

# BARING IT ALL:

Final report from a survey on reproductive and sexual health in women+ with inflammatory arthritis, rheumatic, and psoriatic diseases





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# EXECUTIVE SUMMARY

## OVERVIEW

Inflammatory and rheumatic conditions are chronic diseases that have devastating and debilitating effects on the lives of approximately 6 million Canadians. Psoriasis is estimated to impact the lives of up to one million people in Canada.

The onset and diagnosis of inflammatory arthritis, rheumatic and psoriatic diseases commonly affects people in the prime of their lives, most often between the ages of 30 and 50 for most rheumatic conditions and either between the ages of 15 and 30 or 50 and 60 for psoriasis. About three in 1,000 Canadian children have Juvenile Idiopathic Arthritis (including spondyloarthropathies), often impacting them well into adulthood. Nearly 3 in 5 people (58%) who reported having arthritis in 2007-2008 were younger than 65 years of age. These individuals are often left with a variety of reproductive and sexual health-related concerns related to contraception, menopause, family planning, and parenting.

For many reasons, female-identifying individuals who live with these conditions—including rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis, enteropathic arthritis, undifferentiated arthritis, and psoriasis—have unique reproductive and sexual health considerations and needs. For a full list of the conditions that participants live with, please see Demographics.

Individually, work has been undertaken by the Canadian Arthritis Patient Alliance (CAPA), the Canadian Association of Psoriasis Patients (CAPP), the Canadian Psoriasis Network (CPN), and the Canadian Spondylitis Association (CSA) to address concerns and develop educational resources for these communities. However, no broad or coordinated effort has been taken to address the range of reproductive health issues across the life course for people living with inflammatory arthritis, rheumatic, and psoriatic conditions. To address this gap, CAPA, CAPP, CPN, and CSA have embarked on a two-phased project to address the sexual health and reproductive concerns of people living with inflammatory arthritis, rheumatic and psoriatic diseases who identify as female (women+).

Phase one, the **Women's Sexual and Reproductive Health Survey**, was co-developed and launched on International Women's Day 2021 with the goal of eliciting a stronger understanding of patients' experiences and identifying information gaps across different stages of life. Women+ were asked about their experiences and insights about contraception, family planning, menopause, sexual health, and parenting. The intent of the survey was to be inclusive of the LGBTQ2S+ community. The following report presents the results of this survey and lays the groundwork for the second phase of the project, which will focus on developing tools and educational resources to raise awareness and to facilitate dialogue about the reproductive and sexual health experiences and needs of women+ living with rheumatic, inflammatory, and psoriatic diseases.



## UNDERSTANDING THE ISSUES

The results of this survey highlight many of the shortcomings related to access to information about reproductive and sexual health for women+ living with rheumatic, inflammatory, and psoriatic conditions. In particular, results indicate that there is a high need for information when making decisions regarding reproductive and sexual health, but access to reliable resources and informed discussion is lacking.

The core issues identified through the survey were:

- Varying levels of comfort discussing reproductive and sexual health with healthcare providers, romantic partners, and support networks;
- Disparities in information regarding reproductive and sexual health at different stages of life (i.e., contraception, pregnancy, parenting, menopause, etc.); and
- A general lack of informed discussion or resources regarding the effects of inflammatory arthritis, rheumatic and psoriatic disease diagnosis, treatment, and maintenance on reproductive and sexual health, and vice versa.

The resultant gap of information, has several impacts on women+ with inflammatory arthritis, rheumatic, and psoriatic conditions, resulting in:

- Uncertainty surrounding reproductive and sexual health;
- Communication barriers that leave women+ feeling disempowered and unable or unwilling to engage with their healthcare teams and support networks in a robust discussion about how their condition is impacting—and impacted by—their reproductive and sexual health; and
- Increased pressure and responsibility placed on women+ to be the coordinator and facilitator of their own care without adequate support to make informed decisions, which increases the possibility of adverse outcomes.

## ADDRESSING THE ISSUES: OUR RECOMMENDATIONS

Based on the findings of this survey, CAPA, CAPP, CPN, and CSA make the following recommendations:

- 1) Destigmatizing reproductive and sexual health in women+ living with inflammatory arthritis, rheumatic, and psoriatic conditions is critical. Sexual and reproductive health is part of a holistic approach to patient care and must be included in discussions about care, treatment, and support. We recommend that patients, healthcare providers, romantic partners, and support networks raise these topics in conversations about these diseases early and often.
- 2) Patient education resources must be available to women+ with inflammatory arthritis, rheumatic and psoriatic conditions, their care teams, and support networks, focused on:
  - a) How to communicate effectively with healthcare providers, romantic partners, and loved ones about reproductive and sexual health needs and concerns.
  - b) How to navigate reproductive and sexual health at different life stages (i.e., contraception, family planning, parenting, menopause, etc.).
  - c) The impacts of medications on sexual and reproductive health of women+ and the health of children born to or parented by women+ living with these conditions.
  - d) The role of mental health and wellbeing as an aspect of sexual health and living with inflammatory arthritis, rheumatic, and psoriatic conditions.
- 3) Rheumatologists and dermatologists should counsel patients about the impact of medications and other treatments on reproductive and sexual health early in their disease journey and regularly to ensure patients can make informed decisions.
- 4) Researchers should consider the sex and gender impacts of access to care, medication safety, mental health, parenting and aging and within racialized communities and the LGBTQ2S+ community to ensure that women+ have the best evidence to inform decision-making.

While further research is warranted, implementing these measures will help increase patients' engagement in their own care and provide them with more comprehensive support to navigate the complex and chronic nature of inflammatory arthritis, rheumatic and psoriatic conditions.

This report provides the groundwork for education, awareness, and resources about reproductive and sexual health in women+ with inflammatory arthritis, rheumatic, and psoriatic conditions, and can inform research in the field of chronic inflammatory conditions.



# UNDERSTANDING SEXUAL AND REPRODUCTIVE HEALTH

Even though sexual and reproductive health is an important aspect of health and wellbeing, people who identify as female (women+) with inflammatory arthritis, rheumatic, and psoriatic conditions struggle to talk about these issues. Open communication about these issues is essential to ensuring that women+ have adequate information and options to manage their health. Through the survey, we found that there were varying levels of comfort in speaking with healthcare providers, romantic partners, and their support network about sexual health.

## DISCUSSING SEXUAL AND REPRODUCTIVE HEALTH

Overall, 63% of participants indicated they can discuss sexual health with their healthcare provider, but only 48% indicated they felt comfortable doing so. In some communities in Canada, these numbers were lower: only 54% of participants from Quebec indicated that they could speak to their healthcare provider about sexual health. For younger patients, these numbers were lower yet: participants under 30 across Canada indicated that they were less comfortable discussing sexual health issues with their healthcare provider (39%) than other age groups and that they did not have enough information about sexual health and their condition (21%).

Over 70% of participants indicated that they can discuss the impact of their condition on their sex life with their romantic partner. A lower number of participants in the Atlantic provinces indicated they can discuss the impact of their condition on their sex life with a romantic partner (41%). Just under half (47%) of participants noted they do not have someone to talk to about how their condition(s) affect their intimate relationships. For older women+, this number dropped dramatically: only approximately one-third of participants over the age of 50 indicated that they had someone to talk to other than their healthcare team (40%).

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*“(I want information on) how to discuss intimacy with my partner—not enough on this and it’s a difficult conversation. (I want more information on) accessing sexuality educators and counsellors.”*

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*“(I want) Information for significant others/ couples—maybe a page that is targeted toward partners of those with AS/other conditions, to help them understand that a good sex life is still possible but there are some adjustments that may need to be made.”*

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*“I actually have alopecia universalis and that is the illness that has completely destroyed my self-image etc. PsA causes pain etc but the trauma and loss of self is from alopecia.”*

## RECEIVING INFORMATION ABOUT SEXUAL AND REPRODUCTIVE HEALTH

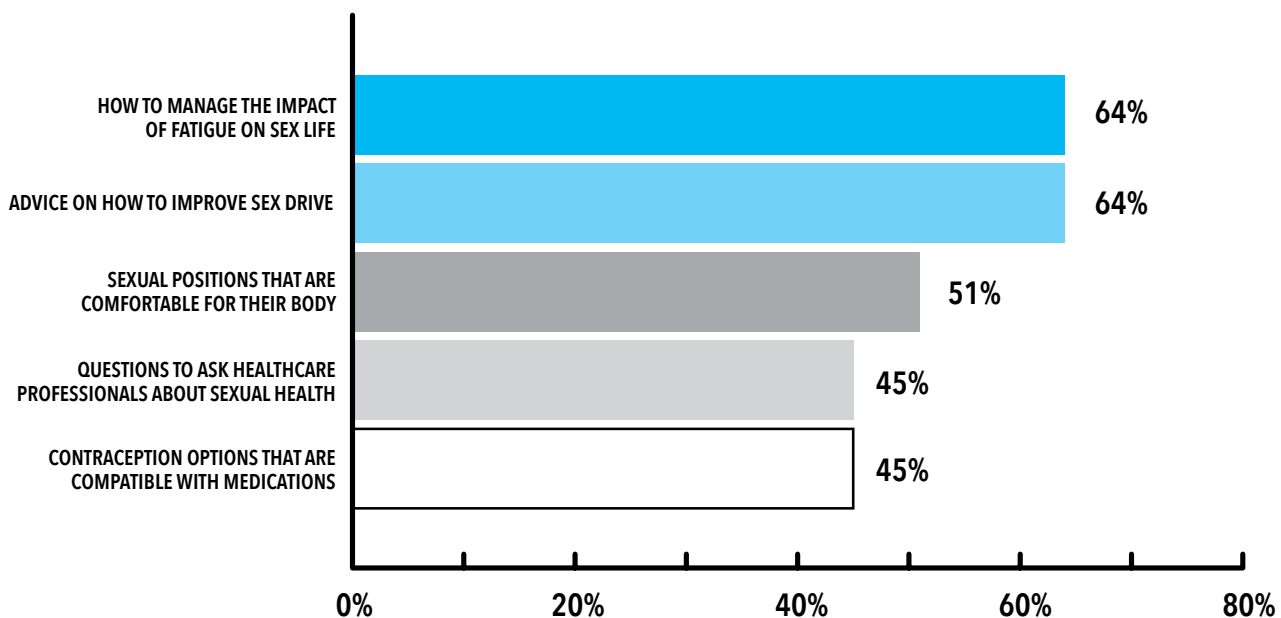
Research studies have found that women+ desire more information about medication safety related to fertility, pregnancy, and breastfeeding ([Rebic et al, 2021](#)). In practice, this appears to be a persistent barrier to comprehensive care for women+ with inflammatory arthritis, rheumatic, and psoriatic conditions.

This survey revealed that women+ receive less information about their sexual and reproductive health than they need. Over 60% of participants indicated that they did not have enough information about sexual health and the impact of their condition(s). Only 33% of participants indicated they had enough information about the impact of their condition(s) on their sex life. For some communities, this was even lower: 29% of participants in British Columbia, 25% of racialized communities, and only 17% of participants under 30 years of age reported that they have enough information about the impact of their condition(s) on their sex life.

Overall, only 37% of survey participants felt they had enough information about the impact of their condition(s) and medication(s) on their fertility. This was lower in participants under 30 years of age (30%) and participants from 31–50 years of age (12%). Participants' responses also varied regionally, ranging from 42% of participants in Quebec and 41% of participants in Ontario reporting they had enough information about their fertility to only 12% in British Columbia.

Less than half (45%) of all survey participants felt that their healthcare provider provided adequate information about the impact of their medication(s) on their ability to conceive. These numbers varied widely by region of Canada: from the Prairie provinces (65%), through to Quebec (58%), Ontario (45%), Atlantic provinces (25%) and British Columbia (18%). Interestingly, more women+ who were older than 50 (59%) and women+ under 30 (56%) reported having received adequate information from their healthcare provider about considerations related to conception. More women+ who identified as LGBTQ2S+ (63%) and those who are part of a racialized community (50%) felt they had been provided adequate information from their healthcare provider.

### A NUMBER OF INFORMATION NEEDS WERE IDENTIFIED BY PEOPLE WITH INFLAMMATORY ARTHRITIS, RHEUMATIC, AND PSORIATIC DISEASES:





LGBTQ2S+ communities (80%) placed greater priority on how to manage the impact of fatigue on their sex life. Participants under 30 years of age (65%) and people from Quebec (59%) placed greater importance on getting information on contraception options that are compatible with medications; however, this was less important for participants between the ages of 31-50 (45%).

Participants from racialized communities indicated they had greater information needs on certain topics, including advice on how to manage the impact of fatigue on their sex life (74%), contraception options that are compatible with other medications (52%), and questions to ask a rheumatologist about sexual health (52%). However, this community had a significantly lower need for information about sexual positions that are comfortable for the body (42%) than participants overall. Participants from racialized communities (52%) and those from the Atlantic provinces (59%) placed more importance on questions to ask their healthcare providers about sexual health.

## RECOMMENDATIONS

- Healthcare providers should include sexual and reproductive health in care and treatment discussions regularly to help to destigmatize conversations about sexual health and to ensure that patients have information that they need.
- Rheumatologists and dermatologists should counsel patients about the impact of medications on fertility and their ability to conceive as soon as possible in their disease journey and regularly afterwards (e.g., when discussing a medication change).
- Patient organizations should provide peer support to allow for the comfortable and safe exchange of information about sexual health, among people with inflammatory arthritis, rheumatic, and psoriatic diseases.
- Patient organizations should work with rheumatologists and dermatologists to develop patient resources that resonate with the audiences most interested in the information.



# FAMILY PLANNING EXPERIENCES AND INFORMATION NEEDS

Research studies have found that patients need to prepare for pregnancy and parenthood, including timing conception, making medication adjustments, achieving low disease activity, and recognizing potential complications (Rebic et al, 2021). Overall, 17% of participants had or were currently planning for pregnancy at the time of the survey. More than a quarter (28%) did not discuss anything to do with having a child until they were pregnant. The further out planning was for the participant, the percentage dropped: nearly one-third (31%) of participants started speaking to a healthcare provider about starting a family six months to one year in advance and 19% of participants raised this topic one to two years in advance.

## EXPERIENCES WITH COUNSELLING AND INFORMATION

Less than half of participants (46%) received counselling from a doctor about pregnancy risks, medication safety, etc. before considering pregnancy. The number of participants for this part of the survey was much lower, limiting the reporting of information by geographic area and other sub-group communities. However, a lower proportion of Quebec participants (only 8%) reported receiving counselling before pregnancy. Similarly, a higher proportion of participants over 50 years old reported receiving counselling before considering pregnancy (80%).

## EXPERIENCE WITH MEDICATIONS

When asked more specifically about their experiences with medications, 63% of participants reported they had to switch medications to ensure they took medications that were safe in pregnancy or breastfeeding. While more than half (56%) did not have any difficulties accessing medications that were safe with pregnancy, one-third (31%) did. Further, more than two-fifths (44%) faced additional barriers with respect to treatments leading up to their pregnancy and/or breastfeeding. In Ontario, there was a higher proportion of participants who switched medications (71%) and who received counselling (62%) than among participants overall.

Participants over 50 years old in this age group also reported difficulties in accessing medications that were safe with pregnancy (67%) and experienced more barriers with respect to treatments leading up to pregnancy and breastfeeding (50%) than those between 31 and 50 years old and under 30 years old.

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*“When first starting medications the most important factor for me was that medication be safe for pregnancy yet I still had to trial methotrexate when sulphasalazine was insufficient. Thankfully I didn’t tolerate the methotrexate.”*

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*“I miscarried during a flare up and was taking naproxen—my rheumatologist told me that the medication may have contributed. I wish I knew before that it was a risk.”*

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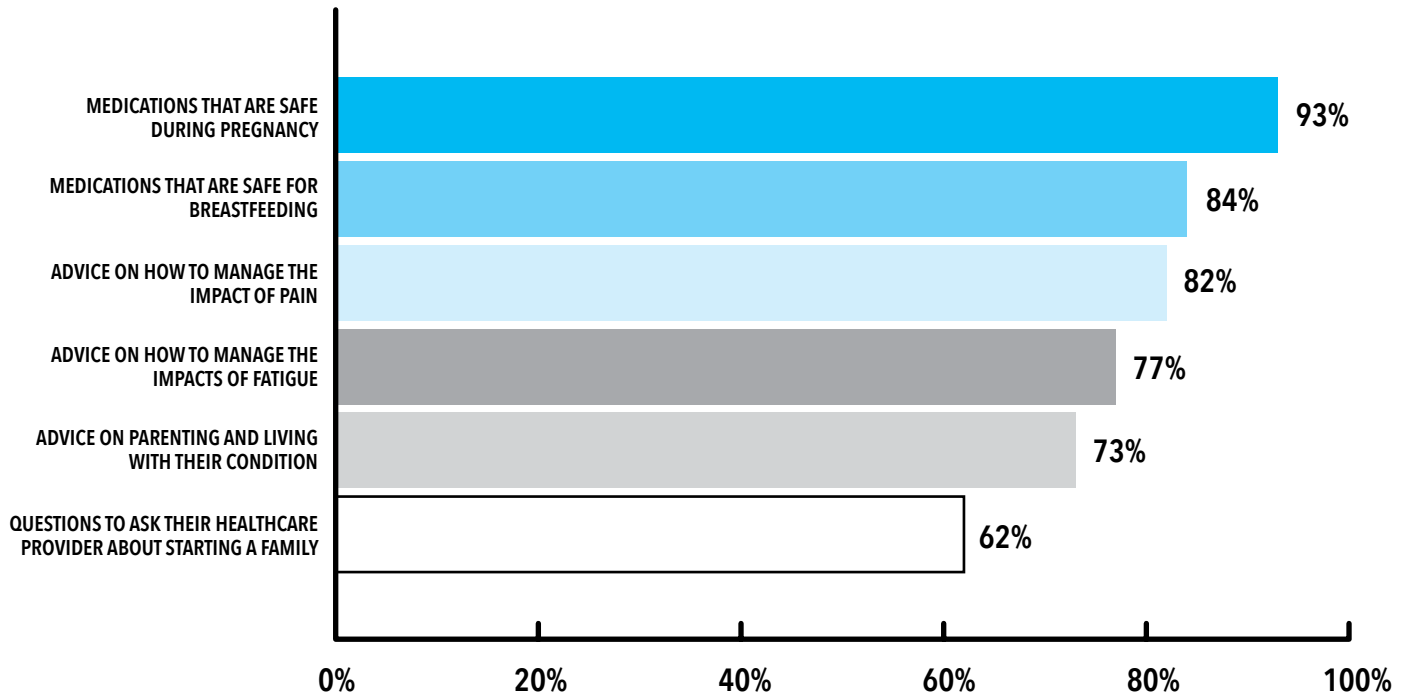
*“La clinique de grossesse à risque m’a fait sentir comme si je n’avais pas les compétences nécessaires pour jouer mon rôle parental une fois mon enfant né. Le capacitisme médical est très fort lorsqu’on a des atteintes arthritiques importantes. Les médecins n’étaient pas accueillants de mon projet parental et ne m’offraient pas d’options adaptées à ma condition.”*

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*“I am currently single and feel that my health is not (good) enough to support a child. With a partner, adoption, fostering, and surrogacy would be options that I could explore.”*

## FAMILY PLANNING INFORMATIONAL NEEDS

### A NUMBER OF INFORMATION NEEDS WERE IDENTIFIED BY PEOPLE WITH INFLAMMATORY ARTHRITIS, RHEUMATIC, AND PSORIATIC DISEASES RELATING TO FAMILY PLANNING:



The number of participants for this part of the survey was much lower, limiting the reporting of information by geographic area and other sub-group communities. However, Quebec participants also noted a higher need for information on medication safety during pregnancy (100%) and advice for how to manage the impact of fatigue (92%) as well as advice on parenting while living with a health condition (91%). In Ontario, there was a higher proportion of participants who wanted advice on how to manage the impact of pain (95%).

Participants' information needs differed with age: while participants under 30 years old noted a lower need for information on parenting (62%), participants over 50 years old reported wanting questions to ask a healthcare provider about starting a family (80%). Participants across the age spectrum also reported a high need for information on medication safety during pregnancy and breastfeeding.

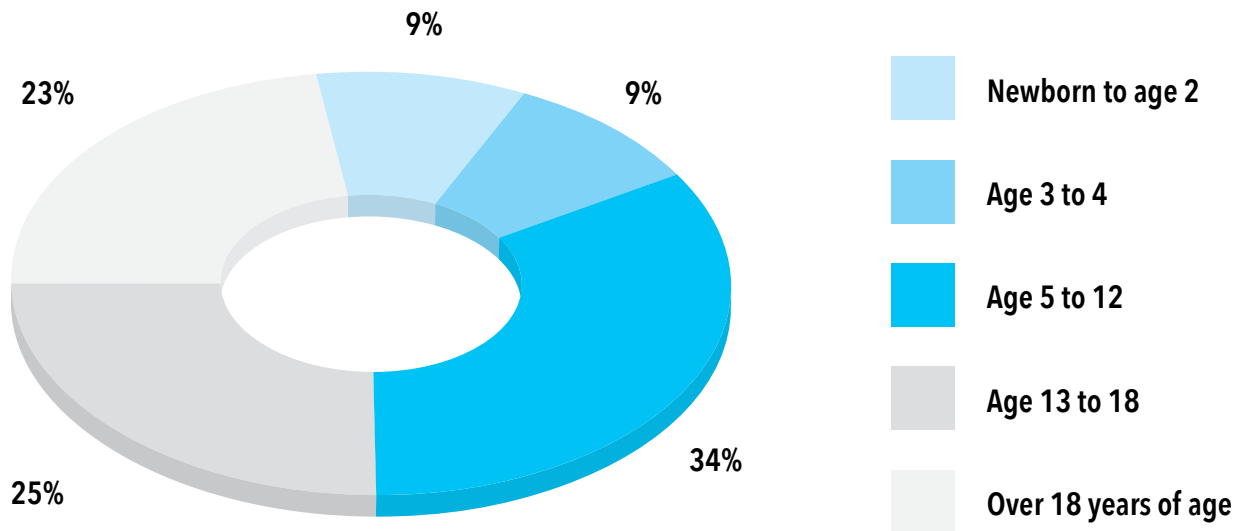
## RECOMMENDATIONS

- Family planning is an essential part of managing inflammatory arthritis, rheumatic, and psoriatic diseases in women+ and should be part of healthcare providers' discussions with patients early and often.
- Patient organizations should work with rheumatology and dermatology experts to develop informational materials that address the specific information gaps identified by women+ participants.
- Rheumatology and dermatology experts should work with patient organizations to develop standards of care for family counselling for women+ living with inflammatory arthritis, rheumatic and psoriatic conditions.

# PARENTING EXPERIENCES

Survey participants represented a broad group of people with different parenting experiences. One-third of participants were actively parenting a child while living with with inflammatory arthritis, rheumatic, and psoriatic diseases and 18% want to have children someday. Over a third of participants (36%) already had children. A breakdown of the age of children is described in the chart.

HOW OLD ARE THE CHILDREN YOU ARE CURRENTLY PARENTING?



The majority of participants actively parenting a child were between 31 and 50 years old. Nearly one in 10 participants was actively trying to prevent pregnancy, the majority of whom were 30 years old or younger.

One in eight (13%) decided not to have children, and one in 11 (9%) decided to not have children because they feared the child will inherit their condition. One in 25 (4%) reported they could not have children. Some participants noted that they are waiting to control their health or waiting until the end of the COVID-19 pandemic before having a child.

*"I am trying to manage my condition and will begin family planning."*

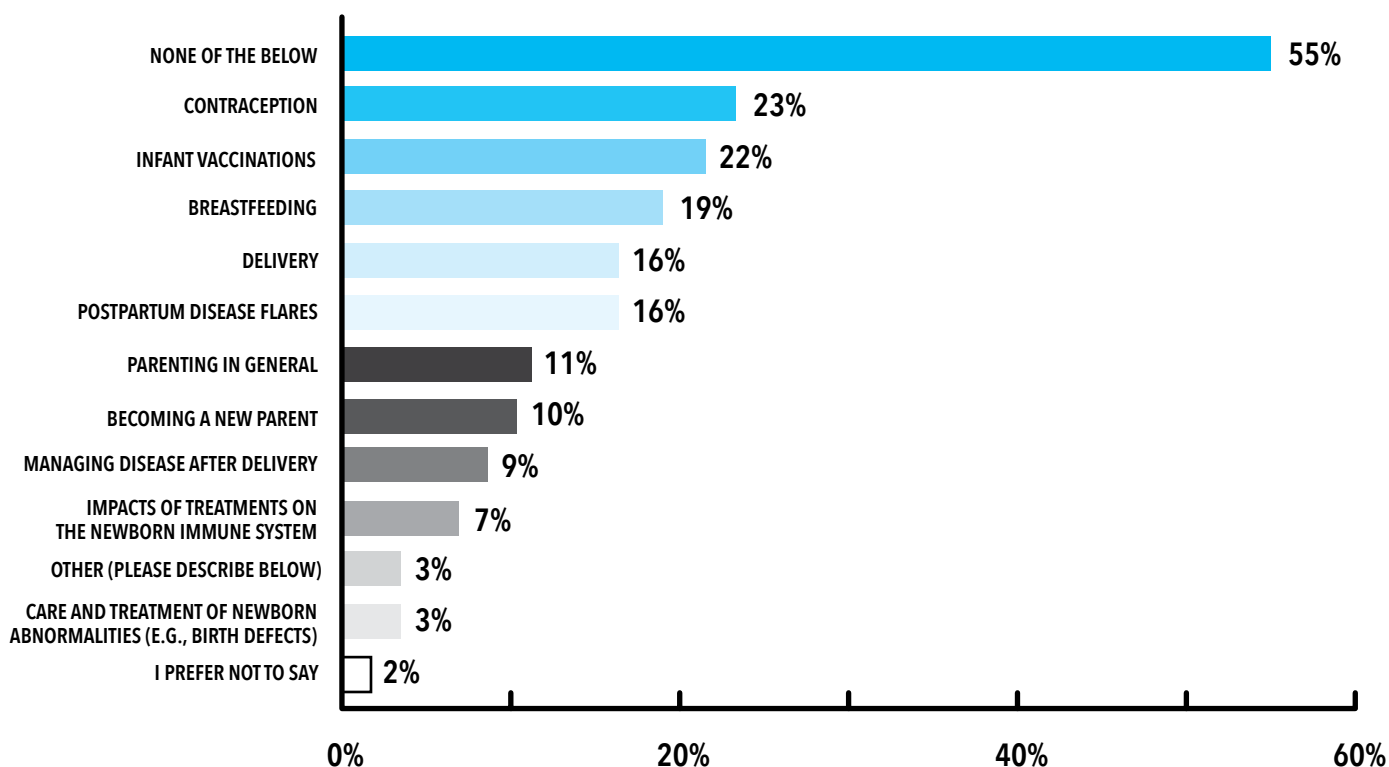
*"J'attends la fin de la pandémie."*

*"I currently have an older child but was told that due to my condition I could never have more children."*

## EXPERIENCES WITH COUNSELLING AND INFORMATION

In terms of access to information, more than half of participants did not receive information about any of the topics noted in the survey (refer to the chart for topics noted).

### HAVE YOU RECEIVED INFORMATION FROM YOUR HEALTHCARE PROVIDER ABOUT ANY OF THE FOLLOWING? PLEASE SELECT ALL THAT APPLY:



However, participants noted that they received information on contraception (23%), infant vaccinations (22%), breastfeeding (19%), postpartum disease activity (16%), and parenting (11%).

Participants' experiences varied depending on region, whether they were part of a racialized community, and age. A higher proportion of participants in Quebec received information on delivery (29%), becoming a parent (27%), and parenting (27%) than participants overall. In Ontario, participants were more likely to receive some information on these issues (52%) and a higher proportion of them were given information on breastfeeding (25%) in particular. In the Prairie provinces, a much lower proportion of participants were given information on contraception (9%), breastfeeding (9%), postpartum disease flares (9%), and delivery (5%). Racialized communities reported receiving more information from their healthcare provider in some situations, e.g., contraception (47%), breastfeeding (40%), postpartum flares (27%), and becoming a new parent (20%).

Interestingly, participants under 30 reported receiving the most information from their healthcare providers about the survey topics listed above. All participants in this group received information about contraception (100%) and higher proportions received information about delivery (80%), postpartum disease flares (80%), breastfeeding (60%), managing disease after delivery (40%), impacts of treatments on the newborn immune system (40%), infant vaccinations (40%), and becoming a new parent (20%). However, 54% of participants between 31 and 50 years old and 73% of participants over 50 years old reported not receiving any information on the topics listed above.

## PARENTING INFORMATIONAL NEEDS

Participants also ranked their information needs relating to parenting with inflammatory arthritis, rheumatic, and psoriatic diseases:

- 1) Dealing with fatigue and flares (89%)
- 2) Managing the demands of work, parenting and their condition (88%)
- 3) Genetic risks of passing their health condition(s) to their child (87%)
- 4) How limitations caused by their condition(s) will impact their child(ren) (81%)
- 5) Tips for accepting how their condition affects their role as a parent (77%)

This is consistent with research studies that indicate a high need for information about the impacts of disease on the ability to be a mother, navigating pain and fatigue, difficulty physically caring for children, and being unable to breastfeed due to physical limitations and medications used for postpartum flares ([Rebic et al, 2021](#)). The number of participants for this part of the survey was much lower, limiting the reporting of information by geographic area and other sub-groups. Quebec participants expressed less of a need for information about how limitations affect children (69%) and the physical care of children (53%) but a higher proportion wanted information on how to talk to your spouse about how your condition affects parenting (81%). In Ontario, more participants wanted information on the physical care of children (81%). In the Prairie provinces, there was generally a lower need for several types of specific information, e.g., dealing with fatigue and flares (76%), managing the demands of work, parenting and health (76%), and genetic risks of passing the condition onto children (70%) than participants overall.

Racialized communities expressed a higher need for information about tending to the emotional needs of children (80%) and the physical care of children (79%); however, they indicated a lower need for information about the genetic risks of passing the condition on to their children (80%). Participants under 30 expressed the greatest need for information on talking with their spouse/partner about how their condition affects parenting (80%) and how to deal with fatigue and flares (80%) than any other age group.

*"I also feel like my condition would hinder my ability to care for them (picking them up)."*

*"Undecided because I don't want them to have the disease, and/or I fear I can't conceive but would like biological children/family."*

*"I'm afraid of being a parent and not having the resources to take care of my children because of my disease (being in pain, tired, having difficulty doing certain movements)."*

## RECOMMENDATIONS

- Healthcare providers should discuss the risks and challenges of parenting with each patient and provide specific advice on how parenting is likely to impact them, depending on their circumstances and specific concerns.
- Healthcare providers should ensure that discussions about the impacts of parenting include mental health, fatigue, pain, and genetic or hereditary risks.
- Interdisciplinary care that includes support from nurses and allied health professionals such as occupational therapists, physiotherapists, and massage therapists, should be considered part of essential inflammatory arthritis, rheumatic, and psoriatic disease care.
- Patient organizations should develop educational resources that meet the diverse needs of women+ across Canada, in collaboration with rheumatologists and dermatologists.
- Healthcare providers should collaborate with patient organizations to ensure that women+ living with inflammatory arthritis, rheumatic, and psoriatic disease have information about accessing services and support in their community to support them as parents.



# MENOPAUSE

Menopause is an important part of the lived experience of women+ with inflammatory arthritis, rheumatic, and psoriatic diseases. Two in five survey participants (40%) indicated they were currently experiencing symptoms of perimenopause or menopause; however, only half of them (21%) indicated they understood how menopause affects their condition(s). This number decreased substantially to 9% of participants between 31 and 50 years old—although this was higher in some geographic areas, such as Atlantic provinces (34%) and Quebec (31%).

Over 50% of participants indicated they understand how menopause affects bone health. In terms of racialized communities, a lower proportion indicated they understood how menopause affects their bone health (39%) and their condition(s) (3%).

More than half of participants (55%) who responded that they are experiencing perimenopause or menopause indicated they are comfortable talking to their provider about sexual health. People who self-identified as being part of the LGBTQ2S+ community were more comfortable talking to their healthcare provider about sexual health (70%).

However, participants' options for managing menopause were not always satisfactory:

*"I am comfortable talking to my physician about sexual health but other than vaginal hormones she has little to offer."*

*"(I experienced) hot flashes affecting the ability to keep ointments in place. Sleep disturbances from hot flashes exacerbate existing sleep problems from pain. Water retention and when to be concerned or seek treatment."*

*"I feel like I am not sure about what I need to know."*

## RECOMMENDATIONS

- Healthcare providers should proactively raise the topics of perimenopause or menopause with women+ living with inflammatory arthritis, rheumatic, and psoriatic disease to help destigmatize these conversations.
- Patient organizations should work with healthcare providers to help improve their skills on engaging in sensitive conversations with patients about menopause and the impacts of aging on their conditions(s).
- Researchers should consider the specific hormonal changes happening for women+ in perimenopause and menopause to ensure that healthcare providers have evidence on which to develop evidence-based recommendations to their patients.
- Patient organizations should develop patient resources that resonate with women+ about perimenopause or menopause.

# EXPERIENCES WITH PAIN

Pain is a common experience for people who live with various forms of arthritis and psoriatic diseases (Lee, 2013; Armstrong et al., 2012). Patients often report using several interventions to help manage pain. In addition to dermatologists and rheumatologists, survey participants reported that they see a physiotherapist (20%) and a massage therapist (17%) as part of their care team. In general, research finds that effective pain management can be challenging, with women being disproportionately impacted compared to their male counterparts (Canadian Pain Task Force, 2020). Multiple factors may contribute to these challenges, including factors related to how pain is assessed and understood by healthcare providers and within healthcare systems.

*“As a woman, I believe my health concerns (no change in pain, swelling of joints, stress, anxiety, etc. related to this disease) are not taken seriously and are often downplayed. I have been told to ‘give [a medication] time’ even after 8 months of no changes and excruciating pain.”*

## EXPERIENCES WITH PAIN COUNSELLING

Though 91% of survey participants indicated that they can honestly discuss pain with their healthcare provider, only 58% feel like their healthcare provider relates to the pain they experience from their condition. In fact, one participant stated, *“Unless the doctor has the same condition, [I] don’t feel like they could understand.”* This number is slightly higher for participants over 50 years old (66%) compared to their younger counterparts (54% of participants between 31 and 50 years old and 42% of those under 30 years old). There were also geographic differences in responses, with those in the Atlantic provinces (70%) and in Quebec (69%) indicating slightly higher agreement that their healthcare provider relates to their pain compared to Ontario (54%) and British Columbia (43%).

Though one’s experience with pain can change over the course of their condition, about a quarter of participants (24%) do not feel like their healthcare provider asks them about their pain regularly. Moreover, about a third of participants (32%) do not feel like their healthcare provider gives them useful and helpful options to deal with their pain. For participants who identify as LGBTQ2S+, however, significantly fewer participants (17%) did not feel that their healthcare provider offered helpful options for dealing with pain. There were also variations in responses across jurisdictions: 35% in Quebec, 34% in the Prairie provinces, 32% in Ontario, 30% in British Columbia and 29% in the Atlantic provinces indicated that their healthcare provider does not offer helpful options for pain. These differences may be related to the options that are actually presented by healthcare providers in these jurisdictions, what medications and resources are available in a given jurisdiction (i.e., through public benefits) and/or how participants perceive the usefulness of the options they have been offered.

For participants under 30 years old, 35% disagreed that their healthcare provider gave them useful and helpful options to deal with pain. There was a higher rate of dissatisfaction with pain options among younger women+ than in the other age groups (31% of those aged 31-50 and 31% of those over 50 years old). This suggests that pain in younger women+ may be undertreated when compared to other women+ in Canada with these conditions.

## EXPERIENCES WITH PAIN MANAGEMENT

The approaches taken by participants and their healthcare providers to pain management varied according to survey comments. One participant indicated, *"My rheumatologist does listen and helps me but he has not prescribed me pain medication even though I have asked"* whereas another felt that, *"I find that my healthcare providers (GP and rheumatologist) are only able to counsel me on pharmaceutical options for managing my pain. They never delve into any other strategies."* Another participant shared that, *"...I feel it is important to tell all [and to] be as honest as you can. You also need to make sure your doc[tor] is a good fit as you need someone to listen [and] act accordingly. We need someone who doesn't judge us for needing pain med(ication)s when we do..."* These different perspectives demonstrate the benefits of honest and collaborative discussions between patients and healthcare providers to enable shared decision making that takes the individual's needs and preferences into account.

With regard to strategies beyond pain medication, many participants provided insights into non-medical approaches to pain management that work for them including, *"...MBSR (Mindfulness-Based Stress Reduction) helped with my pain and my sex life"* and *"[e]xercises such a[s] walking every day"*.

A troubling aspect of pain that emerged from the survey was the perspective of one participant on what it can feel like for women who have experienced marginalization by the healthcare system:

*"There is a lack of support for mental health and the impact [that] being in chronic pain has on people. Women especially are dismissed in the medical field as being hysterical or exaggerating their pain. I was only able to get help when I brought my husband to my GP and he had to reinforce what I was saying as I was dismissed to my face with him sitting there. Only his anger got the GP to agree to further testing which proved I wasn't being hysterical or [that] [it] was 'in my head'. I had x-rays before surgery and even the x-ray technician (who was a woman) said to me 'you don't look like you have psoriatic arthritis!' Just out of the blue she needed to tell me she thought I was faking it. The lack of professional courtesy and support for women especially is shocking and horrible."*

Asking regularly about pain in order to help connect people to appropriate resources and support if needed demonstrates healthcare providers' efforts to understand the impact of pain on a person's life and can help people manage this aspect of their condition(s) better. Increasing education and knowledge about pain among medical students is one way to incorporate this approach into care. This idea is consistent with perspectives provided by the Canadian Pain Task Force 2020 report consultation participants that emphasized the *"importance of having a unified pain curricula and common competency framework for undergraduate and postgraduate medical students, coordinated across universities and education institutions."*



## RECOMMENDATIONS

- Healthcare providers should encourage honest and collaborative discussions with patients to enable shared decision making that takes the individual's needs and preferences into account, especially as these relate to pain management.
- Healthcare providers should ask regularly about pain in order to help connect people to appropriate resources and support if needed and to better understand the impact of pain on a patient's life.
- Governments across Canada and medical schools should adopt the best practice identified in the Canadian Pain Task Force's report of "a unified pain curricula and common competency framework for undergraduate and postgraduate medical students" to increase education and knowledge about pain among medical students.

# IMPACTS OF CONDITIONS ON MENTAL HEALTH

The vast majority (87%) of survey participants worry about the impact of their condition on their mental health, yet only 16% of participants identified having a mental health professional (e.g., psychiatrist, psychologist, social worker) as part of their care team. This number drops to 11% for participants over 50 years old but jumps to 20% for participants between 31 and 50 years old and 21% for participants under 30 years old. Mental health care also varies across jurisdictions (i.e., only 10% of participants from British Columbia indicate that they have a mental health professional as part of their care team compared to 22% in the Prairie provinces). More participants who identified as being part of a racialized community (26%) or LGBTQ2S+ community (28%) reported having a mental health professional as part of their care team.

Concern about the impact of one's condition(s) on their mental health also increases across different demographic groups. Almost all participants who identify as LGBTQ2S+ (96%) and those between 31 and 50 years old (95%) indicated that they worry about their mental health. This number seems to decrease slightly with age, with 78% participants over 50 years old indicating that they worry about their mental health, which may in part account for the lower number of this age group having a mental health professional as part of their care team. Among participants who are part of racialized communities, 63% worry about the impact of their condition on their mental health.

More than 80% of participants said their condition had a negative impact on their self-image. However, participants under age 30 reported a lower impact of their condition on their self-image (68%).

In addition, 80% of participants indicated that they worry about the impact their condition has on their family. This was higher for participants from racialized communities (93%) and for participants who identified as LGBTQ2S+ (91%) as well as for participants between 31 and 50 years old (87%) but lower for participants over 50 years old (73%). Across Canada, responses varied with participants in British Columbia indicating slightly less worry about the impacts on family (76%) and even less in Quebec (71%).

Despite these concerns, only 67% said that they have someone to talk to about their worries and concerns. This was slightly higher for participants from racialized communities (74%) and slightly lower for participants who identify as part of the LGBTQ2S+ community (63%). Though the survey did not specify professional support versus social support, challenges in access to mental health professionals and mental health services in Canada (MHCC, 2012) may contribute in part to the gaps identified here. Responses ranged from across provinces with only 63% of participants in Ontario indicating that they had someone to talk to compared to 75% in British Columbia and in the Atlantic provinces.

In terms of how the mental health of participants is impacted by various forms of inflammatory arthritis, rheumatic, and psoriatic diseases, one major theme that emerged from survey comments is grief, including grieving the loss of one's "old self", grieving the loss of work, and grieving the loss of one's body. In addition, comments reflected on how, beyond the effects of one's health condition itself, the process of care and treatment can affect one's mental health:

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*"Yes, self-image and mental health [issues] result from dealing with my condition. With the length of time it took to diagnose and the number of tests, doctors etc, I had depression by the time treatment started. The depression affected my sexual health as much as my condition did."*





Other insights suggest that mental health is a neglected aspect of care: *“I feel our condition is a very alone (sic) life. There are no groups or individual[s] that help with mental help until you need it. Instead this should be a part of treatment”* and, *“I’ve never had a GP or specialist ask me about my mental health”*. Such reflections highlight the importance of incorporating mental health care into the assessment and treatment of various forms of inflammatory arthritis, rheumatic, and psoriatic diseases. Healthcare providers can actively support people throughout the course of their condition by screening for mental health issues, providing resources and connecting people to interdisciplinary health professionals if needed.

Some participants offered solutions that they feel would be beneficial including online support groups, a hotline for people with these conditions to talk with someone, and seeking out a therapist who specializes in chronic pain or medical issues. The Canadian Pain Task Force report also highlighted the perspective of consultation participants, which has that peer support networks, organizations, and tools are essential (Canadian Pain Task Force, 2020). Patient groups can help fill these gaps by developing and sharing mental health resources geared toward their patient community, creating peer support networks, and providing education to healthcare providers and mental health professionals about what it is like to live with these chronic diseases.

## RECOMMENDATIONS

- Healthcare providers should encourage honest and collaborative discussions with patients to enable shared decision making that takes the individual’s needs and preferences into account, especially as this relates to mental health.
- Healthcare providers should screen for mental health issues in order to help connect people to appropriate resources and support if needed.
- Interdisciplinary care that includes mental health support from psychotherapists and social workers should be considered part of essential inflammatory arthritis, rheumatic, and psoriatic disease care.
- Patient groups should help address gaps in patient resources by developing and sharing mental health resources geared toward their patient community, creating peer support networks, and providing education to healthcare providers and mental health professionals about what it is like to live with rheumatic, inflammatory, and psoriatic diseases.

# PAYING FOR MEDICATIONS

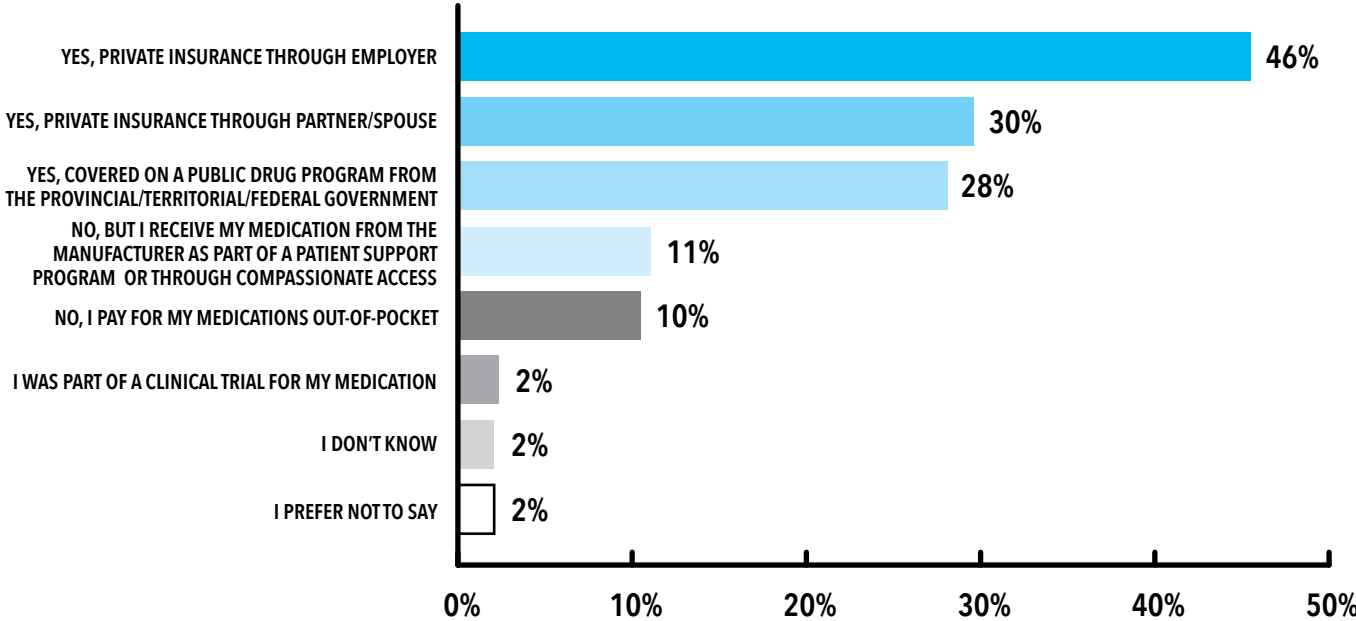
## ACCESS TO INSURANCE COVERAGE

Overall, the majority of participants reported having some access to insurance to cover their medications, whether that be private insurance through their employer (46%), private insurance through their partner/spouse (30%), or coverage under a provincial/territorial/federal government public drug program (28%). Of the participants who did not have access to insurance to cover the costs associated with their medications, 11% received their medication from the manufacturer as part of a patient support or compassionate access program, 10% paid for their medication out-of-pocket, and 2% were part of a clinical trial.

Geographically, there were some disparities in access to insurance coverage across Canada. In British Columbia, fewer participants reported having private insurance through their employer (38%) than in Quebec (56%), the Prairie provinces (55%), the Atlantic provinces (52%), or Ontario (43%). In Quebec, fewer participants reported having private insurance through their partner/spouse (21%) than in the Atlantic provinces (37%), the Prairie provinces (35%), Ontario (31%), or British Columbia (29%). More participants in the Prairie provinces (43%) reported having insurance coverage from a provincial/territorial/federal public drug program than any of the other provinces (36% in British Columbia, 23% in Ontario, 22% in the Atlantic provinces, and 19% in Quebec). More participants indicated that they pay for medications out-of-pocket in British Columbia (18%) than any other province (15% in the Atlantic provinces, 10% in Ontario, 8% in Quebec, and 7% in the Prairie provinces).

Access to insurance coverage also differed across participants in different age groups. More participants between 31 and 50 years old reported having private insurance through their employer (55%) than participants over 50 years old (40%) or under 30 years old (36%). In contrast, more participants under 30 years old reported having insurance coverage through a provincial/territorial/federal drug program (36%) than participants between 31 and 50 years old (28%) and over 50 years old (26%). Lastly, more participants over 50 years old (15%) reported paying for their medications out-of-pocket, in comparison to those under 30 years old (9%) and between 31 and 50 years old (7%).

**DO YOU HAVE ACCESS TO INSURANCE TO COVER YOUR MEDICATIONS?**



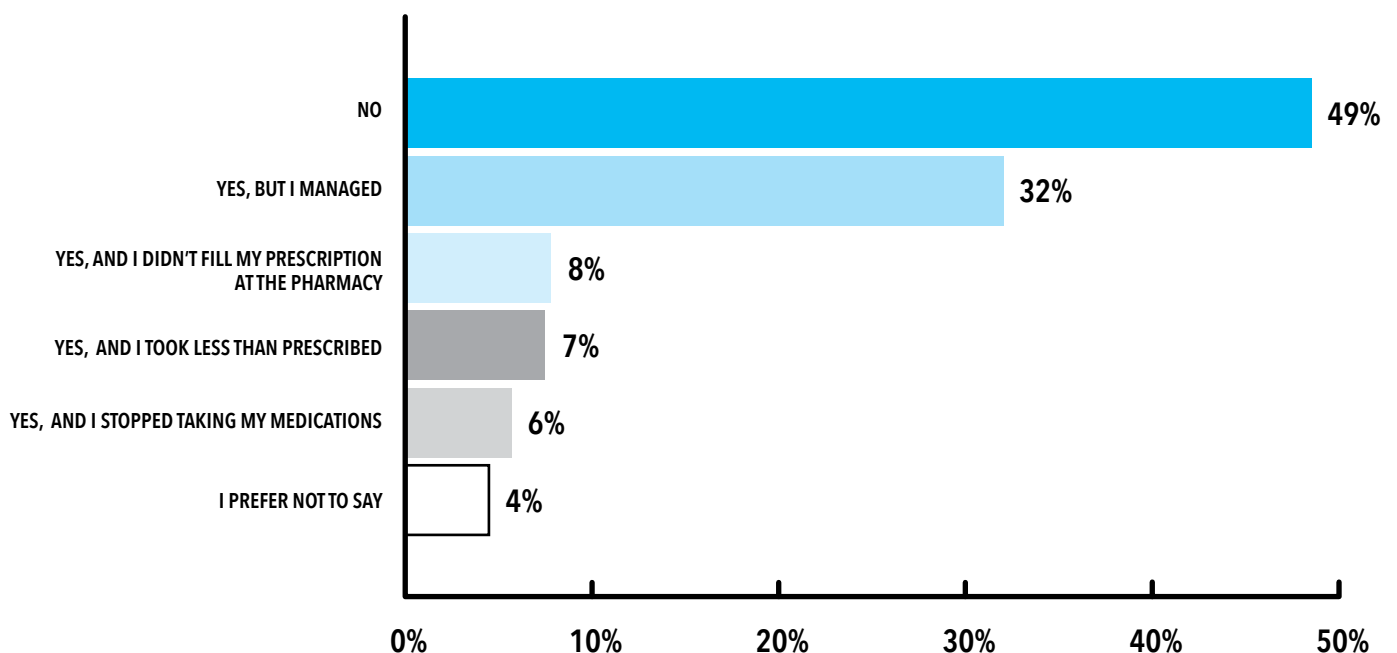
## DIFFICULTIES PAYING FOR MEDICATION

Despite the majority of participants having access to insurance to cover the cost of their medications, over half of the women+ surveyed indicated having experienced financial hardships associated with paying for their medications. Nearly one-third (32%) of participants indicated that while they experienced financial hardship paying for their medications, they were able to manage. Still, some participants reported different strategies to offset the financial burdens they experienced paying for their medications: 8% did not fill their prescription at the pharmacy, 7% of participants took less medication than prescribed, and 6% of participants stopped taking their medication. However, nearly half of participants (49%) indicated no financial hardship associated with paying for their medications.

Similar patterns of difficulties paying for medication can be seen across participants from different regions of Canada. Participants from Quebec report overall less financial hardship associated with paying for medications than participants from any other province. Three-fifths of participants from Quebec (60%) indicated that they have never experienced any financial hardship related to paying for their medications, in comparison to 52% in Ontario, 48% in the Atlantic provinces, 43% in the Prairie provinces, and 42% in British Columbia. This result may be due to the fact that 56% of Quebec residents report having private insurance through their employer, which is more than participants in any other province or territory. Survey results also showed more participants from the Atlantic provinces (15%) reporting not filling their prescriptions at the pharmacy when they experienced financial hardships, in comparison to 11% in British Columbia, 9% in Ontario, 5% in the Prairie provinces, and 2% in Quebec.

More participants under 30 years old (11%) report not filling their prescriptions at the pharmacy when they experienced financial hardships paying for their medications compared to 7% of participants between 31 and 50 years old and 7% of participants over 50 years old.

### HAVE YOU EVER HAD FINANCIAL HARDSHIPS PAYING FOR MEDICATIONS?





## MONTHLY OUT-OF-POCKET COSTS OF MEDICATION

The out-of-pocket costs associated with medications and treatments varied greatly across participants and were largely dependent on their access to private insurance, assistance from pharmaceutical manufacturers, and pharmacy fees. While some assistance is available for prescription medications, many participants indicated that mobility aids, devices, and other treatments, such as physiotherapy, were not options for them as the associated out-of-pocket costs were too much for them to afford.

In general, participants reported spending anywhere from zero dollars up to \$4,000 per month out-of-pocket for prescription medications (prescribed by a healthcare provider). Some participants reported only having to pay the pharmacy dispensing fees while others were required to pay full price for their medications when they reached the limit on their private drug plans. One participant indicated that they used to spend much more per month on medications before switching to methotrexate, which is a less expensive option.

*"If it is out of pocket I do not get it, try it, or utilize it as I cannot afford it."*

*"If medications weren't covered by private and public insurance, along with drug company support, I couldn't afford them. Without medication, quality of life would be horrible and wouldn't be able to work to afford basic needs."*

*"It is impossible to leave a job that is bad for your health when you depend on that job's benefits to pay for your medication. I spent over a year searching on the sly before I could quit the job that was affecting my mental health, because I wouldn't be able to afford to take my meds if I didn't have prescription coverage. My mental health was so bad I verged on suicidal but had to choose between suffering mentally or suffering physically."*

*"We need a way to get meds when our money runs out, a back up plan. If we miss a dose it can sometimes be dangerous for our bodies as we need to taper on & off quite a few of the meds out there and also we might have to start all over again as it takes time for these to take effect and a few missed doses takes us back to the beginning which is awful! We could use more resources to help us get these meds at a reasonable price, some are out of control in their cost!"*

In terms of over-the-counter medications (including shampoo, creams/lotions, pain relievers, eye drops, saliva substitutes, etc.), the majority of participants reported spending less than \$100 per month, with a few participants spending upwards of \$200-\$300 out-of-pocket. Most participants indicated not spending any money on mobility aids, such as walkers, canes, and wheelchairs, indicating that they were either not needed or covered by insurance. Of the participants that did spend money on mobility aids, the costs ranged anywhere from \$50 - \$4,000. However, many participants indicated that these were one-time purchases and not recurring monthly costs. Some participants reported purchasing mobility aids secondhand to offset costs, while one participant reported not being able to afford mobility aids even though they needed them. Similarly, most participants indicated not spending any money on devices, such as splints or home-based phototherapy units. Of the participants that did spend money on these devices, the costs ranged anywhere from \$50 per month to \$1,800 for leg splints every 2 years.

Lastly, when asked about other treatments for their conditions, such as physiotherapy, occupational therapy, and massage therapy, participants' responses ranged from \$10 per month to as much as \$800 per month out-of-pocket. The majority of participants who sought out these additional treatments reported spending between \$100-\$300 a month. Many advised that they do not seek out these treatments as they cannot afford them, even though they are needed.

*"(I have spent) way too much. Been having a flare and have spent upwards of \$250 in 2 months on recommended splints, TENS, cervical pillow."*

*"\$120 for the first 6 visits and \$70 per visit after that.. I should be going 2x weekly but can't afford to. I also can't afford to have massage therapy."*

## RECOMMENDATIONS

- Governments that are working to address patients' inability to access medications should consider proposed policies through a sex and gender lens to ensure that the needs of women+ will be addressed.
- Public plans to address access to medications should include a measure to help people transition between employers so that they can maintain their access to medications and continue to be employed.
- Public and private plan providers (and private plan sponsors) should consider their health benefit plans to ensure that patients have access to supportive services and devices needed to optimize health for patients with inflammatory arthritis, rheumatic, and psoriatic diseases.
- Public and private programs should carefully consider the use of copayments and deductibles to ensure they do not penalize patients who cannot afford these costs and contribute to inequitable access to medications for Canadians.



# SUMMARY OF RECOMMENDATIONS

## UNDERSTANDING SEXUAL AND REPRODUCTIVE HEALTH

- Healthcare providers should include sexual and reproductive health in care and treatment discussions regularly to help to destigmatize conversations about sexual health and to ensure that patients have information that they need.
- Rheumatologists and dermatologists should counsel patients about the impact of medications on fertility and their ability to conceive as soon as possible in their disease journey and regularly afterwards, e.g., when discussing a medication change.
- Patient organizations should provide peer support to allow for the comfortable and safe exchange of information about sexual health among people with inflammatory arthritis, rheumatic, and psoriatic diseases.
- Patient organizations should work with rheumatologists and dermatologists to develop patient resources that resonate with the audience most interested in the information.

## FAMILY PLANNING

- Family planning is an essential part of managing inflammatory arthritis, rheumatic, and psoriatic diseases in women+ and should be part of healthcare providers' discussions with patients early and often.
- Patient organizations should work with rheumatology and dermatology experts to develop informational materials that address the specific information gaps identified by women+ participants.
- Rheumatology and dermatology experts should work with patient organizations to develop standards of care for family counselling for women+ living with inflammatory arthritis, rheumatic, and psoriatic conditions.

## PARENTING

- Healthcare providers should discuss the risks and challenges of parenting with each patient and provide specific advice on how parenting is likely to impact them, depending on their circumstances and specific concerns.
- Healthcare providers should ensure that discussions about the impacts of parenting include mental health, fatigue, pain, and genetic or hereditary risks.
- Interdisciplinary care that includes support from nurses and allied health professionals such as occupational therapists, physiotherapists and massage therapists, should be considered part of essential inflammatory arthritis, rheumatic, and psoriatic disease care.
- Patient organizations should develop educational resources that meet the diverse needs of women+ across Canada, in collaboration with rheumatologists and dermatologists.
- Healthcare providers should collaborate with patient organizations to ensure that women+ living with inflammatory arthritis, rheumatic or psoriatic diseases have information about accessing services and support in their community to support them as parents.

## MENOPAUSE

- Healthcare providers should proactively raise the topics of perimenopause or menopause with women+ living with inflammatory arthritis, rheumatic, and psoriatic diseases to help destigmatize these conversations.
- Patient organizations should work with healthcare providers to help improve their skills on engaging in sensitive conversations with patients about menopause and the impacts of aging on their conditions(s).
- Researchers should consider the specific hormonal changes happening for women+ in perimenopause and menopause to ensure that healthcare providers have evidence on which to develop evidence-based recommendations to their patients.
- Patient organizations should develop patient resources that resonate with women+ about perimenopause or menopause.

## PAIN

- Healthcare providers should encourage honest and collaborative discussions with patients to enable shared decision making that takes the individual's needs and preferences into account.
- Healthcare providers should ask regularly about pain in order to help connect people to appropriate resources and support if needed and to better understand the impact of pain on a patient's life.
- Governments across Canada and medical schools should adopt the best practice identified in the Canadian Pain Task Force's report of "a unified pain curricula and common competency framework for undergraduate and postgraduate medical students" to increase education and knowledge about pain among medical students.

## MENTAL HEALTH

- Healthcare providers should encourage honest and collaborative discussions with patients to enable shared decision making that takes the individual's needs and preferences into account.
- Healthcare providers should screen for mental health issues in order to help connect people to appropriate resources and support if needed.
- Interdisciplinary care that includes mental health support from psychotherapists and social workers should be considered part of essential inflammatory arthritis, rheumatic, and psoriatic disease care.
- Patient groups should help address gaps in patient resources by developing and sharing mental health resources geared toward their patient community, creating peer support networks and providing education to healthcare providers and mental health professionals about what it is like to live with inflammatory arthritis, rheumatic, and psoriatic diseases.

## PAYING FOR MEDICATIONS

- Governments that are working to address patients' inability to access medications should consider proposed policies through a sex and gender lens to ensure that the needs of women+ will be addressed.
- Public plans to address access to medications should include a measure to help people transition between employers so that they can maintain their access to medications and continue to be employed.
- Public and private plan providers (and private plan sponsors) should consider their health benefit plans to ensure that patients have access to supportive services and devices needed to optimize health for patients with inflammatory arthritis, rheumatic, and psoriatic diseases.
- Public and private programs should carefully consider the use of copayments and deductibles to ensure they do not penalize patients who cannot afford these costs and contribute to inequitable access to medications for Canadians.

# ABOUT THE SURVEY

## DEMOGRAPHICS

A total of 439 individuals participated in the Women's Sexual and Reproductive Health Survey. Of these 439 individuals, 92% identified as female, 6% identified as male, 1% identified as non-binary, and 0.2% identified as transgender. The majority of participants (90%) did not identify as members of the LGBTQ2S+ community. The age demographic of this survey ranged from under 18 years old to over 50 years old, with the majority of participants (43%) reporting they were over 50 years of age.

In terms of geographic location, 90% of participants were residents of Canada, with the majority residing in Ontario (36%), Quebec (16%), and British Columbia (14%). Of the 33 international participants, most were from the United States followed by Australia, the United Kingdom, Netherlands, South Africa, India, New Zealand, Colombia, and Singapore. Most participants (86%) indicated that they identified as White. Participants also identified as Latin American, Métis, South Asian, First Nations, Black, Southeast Asian, Chinese, Arab, Filipino, and Pacific Islander.

When asked about their conditions, the majority of participants indicated that they were living with psoriatic arthritis (38%), plaque psoriasis (36%), or ankylosing spondylitis (32%). Similarly, a large portion of participants were affected by osteoarthritis (19%) or rheumatoid arthritis (16%). More than two-thirds of participants identified a GP/family doctor (76%) or a rheumatologist (71%) as a primary member of their healthcare team. Other common responses were a dermatologist (32%), a physiotherapist (20%), and a massage therapist (17%).

The most common medications taken by participants for their conditions were biologics (45%) and non-steroidal anti-inflammatory drugs (NSAIDs; 43%), such as ibuprofen or naproxen. Methotrexate (21%), disease-modifying antirheumatic drugs (DMARDs; 18%), and topical corticosteroids (18%) were also commonly cited as part of participants' medication regimens.

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## ABOUT THE CANADIAN ARTHRITIS PATIENT ALLIANCE (CAPA)

The Canadian Arthritis Patient Alliance (CAPA) works with various groups in the arthritis community to ensure the voice of people living with arthritis is heard and to bring you up-to-date information on issues that affect the arthritis community. We work with healthcare professionals, health organizations, clinicians, industry, health charities, researchers, and various levels of government. We keep Canadian people living with arthritis and their support groups understand more about their disease and have a voice in managing it.

[www.arthritispatient.ca](http://www.arthritispatient.ca)

## ABOUT THE CANADIAN ASSOCIATION OF PSORIASIS PATIENTS (CAPP)

The Canadian Association of Psoriasis Patients (CAPP) was formed in 2012 to serve people impacted by psoriasis and psoriatic arthritis. CAPP's mission is to be a resource to these people by improving their quality of life, raising awareness, providing education, advocating for better access to care and treatments, and supporting research.

[www.canadianpsoriasis.ca](http://www.canadianpsoriasis.ca)

## ABOUT THE CANADIAN PSORIASIS NETWORK (CPN)

The Canadian Psoriasis Network (CPN) is a national, not-for-profit organization dedicated to improving the health and 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, by supporting efforts toward a cure, and by working with others to build awareness and advocacy about the complexities of these conditions.

[www.canadianpsoriasisnetwork.com](http://www.canadianpsoriasisnetwork.com)

## ABOUT THE CANADIAN SPONDYLITIS ASSOCIATION (CSA)

The Canadian Spondylitis Association (CSA) is the first and only patient-led, not-for-profit organization developed for and solely focused on supporting Canadians living with spondyloarthritis (SpA). The conditions that fall under the spondyloarthritis umbrella include ankylosing spondylitis (AS), psoriatic arthritis (PsA), enteropathic arthritis (arthritis associated with inflammatory bowel disease or IBD), reactive arthritis (ReA), juvenile idiopathic arthritis that is enthesitis related arthritis (JIA-ERA), undifferentiated spondyloarthritis (USpA), axial spondyloarthritis (AxSpA), peripheral spondyloarthritis (pSpA) and non-radial spondylitis (nrSpA). The CSA plays an essential role in helping individuals diagnosed with and affected by Spondyloarthritis achieve their full health potential and improve their quality of life. The mission of the CSA is to be the leading voice for the spondylarthritis community in Canada, raising awareness and providing support, education, and advocacy for patients, caregivers, and healthcare professionals. Its vision is that all of those living with, or affected by, SpA receive timely diagnosis and treatment, make informed choices about their well-being, and are supported by a thriving spondyloarthritis community.

[www.spondylitis.ca](http://www.spondylitis.ca)

We appreciate the educational grant from UCB Canada to develop the survey and this report.

