

CADTH Reimbursement Review Patient Input Template

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|-------------------------------------------------|-----------------------------------------------------------------------------------------------------------|
| Name of the Drug and Indication | Rinvoq (upadacitinib) for psoriatic arthritis |
| Name of the Patient Group | Canadian Association of Psoriasis Patients Canadian Psoriasis Network |
| Author of the Submission | Rachael Manion, Canadian Association of Psoriasis Patients Antonella Scali, Canadian Psoriasis Network |
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1. About Your Patient Group

The Canadian Association of Psoriasis Patients (CAPP) is partnering with the Canadian Psoriasis Network (CPN) to develop this submission.

CAPP (www.canadianpsoriasis.ca) is a national, not-for-profit organization formed to better serve the needs of psoriasis patients across the country. CAPP's mission is to be a resource and advocate for psoriatic patients and their families to improve patient care and quality of life.

CPN (www.canadianpsoriasisnetwork.com) is a national, not-for-profit organization dedicated to improving the quality of life of people in Canada who live with psoriasis and psoriatic arthritis. CPN does this by providing current information on research and treatment options and by working with others to build awareness and advocacy about the complexities of these conditions.

2. Information Gathering

CAPP and CPN collaborated with other organizations to develop a **survey** in English and French using Survey Monkey that asked patients and caregivers about their experiences with the disease and the treatment under review (upadacitinib) – specifically, the Arthritis Society (arthritis.ca), the Canadian Arthritis Patient Alliance (arthritispatient.ca), and the Canadian Spondylitis Association (www.spondylitis.ca). Each organization participated in the development of the survey and shared the surveys with their respective memberships or patient communities via newsletters, social media channels and websites. CAPP and CPN analyzed the data and prepared this submission.

- The surveys were available from December 15, 2020 to January 18, 2021.
- Overall, there were 85 responses to the English survey and 9 responses to the French survey (8 of whom told us in which province they received their healthcare): 10 respondents were from British Columbia (10.8%), 6 from Alberta (6.5%), 3 from Saskatchewan (3.2%), 17 from Manitoba (19.3%), 30 from Ontario (32.3%), 13 from Quebec (14.0%), 3 from New Brunswick (3.2%), 5 from Nova Scotia (5.4%), 4 from Newfoundland & Labrador (4.3%); no responses were received from Prince

Edward Island, the Northwest Territories or Nunavut. Only one response was from someone outside Canada.

- In addition to PsA, 90.7% of 54 respondents (n=49) across the two surveys indicated they lived with psoriasis, 16.7% (n=9) live with another inflammatory condition, 35.2% (n=19) also live with another type of arthritis, and 33.3% (n=18) live with at least one other condition, including fibromyalgia, borderline personality disorder, eczema, Raynaud's syndrome, scoliosis, hypothyroidism, allergies, asthma, high blood pressure and bladder conditions.
- Of the English responses, 50 people provided their sex: 66% (n=33) were female, 32% (n=16) were male and 2% (n=1) preferred to not identify their sex. Of the French responses, 4 people responded they were female.
- Fifty-four respondents provided information about their age across the English and French surveys, which is grouped here for ease of reference: under 26 years old (n=1), 26-34 years old (n=4), 35-44 years old (n=6), 45-54 years old (n=11), 55-64 years old (n=14), 65-74 years old (n=13), and more than 75 years old (n=5).
- There were six responses from people who have experience with Rinvoq (upadacitinib) for psoriatic arthritis (English n=4, French n=2).

Representatives from the four patient groups reached out to clinics that were involved in clinical trials of Rinvoq (upadacitinib) for PsA. One patient interview was conducted by the Canadian Spondylitis Association Executive Director with a female patient who has lived with PsA for 30 years and with psoriasis her entire life. Notes from this interview were shared with CAPP, CPN, CAPA and the Arthritis Society.

3. Disease Experience

Psoriatic arthritis (PsA) is a form of arthritis linked to psoriasis and that is chronic and progressive. This inflammatory disease causes swelling and pain in multiple joints and can sometimes result in **permanent and debilitating joint damage**.

“...j’ai eu un épisode de gonflement et douleur intense à mon pouce droit, j’ai été obligée de changer d’anti inflammatoire car celui que j’avais ne faisait plus effet. La douleur est partie mais je vois bien que l’articulation est plus grosse qu’avant.”

Sixty-two respondents identified aspects of their day-to-day lives and quality of life that are affected by PsA:

| Aspect | Total (n) | Percentage (%) | Aspect | Total (n) | Percentage (%) |
|-------------------------|-----------|----------------|---------------|-----------|----------------|
| Ability to work | 39 | 62.9 | Friendships | 26 | 41.9 |
| Participation in school | 1 | 1.6 | Intimacy | 31 | 50.0 |
| Social connections | 42 | 67.7 | Self-esteem | 41 | 66.1 |
| Parenting | 8 | 12.9 | Mental health | 41 | 66.1 |
| Family life | 30 | 48.4 | Other | 16 | 25.8 |

Specific symptoms of PsA include tendon and ligament inflammation (enthesitis), inflammation of the fluid-filled sheath of a joint (synovium), and sausage-like swelling of an entire digit (dactylitis). The pain and fatigue from this disease can be debilitating. Respondents to the survey emphasized **pain, stiffness, lack of mobility**, and **fatigue** which impact their activities of daily living, their family lives and their ability to work and maintain certain hobbies – it *“impacts all aspects of life from work to sleep to everything in between.”*

“EXTREMELY painful joints. To the point that walking, climbing stairs (to the 2nd floor where the master bedroom was located), etc. was a challenge. Pain killers and NSAIDs were a minimal daily requirement just to get out of bed and make it through the day... Sometimes not being able to go to work because of

the pain. When I was first diagnosed with PsA, my son had just been born. I was not even able to do what many fathers do, and take for granted, and that was hold my son up over my head with my arms, smiling up to him as he would be laughing down to me... That was almost 30 years ago. My son passed in March of 2019 and to this day, I still regret not being able to do that simple thing, that "[rite] of passage"... Holding my infant so up in the air. PsA took that from me..."

"Pain in all joints used 5-120 minutes in a day progressively worse during the day. Need to take frequent rests to recharge with bed rest being most beneficial. One or two days with more physical activity than my joints can handle can cause the rest of the week's pain to be worse until I take my dose of methotrexate and begin recovery mostly from bed. My day to day plans are dictated by what I can handle. Planning on going out usually requires leaving chores and other physical activities out the day before and after driving to town and back for more than 4 hours round trip for example. I feel like a quarter of my former self in terms of quality of life."

"First flare (diagnosis) it affected my knee, huge swelling, red, hot skin, extreme pain where I could not put weight on the leg. Second flare was knee & ankle. Same as before: whole leg from just above knee down swelled, red & hot, again no weight bearing. Third flare took out knee, ankle & foot. With same as before. Even with the biologics I am on, I still experience pain most days & find I am tired a lot. I make it through my work day & pretty much am exhausted by the time I return home. Living with the pain & fatigue is a constant part of my life now as is the constant fear of a medication failure. Not being able to participate in a lot of this game with family & friends is also frustrating. I find myself sad a lot these days too."

"Use of my hands is very painful. I have trouble peeling potatoes, carrots, etc. and continually drop items. My feet are painful, but have been helped with an immune suppressant. Unfortunately, I feel nauseated and [have] other side effects."

"Wrist pain prevents me from certain forms of exercise. Fear of injuring joints prevents me from engaging in certain activities. I have general joint laxity which also prevents me from doing certain activities or pursuing some career options."

« Douleurs aux articulations des doigts et orteils. J'aimerais aller prendre des marches mais la douleur est trop intense. J'essaie de tricoter et c'est difficile. »

"Pain in lower back, swelling and pain in fingers that cause a great deal of stress, especially as a musician."

"I no longer can work as a band teacher. Tendons in fingers hands and wrists pain too much to play and/or conduct. On disability pension due to PSA."

Mornings and cold weather can exacerbate the situation: "Weakness in hands in the morning and cold weather. Aching and discomfort."

"Extreme stiffness in the a.m. preventing me from walking without horrible pain. I end up crawling up the stairs from our downstairs bedroom. Lower back pain is constant. Stiff hands make writing difficult."

Some patients describe experiencing a **"brain fog" or forgetfulness**, which is frustrating and demoralizing.

"I'm 35 years old. My symptoms are a roller coaster. Some days I almost feel like my old self and other days can be very difficult. At its worst, I can't physically get out of bed without help, can't dress myself and want to stay in a quiet dark room to preserve my energy and just get through the day somehow. Since my diagnosis, I've been trying to maintain a 4 day work week with a lightened work load. I've been one of the lucky ones as I've had a lot of support at work and they have been trying to make my job manageable, but sometimes it's very hard even then. I used to be one of the top performers in my company, and now I feel like I'm bottom of the barrel. I worry that my work and coworkers' patience has a limit, and eventually I'll be seen as detrimental vs an asset. I find myself profusely apologizing for something that is out of my control. My inflammation moves around my body from my toes, feet, knees, lower back, hips, back ribs, Costochondritis, shoulders, elbows, wrists, hands, fingers and ligaments in my arms, shins and Achilles' tendon. I also have suffered from brain fog, which I think has been just as debilitating, if not more so than the physical pain. When I have brain fog it makes me feel intoxicated, I've said things I wouldn't normally say out loud, my memory can be greatly affected, I've stuttered, forgotten what I wanted to say or words to things. You feel like you're going out of your mind, like you're getting Alzheimer's and it's terrifying. I've

had days I have had to be driven as I was afraid to operate a vehicle. Besides this affecting my work life, it's affected my social life. Sometimes even just sending a bunch of texts feels too taxing and I just lack energy. I miss exercising properly and breaking a sweat. Usually all I can manage is a walk around my block with a cane before my knees feel too stiff and swollen. I'm still grateful I can do that, but I miss horseback riding, barn chores and riding my bicycle. You feel like you're alive when you push your body enough to break a sweat. I'm lucky that I still live with my mom who can help with everyday house chores and cooking, otherwise I'm not sure how I would cope."

Patients living with both psoriasis and PsA have to manage the symptoms and impacts of both diseases, which creates greater strain on their mental health and reduces their expectations of a safe and healthy future.

"Aside from the psoriasis itself and how ugly it is, I have arthritis pain mainly in my hips, knees and feet. Right now I find it difficult to walk because of the pain in my heels. Sometimes I get arthritis pain in my breast bone and it feels like I'm dying. I sometimes get it in my shoulders or neck or back as well. My hands come and go but at one point they were so bad I couldn't hold a pen. I certainly have zero desire to find a romantic partner because I don't want anyone seeing me naked because of the psoriasis. I find I am forgetting words a lot, not sure if that's related to the PsA but it makes me feel stupid. I don't have the energy or ability to work a full time job. I can't get income assistance. My doctor has sent in a form for provincial disability and I've been waiting for word for some time but so far nothing. Some days I feel hopeless. I am definitely in pain all the time it just varies in intensity. I can't really go out and do things for more than a couple of hours without becoming exhausted. On the rare, pre-Covid times when I'd take a day trip somewhere, it would wipe me out for the next couple of days. There is zero financial support for someone in my situation and if I end up homeless and on the streets at some point, I won't be surprised at all."

"Fatigue - makes it difficult to engage in activities that provide quality of life; I have recently had to retire from my professional work because of fatigue; I was a professional in private practice with no safety net for such eventualities. Pain in various (variable) joints and areas of soft tissue - interferes with social functioning and physical functioning; often feel frustrated when the pain interferes with me engaging in activities (such as snowshoeing, walking, skiing, etc.) that bring me joy. Skin problems - is embarrassing; I have often been the target of people's rude comments about my appearance which is demoralizing. Depression - side effect of living with the above"

4. Experiences With Currently Available Treatments

Patients living with psoriatic disease often try a succession of treatments throughout their lives: because of the inflammatory nature of the diseases, treatments that are initially effective can become less effective over time. Patients often describe to CAPP and CPN feeling nervous that they will run out of treatment options as their diseases progress, and they will be left with the significant and debilitating symptoms of uncontrolled psoriasis and psoriatic arthritis.

It is important to note that many people who live with PsA also live with psoriasis. As some drugs are indicated for both diseases, it is not uncommon for people to have some experience taking a treatment indicated for PsA for their psoriasis and vice versa. For patients who take treatments for their psoriasis, these same treatments can but do not always adequately manage their PsA.

"I am on Taltz, [the] only drug he found worked well for skin and arthritis."

"My biologic for psoriasis helps PsA perhaps 10 to 20%."

"I take Naproxen, but they switched me to meloxicam, I feel awful on it, it bothers my stomach!! I was on Otezla, it helped my ear and scalp psoriasis, but did nothing for my psoriatic arthritis, for joint pain, enthesitis, plantar fasciitis, etc!"

"Taking Cosentyx has cured the skin completely of psoriasis. The damage still exists in my spine and hands with stiffness and pain."

"Enbrel worked very well for arthritis but not skin."

Disease-modifying antirheumatic drugs (DMARDs) are a well-known and often-used treatment for PsA,. Respondents (n=54) had experience with DMARDs both alone and in combination with methotrexate:

apremilast (18.5%; n=10), methotrexate (74.1%, n=40), azathioprine (0.02%, n=1), cyclosporine (13.0%, n=7), hydroxychloroquine (13.0%, n=7), leflunomide (Arava) (14.8%, n=8), sulfasalazine (22.2%, n=12), and salazopyrin (0.04%, n=2).

Existing PsA treatments vary in their effectiveness, according to the patients surveyed:

| Treatment | Very ineffective | Mildly ineffective | No difference in symptoms | Mildly effective | Very effective |
|------------------------------------------------------|------------------|--------------------|---------------------------|------------------|----------------|
| Non-steroidal anti-inflammatory drugs (NSAIDs); n=53 | 37.7% (20) | 5.7% (3) | 18.9% (10) | 35.9% (19) | 1.9% (1) |
| Disease-modifying antirheumatic drugs (DMARDs); n=44 | 25.0% (11) | 11.3% (5) | 15.9% (7) | 36.4% (16) | 11.4% (5) |
| Leflunomide; n=15 | 40.0% (6) | 0 (0) | 46.7% (7) | 13.3% (2) | 0 (0) |
| Apremilast; n=11 | 54.6% (6) | 0 (0) | 18.2% (2) | 27.3% (3) | 0 (0) |
| Tofacitinib; n=7 | 71.4% (5) | 0 (0) | 28.6% (2) | 0 (0) | 0 (0) |
| Hydroxychloroquine; n=10 | 50.0% (5) | 10.0% (1) | 30.0% (3) | 0 (0) | 10.0% (1) |
| Biologics; n=36 | 22.2% (8) | 0 (0) | 5.6 (2) | 22.2 (8) | 50.0 (18) |
| Steroid injections; n=26 | 30.8% (8) | 7.7% (2) | 15.4% (4) | 30.8% (8) | 15.4% (4) |
| Oral steroids; n=19 | 42.1% (8) | 5.3% (1) | 15.8% (3) | 31.6% (6) | 5.3% (1) |
| Medical cannabis; n=22 | 18.2% (4) | 0 (0) | 9.1% (2) | 36.4% (8) | 36.4% (8) |

Some patients also tried naturopathic interventions and found some improvement - *“helped with fatigue...yoga and meditation have helped with mental health side effects”* - but *“not with other symptoms”*.

Non-steroidal anti-inflammatory drugs (NSAIDs) can have a helpful effect but it may not last: *“NSAIDs cover the pain but I feel worse after activity and using them.”* One patient reported using naproxen when they flare *“1-2 a month. I am reluctant to take too frequently as it causes digestive issues.”* Others also reported negative effects on other organs: *“I cannot use NSAIDs because it does damage to the kidneys and my levels were below normal on them. After going off one year my levels are normal now.”*

Many patients have experience with **disease-modifying antirheumatic drugs (DMARDs)**. Several respondents had experience with **methotrexate** and noted a variety of side effects, including nausea, raised liver levels, headaches, sore mouth, being *“bedridden with debilitating fatigue for days after each shot”*, *“worsening my brain fog”* and *“feeling ‘worse’ on it in other ways”*:

“I’ve only tried methotrexate and am currently on it. It manages my PsA quite well but I’m still susceptible to joint injuries and cuts and abrasions can still lead to new psoriatic lesions. The side effects I get are poor sleep, nausea, poor balance, mental fog, runny stool, flatulence, and some GI discomfort. The needs not being met by methotrexate are that it doesn’t completely put my arthritis into remission and it doesn’t completely eliminate my psoriatic lesions. Wishful thinking, I know.”

“Methotrexate gave me the most benefit but the 3 days after taking the dose I am weaker, require more naps and I am less tolerable to activity and my eyes are sore.”

The side effects of **sulphasalazine** were noted by several respondents: *“I had fever, chills, a horrible hot tingling rash and fatigue, ended up going off all medications including my anti-inflammatory. So I spent 2 weeks [with] no medications and my pain increased more and more each day till I was able to resume my anti-inflammatory.... My PsA remains uncontrolled.”* Its benefits can be offset by its impact on mood: *“sulphasalazine almost cost me my marriage due to mood swings”*.

Cyclosporine was also noted to impact other organs: *“When I took cyclosporine my kidney function became a problem. I have not been able to achieve comfort with any treatment.”* **Hydroxychloroquine**

(Plaquenil) worsened one respondent's tinnitus. **Leflunomide** was noted by one respondent to *"kill my appetite and I lost 30 lbs so that's cool."*

Some respondents noted that **apremilast** (Otezla) helped their psoriasis but did not improve their PsA, and had challenging side effects, including increased heart rate, nausea, depression and moodiness, diarrhea.

Some respondents had experience with oral **steroids** and steroid injections: *"Steroids seem to give me a false sense of strength that ends up hurting me more when I come off it."*

"The effects of the steroid injections really didn't last long, max 2-3 months, and I have residual injection site sensitivity to this day on my ankle."

Several respondents also had experience with different **biologics** but the benefits do not last forever: *"The biologics do a good job until they fail. Then the search is on for the next one that will work."* One respondent noted that he or she is *"on my 5th biologic since 2007"*.

Despite the variety of medications available to treat PsA, some respondents noted **there remain unmet needs**: *"Needs that aren't met by these treatments include the ease of consumption/tolerance, largely due to their uncomfortable side effects."* Unmet needs can be particularly acute for **women**: *"I spent over 10 years fighting for help for my pain and being told that it was because I was overweight. As a woman we are often dismissed and our pain is not considered valid. ...The treatment helps but other needs that are not being met are the chronic pain..."*

Many patients noted the challenges they face seeing their specialist, and the costs of many available medications (e.g. biologics).

5. Improved Outcomes

Patients living with PsA – and living with both PsA and psoriasis – already experience a raft of side effects from available medications, and generally expressed that they have "had enough of them" and would not be willing to accept more or serious side effects from a new medication. There was specific concern about a compromised immune system, especially during the COVID-19 pandemic. One respondent also expressed concerns about not being able to take live vaccines. Ultimately, they *"don't want to be sicker."*

There are many outcomes patients wish to see in a new medication, foremost among them remission of PsA, improvement in psoriasis (if they are also living with this disease), better pain management, improved mobility, reduced episodes of flares, reduced fatigue, and a longer period of effectiveness than often experienced by patients with existing treatments.

"Given that this is an oral treatment option, I can see this greatly increasing quality of life for PsA patients who struggle with dealing with the pain and hassle of injection-based medications. Oral medications are much more convenient to take and store, but typically don't have the same powerful, specific efficacy of biologic medications which typically come closer to targeting the "root" of the issue and not just the symptoms. ... If the side effects greatly impede everyday life (nausea, fatigue etc), then I would say that I personally would not be keen to take this medication. However, if we're talking more about "potential risks" such as suppressed immune function leading to increased risk of infection, etc. - I already take that risk with adalimumab, but it would be nice to see data comparing the two on this metric. That's also something to consider given the current state of the pandemic and risk for immunocompromised patients. I would hope that this medication would allow patients to achieve near complete remission from their conditions."

"I would hope it would not have side effects and I wish it would work on my psoriasis as well as my arthritis. I would hope to gain more confidence in my appearance (psoriasis plaques lessened) so that I would desire to be more social. Being more social would get me out of the house and more active which would help with the everyday aches and pains of arthritis. It's all linked....you cannot separate the arthritis and the psoriasis. They work together against the body and mind unfortunately."

"I would expect it to alleviate symptoms, maybe not completely but very well. I would NOT accept serious side effects. If the side effects are serious, what's the point? Your life will be horrible with or without it. I

would want a good medication to both clear up the psoriasis and lessen the arthritis pain/brain fog so I could live a normal life.”

6. Experience With Drug Under Review

As stated previously, there were six responses from people who indicated that they have experience with Rinvoq (upadacitinib) for psoriatic arthritis (English n=4, French n=2).

Of these survey respondents, five provided their sex (3 female; 2 male) and five provided their age which ranged from 38-75 years old. Four of these respondents were from Manitoba and two were from Quebec. Five indicated that they live with psoriasis. In addition, one lives with another form of arthritis; one lives with another inflammatory condition; and one also lives with borderline personality disorder. Five of the six respondents who have experience with Rinvoq (upadacitinib) indicated that they have used DMARDs.

When asked about their **positive and negative experiences with Rinvoq (upadacitinib)**, they noted:

“Only negative as mentione[ed] before is feeling of being cold all the time. I have had 80-90% relief of pain.”

“It has helped a lot with my pain and joint swelling, I really haven’t noticed any side effects. It’s definitely better than the injections I take, I hope that taking this now will prevent worsening problems on my joints as I age. It makes day to day easier and less painful.”

“All positive no negative. 100% better than any other meds so far...I think not having as much pain is great for long term and quality of life.”

“Joint pain and swelling significantly reduced. Psoriasis is also reduced in most areas.”

« Le Rinvoq est un comprimé pris à tout les jours cela m’a permis d’avoir une qualité de vie bien meilleure. Mon psoriasis a arrêté complètement et j’ai des beaux ongles. La douleur est vraiment minime et mon arthrite est contrôlé. Les effets secondaires sont très faibles. »

« Aucun effet secondaire et disparition des douleurs et des lésions cutanés. »

When asked about the **impact of Rinvoq (upadacitinib) on caregivers and their family** and their day-to-day activities, these six respondents answered:

“Yes. I am able to move more freely and exercise more often.”

“No, I don’t need assistance with these things.”

“Some definitely.”

“Greater self-esteem and easier to get around.”

« Oui, j’ai plus d’énergies pour effectuer des activités avec mon conjoint. J’ai eu du soutien de la part de mon conjoint, il fait les courses. Le soutien de l’équipe du centre de recherche a été très importante pour moi, mes angoisses et mes peurs face à la maladie. »

« Mon arthrite n’était pas très actives sauf des lésions cutanés au pieds mais après 10 jours de prise du Rinvoq tout a disparue et aucune limitation pour mener une vie active. »

As mentioned above, one interview was conducted by the Executive Director with a female patient who has lived with PsA for 30 years and with severe psoriasis her entire life, who also had experience with Rinvoq (upadacitinib) through a clinical trial. Her PsA caused pain and reduced her mobility to the point that she had to retire from her job as a truck driver, which she loved. Her wrist mobility in particular was very impacted by PsA. Her psoriasis covered 87% of her body and led to a life being covered up, not showing her skin in public despite the fact that the sunshine helped with her skin lesions. As well, her toenails were not attached to the nail bed. She was bullied about her skin throughout her life. Both diseases impacted her relationship with her boyfriend.

Her past medication history included methotrexate, “every topical under the sun”, and a couple of biologics that she injected but that were not effective for her.

Her experience with Rinvoq (upadacitinib) was positive: within two weeks after beginning treatment, she was able to walk around her home without walking aids and her pain was significantly better. Her skin was almost entirely clear with the exception of a couple of small spots. Within four weeks, she was able to walk outside without walking aids which was something she was not previously able to do. Her nails began to grow properly again, allowing her less pain and enabling her to wear close-toed shoes. She noted no side effects, despite previously being very prone to them and unable to tolerate other medications. She also commented that as an oral medication this form of treatment was less of a reminder of her diseases than when she used injectable medications.

She has been able to return to work part-time in another capacity (driving and supervising young clients) and she is hoping to go back to full-time work after the COVID-19 pandemic. She feels better than she has in the past 30 years and her relationship with her boyfriend has also improved. Her confidence has improved and she is no longer afraid to be out in public and around friends. She commented that for her, this drug is life-altering, has given her freedom, and she can't believe how much she can move around and not be in pain all the time.

7. Companion Diagnostic Test

Not applicable.

8. Anything Else?

Like psoriasis, PsA is complicated, frustrating and can be debilitating without access to appropriate treatments. Patients are very different in how they react to changes in lifestyle, topical treatments and biologics. What works for one patient, may not work for the other, even if their symptoms are very similar.

Yet, PsA is a disease that often “falls through the cracks.” Some patients are seen by a dermatologist while others are seen by rheumatologists. Joint pain is not always discussed with a dermatologist and plaques on the skin are not always discussed with rheumatologists. These challenges often lead to delays in diagnosis and consequently severe and irreversible damage to the joints.

It is still not clear which individuals who have psoriasis will get PsA. Roughly 30% of people with psoriasis will develop PsA. Both diseases are caused by the immune system being inappropriately activated. Most of the time (80%), psoriasis comes first but it remains difficult to predict whether a person living with psoriasis will later develop PsA, despite research advances that have identified a number of biomarkers associated with PsA and advances in developing predictive screening tools¹.

All patients are looking for a treatment that will control all of their symptoms but ultimately they would like a cure to this debilitating disease. Earlier treatment of PsA can result in better outcomes and reduce the risk of permanent and debilitating joint damage. PsA is also linked with an increased risk of cardiovascular disease, specifically atherosclerotic disease (low grade inflammation in blood vessels). Controlling inflammation can reduce the risk of PsA patients later developing heart disease.²

¹ Eder, L. et al., The Prediction of Psoriatic Arthritis Tool (PRESTO) Study – Interim Report, American College of Rheumatology Convergence 2020 conference, online: <https://acrabstracts.org/abstract/the-prediction-of-psoriatic-arthritis-tool-presto-study-interim-report/>.

² Eder, L. et al. Cardiovascular Diseases in Psoriasis and Psoriatic Arthritis, The Journal of Rheumatology Supplement June 2019, 95 20-27; DOI: <https://doi.org/10.3899/jrheum.190114>

Appendix: Patient Group Conflict of Interest Declaration

To maintain the objectivity and credibility of the CADTH reimbursement review process, all participants in the drug review processes must disclose any real, potential, or perceived conflicts of interest. This Patient Group Conflict of Interest Declaration is required for participation. Declarations made do not negate or preclude the use of the patient group input. CADTH may contact your group with further questions, as needed.

1. **Did you receive help from outside your patient group to complete this submission? If yes, please detail the help and who provided it.**

No.

2. **Did you receive help from outside your patient group to collect or analyze data used in this submission? If yes, please detail the help and who provided it.**

CAPP and CPN collaborated with other organizations to develop a survey in English and French using Survey Monkey that asked patients and caregivers about their experiences with the disease and the treatment under review (upadacitinib) – specifically, the Arthritis Society (arthritis.ca), the Canadian Arthritis Patient Alliance (arthritispatient.ca), and the Canadian Spondylitis Association (www.spondylitis.ca). Each organization participated in the development of the survey. CAPP and CPN analyzed the data and prepared this submission.

3. **List any companies or organizations that have provided your group with financial payment over the past two years AND who may have direct or indirect interest in the drug under review.**

| Company | Check Appropriate Dollar Range | | | |
|------------------------------------|--------------------------------|-------------------|--------------------|-----------------------|
| | \$0 to 5,000 | \$5,001 to 10,000 | \$10,001 to 50,000 | In Excess of \$50,000 |
| AbbVie Canada | | | X | |
| Amgen Canada | | | X | |
| Bausch Health | | | X | |
| Boehringer Ingelheim International | | | X | |
| Eli Lilly Canada | | | X | |
| Janssen Canada | | | X | |
| LEO Pharma Canada | | | X | |
| Novartis Canada | | | X | |
| Novartis Global | | X | | |
| UCB Canada | | | X | |

I hereby certify that I have the authority to disclose all relevant information with respect to any matter involving this patient group with a company, organization, or entity that may place this patient group in a real, potential, or perceived conflict of interest situation.

Name: Rachael Manion
 Position: Executive Director
 Patient Group: Canadian Association of Psoriasis Patients
 Date: January 28, 2021

| Company | Check Appropriate Dollar Range | | | |
|------------------------------------|--------------------------------|-------------------|--------------------|-----------------------|
| | \$0 to 5,000 | \$5,001 to 10,000 | \$10,001 to 50,000 | In Excess of \$50,000 |
| AbbVie Canada | | | | X |
| Amgen Canada | | | X | |
| Bausch Health | | | X | |
| Boehringer Ingelheim International | | | X | |
| Eli Lilly Canada | | X | | |
| Janssen Canada | | | X | |
| LEO Pharma Canada | | | X | |
| Novartis Canada | | | X | |
| Pfizer Canada | | | X | |
| UCB Canada | | X | | |

I hereby certify that I have the authority to disclose all relevant information with respect to any matter involving this patient group with a company, organization, or entity that may place this patient group in a real, potential, or perceived conflict of interest situation.

Name: Antonella Scali
Position: Executive Director
Patient Group: Canadian Psoriasis Network
Date: January 28, 2021