

BARING IT ALL:

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

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Background

Inflammatory arthritis and psoriasis are each estimated to impact roughly one million people in Canada. The onset and diagnosis of these diseases commonly affects people in the prime of their lives and these individuals are often left with a variety of reproductive and sexual health-related concerns, such as contraception, family planning, parenting, and menopause.

To address this gap, the Canadian Arthritis Patient Alliance (CAPA), the Canadian Association of Psoriasis Patients (CAPP), the Canadian Psoriasis Network (CPN) and the Canadian Spondylitis Association (CSA) co-developed and launched the **Women’s Sexual and Reproductive Health Survey** on International Women’s Day 2021. People who identified as female were asked for their experiences and insights about contraception, family planning considerations, sexual health, parenting, and menopause.

Methods

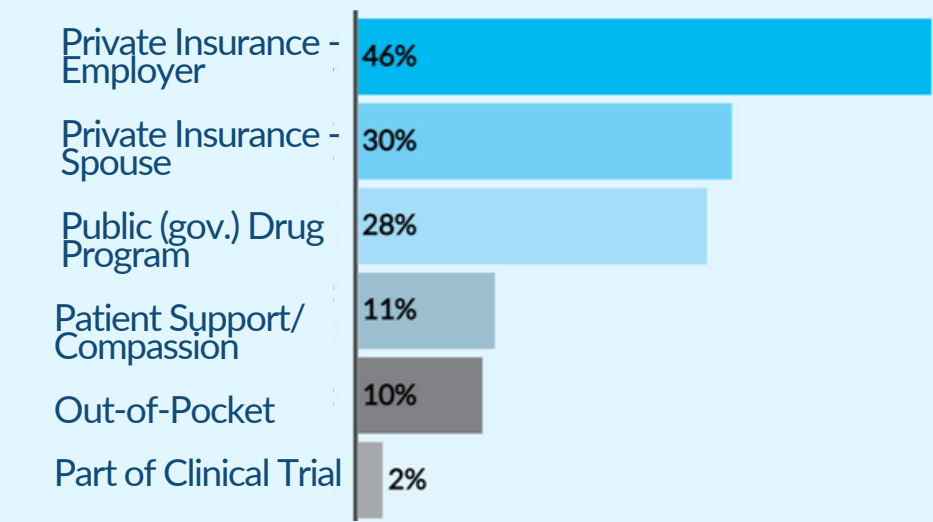
A total of **439** individuals living with these diseases participated in the survey and results were analyzed to provide a national picture and insights based on geography, age, and identification as a member of a racialized community and/or as LGBTQ2S+. Information was collected and analyzed by the four organizations about:

- counselling and medication safety related to pregnancy and breastfeeding
- postpartum disease flares
- pain
- perimenopause / menopause
- accessing health benefits (including prescription drug, device and professional services)
- challenges with paying for medication and monthly out-of-pocket costs for health products and services



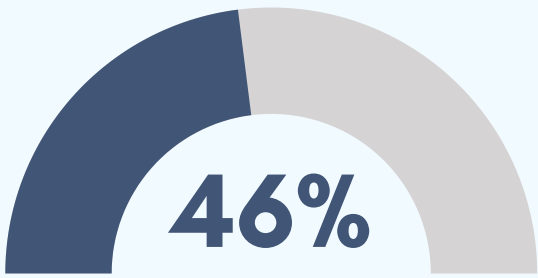
Results

HOW PARTICIPANTS HAVE MEDICATIONS REIMBURSED:




More participants over 50 years old (**15%**) reported paying for their medication out-of-pocket, compared to **9%** of participants under 30 years old, and **7%** of participants between 31 and 50 years old.

PERCENTAGE OF PARTICIPANTS WHO REPORT NOT FILLING THEIR PRESCRIPTIONS:



Less than half of the participants (**46%**) received counselling from a doctor about pregnancy risks, medication safety and other relevant factors before considering pregnancy.

MONTHLY OUT-OF-POCKET COSTS FOR MEDICATION:

-  Participants reported spending anywhere from zero dollars up to \$4,000 per month out of pocket on prescription medications.
-  The majority of participants reported spending less than \$100 per month on over-the-counter medications (including shampoo, creams/lotions, pain relievers, eye drops, saliva substitutes, etc.)
-  The costs for mobility aids ranged from \$50-\$4,000

EXPERIENCE WITH MEDICATIONS AND FAMILY PLANNING:



63% of participants had to switch the medications they were taking to ones that were safe in pregnancy or breastfeeding.

Recommendations

1. **HTA processes should incorporate a sex and gender based analysis** including considerations of child-bearing potential, pregnancy and breastfeeding, to ensure women+ have access to the best treatment options throughout their life cycle.
2. Federal, provincial and territorial governments & private payers should **consider proposed pharmaceutical policies (e.g., national pharmacare) through a sex and gender lens** to ensure that the needs of women+ will be addressed – including drug plan copayments and deductibles.
3. **Researchers should consider the sex and gender impacts** of access to care, access to medication, medication safety, mental health, pain, parenting and aging and within racialized communities and the LGBTQ2S+ community to ensure that women+ have the best evidence to inform decision-making.

Additional recommendations were developed including the need for patient information to support informed decision-making of women+ with inflammatory arthritis, rheumatic and psoriatic diseases across the life cycle.

Conflict of interest declaration

CAPA, CAPP, CPN and the CSA appreciate the unrestricted educational grants from UCB Canada for this project. All data collection, analysis and recommendations were developed by CAPA, CAPP, CPN, and CSA independently.

