me remain well enough to love my life with less pain and no more disfigurement.”
- “I would like my treatment to slow the progression of long term joint damage as well as reduce inflammation for ease of daily activities.”
- “No joint deformity. More mobility. Less discomfort and tiredness.”
- “Would like to stop or limit flares and halt the joint damage already done to my body.”

Respondents identified wanting to feel normal and be able to do activities that others take for granted as a desired outcome for RA drug therapies:

- “To feel normal without harsh side effects.”
- “I want to feel normal and have a full work, social and family life, along with the ability to engage in sports and hobbies.”
- “For me to be able to achieve a quality of life that I remember. Not the same but of good quality. My life is totally different now than before getting RA.”
- “Make me have a normal life. Without pain in my articulation, without regular stomach aches.”
- “I would like my life back. I used to be an active, happy person.”
- “Increased quality of life and mobility which allows me to live a relatively normal existence and which allows me to continue to work and travel. Enjoy my free time.”

Respondents identified affordable, effective treatment options as a desired for RA drug therapies:

- “Effective relief from symptoms and affordable.”
- “I would like for a treatment to be affordable, and be able to treat and manage my disease without creating a whole other slew of symptoms. I don't want to have to ask myself if I want to deal with nausea, vomiting and diarrhea in place of my arthritis. I just want manageability without so many consequences.”

2. If treatment were able to achieve these outcomes, what would it mean for patients', their families', and caregivers' daily activities and quality of life?

Here is the input from our respondents:

- “It would mean getting my life back. It would mean not budgeting my energy so I can complete necessary tasks. It would mean not scheduling my week around a day of being sick from my methotrexate dose. It would mean not being afraid to make plans or cancel plans because my joints are hurting badly. It would mean days without joint pain.”
- “I would be able to do more than just work and sleep. I don't get out to exercise as much as I would like and I miss out on social events due to exhaustion from pain.”

- "I could live the life I want instead of the one I'm forced to have to accommodate my RA."
- "Our lives would have been different. I was so sick with arthritis that I was not the mom I wanted to be and this had a long term effect on my kids and my husband. I was unable to be a caregiver for aging parents and in-laws, and a disabled brother in law."
- "In my work life, my partner said she would never have joined me in our business venture if she had known the effects of RA. In my ideal life, I would be wearing nice shoes, not New Balance orthopedic model shoes, and would have had more success in my work life. I have had 10 operations and at least 500 doctors' appointments all considered, I assure you I could have made better use of all of that time."
- "It would mean more than words can express. I am only 24 and have had to give up so much of my life, and my goals. To get my disease under control after seven years of treatment would give me my life back, and give me hope again."
- "As a new mom it would mean I could get back to exercising, even stroller walks have been difficult as my ankle is still inflamed. It would also help my mood, most days I am good but when things flare my mood sinks as well as my energy and with an 8 month old it makes everything more difficult."
- "Right now, my fiance and I are having to decide whether or not to start a family, due to the challenges we anticipate with my being able to care for children based on the level of pain I am in, and the unpredictability of this disease. If my treatment could eliminate my pain altogether, the major source of stress in my family life would be eliminated."
- "I have been forced to leave work early due to my RA. If my treatment had kept me pain free and feeling well, I would have been able to work longer whereby achieving a better pension. This would have been beneficial to my family for a variety of reasons including ability to help pay for university for my children. Daily activities are totally dependent on how I feel when I wake up. If I have a good night of uninterrupted sleep (10-12 hours), I am able to do more the following day (housework, grocery shopping, etc. are difficult). My quality of life has decreased substantially in the past 10 years. I used to lead a very active work/personal life. Now, I expend most of my effort taking care of myself and trying to get well."
- "Normality! Being able to participate in my children's lives to the best of my abilities. Being a more productive member of society. No restrictions on my work, meaning more opportunities for employment."
- "It would mean a lot as this disease can steal your freedom at times, along with your ability to feel independent."
- "I would be able to help my children in everyday activities. I would not be angry all the time. Living in a chronic state of pain and exhaustion causes a state of little patience. I would love to be able to exercise and enjoy the outdoors without it taking away valuable energy levels and causing even more pain."
- "Pain free life would equal different job opportunities for me."
- "My life expectancy may improve; I could look forward to my future with optimism instead of always preparing for the worst case. I worry I won't be able to help my aging parents when they need it most, meaning even more of a burden on society."
- "I would be able to go about every day activities without help from my parents. I would also be able to finish school and work a full time job."
- "It would be a miracle. It would take away all the stress and inconvenience and frustration that this disease brings."

- "It would mean I could slow down, as now I feel I have to do everything I want to do before I can no longer do anything. I feel harried."
- "I could clean my house. I could care for my grandson. I could be more reliable and be able to work a regular job and contribute to the family income. I could be more active in the community and volunteer."
- "Such a far off goal. I can barely comprehend. It would mean more than anything."
- "Freedom of pain, being able to work full time without having to be careful with bending, lifting, typing (all day). I would be able to look after myself better than I can now, which means being able to cook and clean, and greatly improve my mood!!!!"
- "Quality of life would be much higher; I wouldn't have to rest as often. If the brain fog was addressed, I'd have the ability to concentrate on things longer than a few minutes and remember things!"
- "Resume some or all daily activity, such as standing; walking farther than one aisle in the supermarket (even though assisted by cane or rollator); preparing, cooking and serving meals again; driving easily; being independent; taking beach walks. Just about every facet of my life has been severely diminished."
- "It would mean I could live life without ever worrying my boss would find out I have severe RA."
- "I'm pretty good at acting and put on a brave face so they don't know but for me it would mean an easier life."
- "This would be amazing and I wouldn't have to take 12 pills a day to control pain."
- "I might feel like my old self instead of feeling old. The ability to start something, finish it and not feel it for days."
- "It would mean living an active quality of life, not being hindered in enjoying travel, and continue to do enjoyable activities with family and friends, not being so exhausted that a normal work day means you need to be in bed by the time you get home, and sleeping over the weekends to recuperate in preparation for to get through the next work week."
- "Quality of life would be much improved and allow me to have some semblance of a normal life again. One of the most frustrating aspects of all this has been the stress from not being able to work, and to accept the fact that I am unable to do even the simplest of tasks. I still remember when first being diagnosed the terrible pain and inflammation I experienced. As an example, I couldn't even lift a glass of water, bathe properly, open a door, or even feed myself without someone to cut my food for me."
- "It would mean not having to constantly worry. To be able to do all the simple little things like open a door or go out for drinks with friends (something I am unable to do while on some of these harsh medications)."
- "I dare not hope! It would be amazing."

Section 3 — Lived Experience

1. From patients' experiences outside of clinical trials, are there any notable harms or safety concerns with any of the drugs included in this project?

Methotrexate

- "Methotrexate was discontinued after I was diagnosed with lymphoma."
- "Methotrexate caused infections not to be cured. I developed pneumonia and was hospitalized."
- "Bad gastrointestinal side effects, I only took for two or three months and stopped."
- "Developed chronic ulcerative colitis after taking methotrexate for four months."
- "Methotrexate made me extremely ill with daily nausea and vomiting."

- "Methotrexate causes nausea and sickness which I experienced after the weekly injection."
- "I get nauseous every week when I self-inject methotrexate. I also suffer brain fog for a couple of days."
- "Methotrexate makes me really sick. I spend at least one day in bed after taking this medication."
- "When I was on methotrexate I was extremely ill. I vomited for days after taking the medicine (I was on a bi-weekly dosage). The nausea was extreme taking both pills and injections. I lost so much weight it was unhealthy".
- "Loss of identity - lost 100 lbs. on methotrexate, lost all hair, lost ten teeth, temporary pain relief."
- "I was on for approximately 10 years, first and longest lasting side effect, loss of hair all over the body; stopped due to severe nausea and diarrhea, gross metallic taste in mouth, was on brand for number of years, when changed to generic, problems started as noted above."
- "Methotrexate made me feel horrible all the time and did not give me any relief from any symptoms."
- "Nausea and just having discomfort when giving myself a needle."
- "Methotrexate and plaquenil caused nausea and food sensitivities but I could manage."
- "Methotrexate caused me to feel unwell, lose hair and family planning issues."
- "Pill form methotrexate made me extremely ill. Injectable was fine."
- "Hangover feeling with methotrexate."
- "I get monthly blood work to make sure my blood counts, liver etc. are doing okay while taking the methotrexate. I take my injection on Friday nights and I have side effects for 24-48 hours afterwards. The side effects I get are really bad fatigue, bad headaches similar to migraines and occasionally some nausea but mostly while in a moving vehicle."
- "I was on methotrexate for four years - two years on pills then two years on injections. Yes, it worked but the side effects were terrible. Constant nausea and I got tired of all of that - four years of methotrexate was enough."
- "Hair loss, loss of appetite, weight loss of over 10 lbs., nausea, diarrhea, mouth sores, headaches."
- "No side effects from methotrexate except weight gain."
- "Methotrexate made my blood pressure rise, profuse sweating, scarlet face, irritable, etc."
- "Fatigue, liver damage, constipation."
- "Mouth sores, elevated liver enzymes."
- "I have had liver and bladder problems resulting from methotrexate."
- "Methotrexate did start to attack my liver, but coming off for a while, then lowering the dose returned things to normal."
- "Methotrexate caused liver problems and mouth blisters for me."
- "I developed fatty liver hepatitis from methotrexate."
- "Extreme fatigue, headaches (on injections), hair thinning."
- "Hair loss, ulcers, loss of appetite and energy."
- "Methotrexate gave me a racing heart."
- "I experienced bruising on stomach and legs with methotrexate."
- "My husband didn't like me on Methotrexate. He said my mood changed constantly while being on it."
- "Ten years on methotrexate, and still taking it. No serious side effects to date. Have found it to be extremely effective for my treatment. Diagnosed at 17, almost all joints affected at the time, now effectively in remission."

Hydroxychloroquine

- "Potential damage to kidneys and liver from prolonged use. Plus, the fact of eye damage from use of hydroxychloroquine."
- "Hydroxychloroquine caused stomach bleeding."
- "Had severe constipation and gastric problems after taking hydroxychloroquine for three months."
- "Plaquenil caused me to have dry itchy skin, a rash on my scalp and face but it is getting better with time."
- "I had side effects during the first month of being on Hydroxychloroquine, such as an upset stomach. I haven't experienced any side effects since. I do have to do regular eye/vision checks and visual field testing once a year, I don't have any blood work done for this medication."

Sulfasalazine

- "Very hard on my stomach. I was supposed to take four pills, but I decreased to three. Besides, at four pills, I was having blood loss, as if I was in my period."
- "I was too nauseous on sulfasalazine and stopped it after a couple of weeks."
- "Hives, fever, light sensitivity, and migraines from sulfasalazine."
- "Very toxic yellow looking pee from sulfasalazine."
- "Bad gastrointestinal side effects and headaches from sulfasalazine."
- "Sulfasalazine gave me a rash and massive headaches."
- "Sulfasalazine gave my face a painful rash."
- "I experienced excessive urination and discomfort on sulfasalazine."
- "With methotrexate it's very harsh in the stomach, I really dislike taking it. Sulfasalazine made me gain weight, didn't like that either."
- "Both methotrexate and sulfasalazine have caused nausea for months after starting. Settling down a little now. I have been on them both for about 3 years."
- "No problems so far with sulfasalazine."

Leflunomide

- "Experienced nausea, weight loss, hair loss, chest pain and hot tingling on feet on leflunomide."
- "Difficulty breathing, fatigue, headache when on leflunomide."
- "Discontinued leflunomide and gabapentin due to increased high anxiety and disorientation."
- "Leflunomide caused serious diarrhea that prevented me from working. I stopped this treatment."
- "Leflunomide gave me severe diarrhea and was discontinued."
- "Leflunomide has a side effect of loose stools."
- "Leflunomide gave me severe nausea."
- "In almost two years of taking this medication (leflunomide), mild metallic taste to start, certain foods do not taste the same as before (cabbage and turnip). When changed to a certain generic formulation, the metallic taste increased drastically, taste of regular foods changed, I developed rashes and very loose stools. Went back to the other generic and everything changed back to the way it was."
- "Leflunomide raised my blood pressure."
- "On leflunomide I developed extreme exhaustion, an extreme activity intolerance and shortness of breath."
- "Could not take leflunomide, it made me sick to the point of being bedridden and I missed a week of work."

- "I experienced low white blood cell count while on both methotrexate and leflunomide."
- "Hair loss and rash on leflunomide."
- "My doctor put me on leflunomide and that works great..... I actually feel so much better."
- "I have used all the marked DMARD's mentioned above but got the maximum relief and benefit from leflunomide. My body always opposed methotrexate."
- "No difficulties encountered on leflunomide."

Adalimumab

- "Taking Humira gave me psoriasis like symptoms."
- "On Humira I had demyelination syndrome and pustular psoriasis."
- "I had reoccurring ear infections on Humira. Had to come off of it completely to clear it up."
- "I was in the drug study for Humira and had to be taken out of it as I developed a dreadful cough. Shortly after I stopped using Humira I had a blot clot that went to my brain."
- "Humira left me with tremors."
- "I found the Humira (adalimumab) injection very painful! Otherwise the only concern I have had recently is how sick I was with influenza."
- "Numbness/tingling throughout body then subsided after about a day. Subsequent injections tingling/numbness on left side of body persisted after each injection. Gradually became less noticeable and duration was less. Now, about one year after initial injections slight numbness on left side of face after injection persists. For about three days after injection I am very sleepy and not able to function normally. The rest of the days make up for this as I have greater mobility than I had for many years prior to starting the adalimumab."
- "Humira caused an allergic reaction which became more severe with every injection. Large red welts and itchy skin which started as the size of a grape and increase to over 10 cm in radius."
- "Adalimumab gave me injection site reactions."
- "Adalimumab (Humira) would burn when injecting."
- "Slight allergic reaction at the injection site of Humira."
- "I went into slow cardiac failure and had to cease treatment immediately."
- "Currently taking Humira and it has been a life saver!"

Certolizumab pegol

- "I experienced a rash at the injection site one time."

Etanercept

- "Etanercept (Enbrel) was likely the cause of my pancreatitis."
- "Etanercept and adalimumab both presented me with skin issues."
- "Enbrel and Humira gave me psoriasis like symptoms."
- "With everything I have taken there has been bad reactions other than etanercept."
- "I experience injection site reactions."

Golimumab

- "Golimumab is very recent for me, on four months, so far have not noticed any side effects (taking in conjunction with leflunomide). I do wonder about long term use and what changes may or may not be taking place in my body."

Tocilizumab

- "Raised my cholesterol."

- "On Actemra I developed a low white blood count."

Abatacept

- "Abatacept delayed my healing process a lot. I have a scar from a joint replacement. It took two years for it to heal."
- "I have been on Abatacept (Orencia) for over seven years. Wonderful results."
- "Orencia is the one biologic that works best for me."

Rituximab

- "I had an anaphylactic reaction on rituximab."

Tofacitinib

- "I got gastroparesis on Xeljanz."
- "I got shingles from Xeljanz."

Infliximab

- "Remicade gave me hives and my throat closed over after 8th injection."

Anakinra

- "Methotrexate and anakinra caused lymphadenopathy."

2. Describe any difficulties patients and their families have in using or accessing any of the drugs included in the project.**Access to treatment**

- "I have encountered irreversible damage to my joints because I was not diagnosed early enough. Once I became REALLY sick it took me over a year to get someone to refer me to a rheumatologist. Then I had to fail on all the first line treatments before I could qualify for a biologic. Once I finally could access biologics my life improved immensely. I've been on two so far as I failed one after six years. I'm hoping they continue to work as I now have quality of life and can continue to function independently."
- "Being put on a biologic much sooner would have alleviated years of suffering from having to exhaust the DMARDs first."
- "There is a lot of paper work in receiving Humira and the communication between extended health, government and pharmacies can sometimes be bothersome. They withhold the medication until each agency is satisfied. Therefore, sometimes delaying treatment. Added stress and running around, when you are exhausted and can barely move."
- "Getting access to a rheumatologist can be difficult."
- "My doctor seems reluctant to try me on anything other than the sulfasalazine. I have been taking it for years."
- "I have excellent health care providers. I have friends who drive me into Halifax to the Rheumatology Clinic. A wonderful, caring nurse comes to my home to give me my Orencia."
- "Filling more than a one-month supply of biological when traveling."
- "My infusion is only available one morning each week which provides a challenge to a working person."
- "The only difficulty I can think of is when the drug store changes brand from one to another and it is a different experience."

Geographical access barriers

- “Access to specialists have been hard in my home town. I live on a small island in Canada and it can be hard to see doctors. Medications are also very expensive. My family has insurance, but must pay up front first, which can be expensive.”
- “I live in an area of limited RA specialist care. My rheumatologist left the community. Now I am on wait list for a travelling doctor. Inconsistent care is very frustrating.”
- “The only difficulties I have had in accessing Rituximab is that no one in my city offers the infusions. I have to drive to a city 80 km away to have my treatments. All the biologics are very expensive. I am fortunate to have a drug plan that covers most of the cost.”

Approval process

- “Being required to fail three DMARDs before being eligible for biologics. Waiting extended periods for approval for new drug after adverse reactions to previous drugs.”
- “I needed to wait for special authority from Pharmacare in order to get an alternative to methotrexate.”
- “For a very long time I have had to prove to the government over and over that I still have arthritis and need my medication (etanercept) to have it covered by MSP.”
- “My pharmacy had to special order my medication after already having to wait a week for special approval.”
- “The initial process is cumbersome and many hoops to go through in order to get the necessary coverage. The patient has to be very proactive in order to find out ways to apply for non-group coverage, etc.”
- “Biologics necessitate a special authorization to be covered by insurance.”
- “Takes a long time to get access to new medication with paperwork, insurance, provincial and 3rd party coverage.”
- “Biologic were terrible to try and get approval for. Through family insurance or through disability. The cost and mental woes were unbelievable. Now as an adult who is no longer eligible to be on my parent’s insurance plan, my coverage is terrible. I can’t work because I am physically drained from not being able to purchase the medication that will help me get back on my feet, the emotional side of RA has created such stress on me mentally I have to take anxiety and depression medication, and I feel like it’s not getting any better from here.”

Cost and coverage

- “Just the cost in general. Yes, they do have companies that help pay for the medication but the price is crazy.”
- “The drugs are so expensive. It is crazy to think there are drugs out there that can help control, not cure, the rheumatoid arthritis and yet a lot of us can’t afford them.”
- “There hasn’t really been any difficulties, affordability long term has been the main concern. Finding jobs with benefits isn’t all that easy.”
- “Even with health insurance and annual renewal of government coverage, it’s still hundreds of dollars each month until I reach my deductible. I worry what will happen if I lose my health coverage, like when I retire.”
- “Some of the medications are very expensive and though for the most part have been covered, I have had to pay large sums of money for some of the medications mainly the biologics. Some of my biologics have been IV infusions and I’ve had to travel 1.5 hours to have them.”
- “Expensive. Could not afford it even with extended health benefits through work. Moved provinces where there is more pharmaceutical coverage so I’m okay now. No one ever took the

time to show me how to inject myself. Pharmacy said it was their job, but so did the clinic. Had to use a YouTube video to figure it out.”

- “My current treatment is Enbrel. I was on it for several years in my early teens and saw amazing results. When my father was laid off from his job, I lost my plan coverage and was forced to go without any medication which resulted in about 7 years of extreme pain and joints frequently locking. Now I am on my boyfriend's health plan and my Enbrel is finally covered again and I am doing much better.”
- “I've had challenges every time I've changed jobs. The time it takes to get my insurance coverage in place is never fast enough, and I end up having to pay for at least one-month worth of medication without any coverage. If I didn't have insurance coverage through work, there is no question that I could not afford this medication.”
- “Adalimumab is expensive!! I was able to participate in a study with the drug. The company continued with compassionate care afterwards.”
- “Lack of noticeable benefit to the treatment options was very discouraging. After trying all the required medications before I could start the adalimumab, I finally began to see some benefit. Prior to this I had to discontinue studies at university due to the effects of the disease. Had I been able to access the adalimumab a few years prior, I may have been able to continue my studies. One main difficulty was the cost of the adalimumab as I had no insurance plan. The drug company provided some assistance with adalimumab until the pharmacare deductible was reached. The refrigeration of adalimumab requires extra planning for extended stays away from home. I am concerned about travelling out of country or by plane with this medication.”
- “I had difficulty getting coverage for Cimzia. I flared after having my first child and because I was nursing Cimzia was my best option. Coverage was difficult however because I had never tried methotrexate. It took me over two months to finally access the medication.”
- “My insurer denied Orenzia because I am seronegative. My secondary insurer paid for it.”

Drug Therapy Issues

- “My sister died after two years of having rheumatoid arthritis treatment due to complications.”
- “I now have unexplained infertility. There's no way to know if all these drugs contributed to that - equally there's no way to rule it out either.”
- “One made my white blood count go too low, I had to stop my medications, and ended up off work while waiting for my white count to go back up. I had to switch due to this.
- “There is one thing that is irksome. When I am in a flare my hands are so painful, I have trouble inserting the needle and then depressing the plunger.”
- “I have to inject myself weekly and am only allowed a month supply of injections so means frequent calls to the doctor to get more prescribed. I also have to have monthly blood tests to monitor my levels.”
- “Lots has happened since I was diagnosed at 15. We have gone through many trial and error paths in order to create a balanced point with my RA. The only really difficulty has been trying to mentally make me want to take medications that make me sick but help the disease.”

Section 4 — Additional Information

1. Please provide any additional information related to this project that would be helpful to CADTH. Here are some additional comments from our respondents:

- “I read a research paper called "If it gave me two heads I would have taken it" That sums up my feelings about RA drugs. I live with the after effects of uncontrolled RA and it has been painful and expensive to me and to the healthcare system. I have had numerous surgeries caused by

misdiagnosis, slow treatment and ineffective drugs. The skill of my rheumatologists could not keep this from happening. I had the benefit of treatment from a rheumatologist and a team of AHPs, and it helped me cope, but only effective drug treatment made a difference, and it was often too little or too late. If I had not done my own research on treatments and pushed my doctor to prescribe them I would not feel as good as I do now, even though many would describe my current quality of life as about a 4 out of 10 where 1 is the lowest.”

- “Any of the drugs offered to RA patients are so detrimental to our health. They shorten our life span. They can cause cancer and many other serious side effects. The side effects we do suffer, we do so willingly because life without medication is not a life to wish on your worst enemy.”
- “I am a strong advocate for biologics - my treatment improved exponentially when I started taking Enbrel. I am apprehensive about the potential introduction of generic biologics. I know my current medication works, and if generics are introduced it's likely my current insurance coverage would no longer cover my current biologic - which would then put my current health and quality of life at risk.”
- “Although I take biologics for my RA, I am concerned about the toxic drugs I am introducing to my system. I feel sick to my stomach most days and find it extremely difficult to justify why I am taking them. The cost and the way I feel don't seem worth it. Unfortunately, I have no alternative.”
- “I want there to be more studies on how to understand why the immune system is attacking the body. How to reverse that. I would like to not be in pain and not have to compromise my health by taking all these harsh drugs.”
- “What can be successfully tested and proven within mice cannot be comparable to human children. Please be cautious, these are our lives.”
- “These questions are too basic and too limited for such an important review. Many of these drugs are associated with long term as well as short term health consequences. They frequently result in the need to take other medications (which have their own side effects) for side effects e.g. I am now also on a PPI, stool softener, laxative and folic acid all because of side effects from RA drugs. However, I am sincerely grateful for the progress in RA disease control achieved because of the RA medications. Side effects are the price we pay for trying to control the symptoms and long term consequences of RA (such as heart attack).”
- “Most drugs have risks in long term use. Think long and hard if you are willing to take the risks. I was recently in hospital and my roommate was in the same drug study for Humira. She has been battling lymphoma for the past 5 years and now has an issue with her spleen.”
- “Finding the best RA treatment is hit and miss. It took quite some time to find a drug that fit my particular needs. The RA clinic I go to has the most amazing staff, nurses and doctors. An RA patient can be difficult and demanding at times. Pain does that to you. Orencia has been a God-send! Adding the Arava after a very intense flare in May has been a good thing. Minimal side effects from either one. Headaches I can deal with. I take Tylenol 1 hour before my Orencia IV. works wonders. I will NEVER EVER use methotrexate again.”
- “With close monitoring by health care professionals and education of patients, these drugs are very effective. What is critical is health care professional education and awareness of RA and the need for early intervention. More emphasis on this needs to be applied in curriculums. While there are risks when taking these drugs, they are the only medication that has helped me continue to live independently.”
- “I have found that these medicines make me very sick and have helped me very little.”
- “Strength training and yoga are both useful in minimizing medication consumption. They both help maintain flexibility and movement.”

- "Having gone from being effectively disabled and in pain to getting my life back, completing university, obtaining a good job, and support myself has meant the world to me. The disease is so terrible I'm more than happy to risk unpleasant side effects, if it means I can get my life back and not live in pain."
- "I am putting off trying biologics because of the expense. I am also concerned about the side effects."
- "One problem I have with the medication I take is the amount. I take too many pills for my liking. I wish it could be a combo pill."
- "I have multiple drug allergies which severely limits the drugs I am able to be on for pain relief and for RA treatment. Speaking for myself, if you have been given a brand name drug for your RA, you should be able to keep using it (especially if it works for you). I will say that if I am asked to use a bio-equivalent in place of golimumab, I would refuse outright. I know of several people who are being ruled by their insurance companies, and are being told what they can take, contrary to what the doctor wants them on."
- "I'm lucky that my RA is not severe and seems to be managed ok with plaquenil. When I do flare, what is frustrating is that my rheumatologist will only prescribe steroids and try to get me back on methotrexate. She will not prescribe pain medication, which I hate even to ask for, but some days I can't sleep or move because of pain. I don't even know what pain medications are available to me. What is also frustrating is that no other medications are available to me as I've refused methotrexate. This is not acceptable."
- "I believe that biologic treatment should be available sooner. I had to try many medications before I could be approved for biologic treatment. I think more patients would benefit from biologic treatment without having to try so many medications beforehand. I understand the reasoning behind the process, however there are a lot of patients, myself included, who did not see any or very little improvement until the addition of biologics."
- "I'm just grateful that these drugs are available to me, without them well it doesn't bear thinking about."
- "Possible side effects of these drugs are not always clearly explained and sometimes you end up with even more problems."
- "Quality of life should be considered over the cost of expensive drugs. Since being put on biologics I've gotten my life back."
- "Any side effects are serious and I believe it should be stated that if you have any side effect, whether mild or serious, you should be seen by your rheumatologist and/or family doctor as soon as you can."
- "I felt rushed by my rheumatologist and was never told that if I had to go on antibiotics that I would have to stop methotrexate. Most of my education was done online. More education of patients and better monitoring needed."
- "Early access to biologics in cases of severe RA is definitely a must since I suffered deformities trying all the old medications before being treated with the new biologics."