

Drug Evaluation  
Questionnaire for Patient and  
Caregiver Associations and Groups

Une production de l'Institut national  
d'excellence en santé  
et en services sociaux (INESSS)

## **Section A – Context and guidelines**

### **Context and objectives of the questionnaire**

INESSS recognizes that patients and caregivers have first-hand knowledge of life with a disease or specific health condition. They can describe the benefits and drawbacks of currently available treatments, which are not always reported in the published literature, and assess new treatments.

This questionnaire was created to help patient and caregiver associations and groups contribute information to the evaluation of a specific drug. Their knowledge on the subject may influence the recommendations of INESSS.

Completing this questionnaire requires significant resources. We are therefore committed to making all contributions available to everyone involved in the evaluation process. Our notice will explain how your answers will be used in developing recommendations.

**Responses to this questionnaire may be published on our website; any personal and financial information that may allow respondents to be identified will be removed.**

### **How to complete the questionnaire**

In this questionnaire, the term “patient” refers to a person who has or had a disease or health condition that requires the prescription of the drug. The term “caregiver” refers to a person who takes care of a patient by providing, for example, care, support and assistance, and includes family members, friends and any other support person.

The first section of the questionnaire concerns information about your patient or caregiver association or group. This information is required so we can get to know the associations that respond to our questionnaire, and their representatives, in the interest of transparency. This section also includes questions about conflicts of interest, since INESSS asks that all participants in the evaluation procedure, whether individuals or organizations, disclose any conflicts of interest they may have in order to ensure an objective and credible procedure. This information will not be used to reject questionnaires or any of the information provided.

The second section of the questionnaire is made up of three major subsections that deal with the impact of the disease, currently available treatments and drugs under study. More specifically, in sections B-2 to B-6, we ask you to describe the difficulties faced by patients and caregivers, experiences with current treatments, expectations of the drug under study and, if you are aware of them, the potential benefits or drawbacks of this drug.

For each of these questions, please think about any existing issues that could be useful for evaluating the drug and making a decision. The issues listed beneath each question are given as examples; these lists are not exhaustive. Identify which issues your association or group thinks are important, and describe any other relevant issue that is not mentioned. Please describe the facts, provide information and summarize the experience of the patient and their family in order to give balanced and specific insight into their perspective. Please specify the source of this information by providing references. For each section of the document, please specify any groups you think should be given particular consideration (e.g., men, women or children; ethnic groups; people living in a specific region; people with disabilities; subtypes of the disease), and indicate their particular needs or problems.

There is no need to send us scientific articles, as we already have access to this type of information. However, if you have a particular interpretation of specific clinical trials, we would be interested in hearing about it.

If you have any questions about this questionnaire, please write us at:  
[plan.commentaires.inscription@inesss.qc.ca](mailto:plan.commentaires.inscription@inesss.qc.ca)

Once you have completed the questionnaire, please send us a digital copy at the above-noted email address, or a hard copy at the following mailing address:

**Institut national d'excellence en santé et en services sociaux (INESSS)**  
**Direction du médicament**  
**2535 Laurier Boulevard, 5th Floor**  
**Québec, Québec G1V 4M3**

## Section B – Feedback about a drug

### 1. Information about the organization and conflict-of-interest declaration

Name of the drug and indication: Treatment of moderate to severe plaque psoriasis

Name of the organization: Canadian Skin Patient Alliance (CSPA), Canadian Association of Psoriasis Patients (CAPP) and the Canadian Psoriasis Network (CPN)

Website : canadianskin.ca; canadianpsoriasis.ca; canadianpsoriasisnetwork.com

Name of the respondent to the questionnaire: Rachael Manion (CSPA & CAPP) & Antonella Scali (CPN)

Name of the contact person : Rachael Manion

Email address : executivedirector@canadianskin.ca

Telephone : (613) 224-4266

Mailing address : 111-223 Colonnade Rd S, Ottawa, ON, K2E 7K3

#### 1.1 Information about the organization

Type of organization (check all that apply):

- Association:** Group of persons brought together with a common interest, other than that of making profits to be shared among its members, whose activities promote the study, defense and development of the economic, social or moral interests of its members (Registraire des entreprises, Gouvernement du Québec)
- Group of persons:** Any aggregation, other than an association, which joins two or more persons who share a common interest (pecuniary or not). (Registraire des entreprises, Gouvernement du Québec)
- Non-profit legal person:** Group of individuals that engages in non-profit activities (Registraire des entreprises, Gouvernement du Québec)
- Community organization subsidized by the MSSS:** Group of persons from the community that is supported by the community and mobilized around shared objectives in the field of health care and social services, and which is subsidized through the Programme de soutien aux organismes communautaires of the Ministère de la santé et des services sociaux (MSSS) of Québec
- Registered charitable organization:** Charitable organization registered with the Canada Revenue Agency or Revenu Québec
- Public foundation:** Foundation operated for charitable purposes; the majority of its administrators or other managers deal with each other at arm's length (Ministère du Travail, de l'Emploi et de la Solidarité sociale)
- Private foundation :** Foundation in which more than half of the administrators are related persons or have a non-arm's length relationship, and for which over 50% of the

funding comes from a single person or group of persons that have a non-arm's length relationship (Ministère du Travail, de l'Emploi et de la Solidarité sociale)

- Mixed association or group:** Association or group that brings together patients and professionals
- Group of associations:** Union, federation, coalition or any other type of group of associations, community organizations, groups of persons, charitable organizations, etc.
- Other, please specify:

#### Jurisdiction

- National
- Provincial
- Regional
- Other, please specify:

#### Mandate/role (check all that apply)

- Defense of members' rights and promotion of their interests
- Improvement of access to new treatments
- Support for individuals
- Research funding
- Research promotion and support
- Training
- Information and awareness campaigns
- Other, please specify:

Describe the make-up of the main branches of your organization, and give the names of managers and their titles.

*For example:*

- *Organization chart (provide a reference to the organization's website, where applicable)*
- *Main branches, units, departments, etc.*
- *Board of directors (BOD), where applicable*

CSPA and CAPP are separate organizations with their own Board of Directors. They also have a shared staffing model with two employees: Rachael Manion (Executive Director) and Helen Crawford (Communications Manager).

CPN has one employee: Antonella Scali (Executive Director). Members of the Board of Directors are Simmie Smith, Brian Moher, Brenda Spinozzi, Andrew Gosse, Odarka Decyk, and Jessica Joly.

Describe your members.

*For example:*

- *Number and types of members*
- *Regions served*
- *Demographic data*

The members of CSPA and CAPP are the members of the respective Boards of Directors.

CPN's voting membership consists of its Board of Directors. CPN's broader membership is made up of people across Canada with lived experience of psoriatic diseases, family members and health care professionals serving these groups.

### *1.2. Conflict-of-interest declaration*

A conflict of interest arises when a person is in a situation in which, objectively, their judgment in a particular role may be or appear to be influenced by other considerations, whether personal, financial or professional. A conflict of interest may be real, potential or apparent. Organizations may also have financial or reputational interests that are in conflict with their obligations under their mission or mandate.

Please list all the companies or organizations that have provided you with resources (financial, human, material or other services, including consulting, communications, representation or research) in the last two years AND that have an interest in the drug under evaluation. Your list should not be limited to the manufacturer of the drug under evaluation but also include any organization involved directly or indirectly with this drug.

Reminder: This information is not used to reject questionnaires or any information provided.

#### **Organizations**

Canadian Skin Patient Alliance

Amounts

Janssen Canada, UCB Canada, LEO Pharma Canada, Bausch Health (Canada): \$0 to 5,000 (respectively)

Merck Canada, Novartis Canada, Galderma Canada: \$10,000 to \$50,000 (respectively)

AbbVie Canada, Pfizer Canada, Celgene: Over \$50,000 (respectively)

#### **Organizations**

Canadian Association of Psoriasis Patients

Amounts

Amgen Canada: \$0 to 5,000

AbbVie Canada, Janssen Canada, Novartis Canada, Eli Lilly Canada, UCB Canada, Bausch Health (including Valeant), LEO Pharma Canada, Celgene: \$10,001 to 50,000 (respectively)

**Organizations**

Canadian Psoriasis Network

Amounts

Amgen Canada, Bausch Canada, Eli Lilly Canada, Janssen Canada, Leo Pharma Canada, Novartis Canada, Pfizer Canada \$10,000 to 50,000 (respectively)

AbbVie Canada over \$50,000

**Organizations**

N/A

Amounts

N/A

Has your organization, or one of its managers, ever published or publicly expressed (e.g., in a press release, media interview, online) a clear opinion about the treatment under evaluation? If so, of what nature ? Reminder: This information is not used to reject questionnaires or any information provided.

**Opinion published or publicly expressed**

N/A

Reference (if applicable)

N/A

**Opinion published or publicly expressed**

N/A

Reference (if applicable)

N/A

**Opinion published or publicly expressed**

N/A

Reference (if applicable)

N/A

**Opinion published or publicly expressed**

N/A

Reference (if applicable)

N/A

Does your association or any of its managers have any other conflicts of interest to disclose?

Yes  No

If so, of what nature ?

*For example:*

- *Personal benefits received from a manufacturer or organization with an interest in the INESSS evaluation (donation, gifts, promotional items, trips, services, shares, call options, etc.)*
- *Activities funded by a manufacturer or organization with an interest in the INESSS evaluation (research grant or scholarship, consultant fees, conference participation or organization, committee, salary, etc.)*
- *Support for the association from a manufacturer or organization with an interest in the INESSS evaluation*
- *Affiliation*
- *Personal or business relationship with a manufacturer or other interest group*

N/A

### *1.3 Information on the method, help received and sources of information used to complete the questionnaire, if applicable*

Indicate whether you received help to complete this questionnaire, and, if so, specify what kind of help, who provided it and in what capacity.

The information presented in this questionnaire was generated using surveys that our organizations created, managed and analyzed. We provided a patient input submission to INESSS's first review of Cimzia, but this was not included in the review for reasons that are unclear to us. It appears to have been lost internally at INESSS. INESSS's recommendation regarding Cimzia noted that the institute did not receive any patient input.

Indicate the nature of the information and the method used to complete the questionnaire.

*For example:*

- *Number of participants*
- *Method used: solicitation of members; investigation online or elsewhere; comments on social media, in working groups or discussion groups; testimonials; analysis of calls to a telephone help line; medical files; conversations with patients or family members of patients during clinical trials; stories told by patients or their families; etc.*
- *References*

Sections 2-3 build on data developed for other recent submissions on the patient experience living with psoriasis, in particular, the submission for risankizumab sent to INESSS by email on November 5th, 2018. We designed a patient survey for the risankizumab submission that was hosted on Survey Monkey and available from August 26 - September 2, 2018. We received 19 responses from patients across the country. Of the 11 respondents who provided their age, five were more than 55 years old, four were between 35-54 and two were under 34.

The patient experience with Cimzia (section 4) was captured through a separate patient survey hosted on Survey Monkey that was developed specifically to collect information for the patient submission for this treatment. The survey was in English only and live from July 10 - October 22, 2018. The survey was advertised on our social media platforms, websites, newsletters, personal contacts and membership lists. Of the 23 respondents to this survey, 13 were female and most were between the ages of 26-65.

This submission also includes information that CAPP and CPN gathered through a recent questionnaire of over 286 people to explore what it takes for patients to feel their psoriasis is stable (see also our Journey to Stability Report). In addition, it includes information from a survey of women-identified people in Canada run by CPN from August-September, 2019 in English and French. The survey received 112 responses, with respondents ranging from 18-65+, with the majority between the ages of 35-64. Survey responses were received from every province except Prince Edward Island, with 14 responses from Quebec.

This submission is also informed by our years of experience working with this patient community.

## **2. Impact of the disease or health condition**

2.1. How does the disease or health condition treated by the drug under evaluation affect patients' quality of life? Which aspects cause the most difficulty?

*For example:*

- *Primary symptoms to control*
- *Impact on daily activities and domestic life*
- *Need for assistance in daily life*
- *Impact on social life and relationships*
- *Family balance*
- *Intimate relationships, sexual issues*

Psoriasis is a chronic inflammatory skin condition that affects the regeneration of skin cells. Normal skin cells grow, mature and are shed as part of a natural cycle that takes 28 to 30 days. Psoriasis is a skin condition that happens when faulty signals in the body's immune system trigger new skin cells to form in three to four days instead. Because the skin cells grow too quickly, they are not shed normally. Instead, they pile up on the skin's surface, creating sores or lesions—often called plaques. Thick, silvery scales form atop these itchy and sometimes painful red patches.

Psoriasis usually affects the elbows, knees and scalp, but it can also occur on the palms of the hands, soles of the feet, nails, genitals and torso. Psoriasis is a persistent, chronic condition that may come and go—flare up then go into remission. During flare-ups, psoriasis causes itchiness and pain in the inflamed skin. Under this stress, the skin may crack and bleed.

Psoriasis can range from a few dandruff-like scales to widespread patches that cover large areas of skin. For many people, psoriasis is nothing more than a nuisance. For others, it's an embarrassment. And for a few, it's a painful and disabling condition.

Responses to the survey reinforced our knowledge that many people with psoriasis perceive their condition to be uncontrolled. Twenty-one per cent identified as having controlled psoriasis, while 74% identified as being a person with psoriasis that they feel is uncontrolled. The remaining 5% identified as a family member or caregiver of a person with psoriasis. Findings CPN and CAPP's Journey to Stability Report found that over 38% of English survey respondents (n=286) have lived for 10 or more years feeling that their condition was not satisfactorily controlled.

The length of time respondents' lived with psoriasis ranged from 2-55 years. Of the 16 people who responded to this question, the majority (87.5%) experience psoriasis on their legs/knees, 75% on their arms/elbows and 75% on their scalp. Others indicated involvement of their back (56%), their face (50%), their feet (31%) and their palms (25%).

Gaps in treatment can have profound effects on all aspects of a person's life. When asked about how often they were impacted by specific physical, emotional and social factors, one-third identified that they were frequently impacted by: feelings of embarrassment, sleep loss, problems with intimacy, and negative effects on their self-confidence. Nearly half (47%) indicated that their concentration at work is frequently affected by their psoriasis and more than half (53%) indicated that they frequently experience feelings of depression.

Patients who answered the survey were very clear and passionate about the impact of psoriasis on their lives and the importance of effective treatments:

- o "Unable to go out due to the severity of pain and discomfort on my feet. Not able to sleep."
- o "I am excessively tired from dealing with itching, scaling, swelling and bleeding."
- o "I just feel awful. Flakes everywhere. It's depressing for me and I don't feel like going to the gym or eating well when I don't like myself."
- o "Physical discomfort and embarrassment about appearance led to decreased exercise, comfort eating, and depression."
- o "Psoriasis on palms can make easy everyday chores hard, if not impossible. Brushing hair, teeth, cutting sandwiches, etc."

Of the 16 people who responded to the question "How does psoriasis affect your day-to-day life?", 81% indicated that they do not wear certain types of clothing; 50% indicated that they have trouble sleeping; and 31% had to miss social events. Only four respondents indicated that psoriasis does not affect their day-to-day lives. One patient respondent shared with us: "In general ... it's isolated my life to the extend [sic] I am depressed, how can one not be with this 'disease'. The worst part is the itch, pain and the bleeding. ... and it is so hard to control!"

Patients also have to contend with other conditions or situations related to psoriasis. Of the 16 respondents to our question about their experiences, 62.5% identified depression, 37.5% identified joint pain and more than 56% identified weight gain. All of these sequelae also place a burden on patients' lives and the healthcare system. As one patient respondent noted: "At times I sink into depression and cut myself off from any socializing, [and have] total unreasonable behavior with my spouse."

Moreover research finds that, for many reasons, women with psoriasis and psoriatic arthritis can experience and perceive things like self-image, mental health, stigma (negative stereotypes) and treatment decisions differently than people with other gender identities. A recent survey of women-identified people with psoriasis and psoriatic arthritis by CPN found that self-image and mental health emerged as prominent concerns for respondents over the life span.

In particular, women with psoriatic diseases may be disproportionately impacted by treatment and lifestyle considerations related to family planning. Women who are planning a pregnancy or who become pregnant, and those who decide to breastfeed, are more limited in their treatment options throughout the course of planning a pregnancy, during pregnancy, post-pregnancy and breastfeeding.

This survey also highlights the challenges that respondents have with accessing treatments. Notably 10% of the survey respondents who answered this question (n=98) indicated that they pay for their medication treatments out-of-pocket and 3% responded that they don't take medications because they cannot afford them.

## 2.2 How does the disease or health condition affect patients' families and friends?

*For example:*

- *Emotional/psychological effects*
- *Family balance*
- *Intimate relationships, sexual life*

In terms of the effects of psoriasis on family members and caregivers, the following challenges for family members and caregivers were identified by survey respondents – emotional challenges (more than 66%); costs, associated with travel to appointments, medications, other (55%, respectively); lack of support or information about psoriasis (44%); missing school or work, difficulties with intimacy, and missing social events (more than 33%, respectively).

## **3. Experience with currently available treatments (other than the one under evaluation)**

3.1. To what extent do the patients, with the help of their families, where applicable, manage their health condition with current treatments? Treatment refers to any form of intervention,

such as drugs, rehabilitation, psychological support or hospital procedures. If no treatment is available, this should be stated.

*For example, list the main treatments used and their effects in terms of:*

- *Procedure for administering/taking the treatment (frequency, treatment at home or at the hospital, access, route of administration)*
- *Difficulties taking a drug as prescribed (swallowing, use of a device, schedule, etc.)*
- *Specific actions involved in current medications (tablets, injections, checkup, review of dosage and frequency, etc.)*
- *Required consultations and complementary examinations (checkup, biological and X-ray exams), related treatment (kinesitherapy, psychiatry), need for hospitalization or other treatments*
- *Effectiveness for controlling or diminishing the most difficult aspects of the disease*
- *Adverse effects, specifying the effects that are acceptable and those that are most difficult to tolerate*
- *Control or reduction of symptoms (primary benefits and adverse effects of this drug, etc.)*
- *Impacts on daily life and domestic activities*
- *Impacts on personal and social life and relationships (work interruptions, changes in physical appearance, difficulty getting around, etc.)*
- *Concerns regarding long-term use of the existing treatment*
- *Ease of access*

People who responded to the survey indicated experience with a range of different therapies including topical treatments, phototherapy, oral systemic drugs and biologics. A few indicated that they have not tried any treatments with one person indicating, “none, just live with it.” 58% said their current medications were “very convenient” to use.

Nine people responded to the question about what side effects they experience with their treatment. While roughly half told us they did not have side effects, others said:

- o “For a month, I felt tired and experienced extreme dryness on my face and lips.”
- o “Redness, soreness, thinning skin, painful burns.”
- o “None but it's greasy for about an hour after application.”
- o “Hair loss, weight gain otherwise good.”
- o “I am not using anything at the moment ... the worst is the uncontrollable itch and shedding and bleeding!”

When asked, “Are there any needs you have that are not being met by this treatment?” We heard:

- o “I still have new outbreaks.”
- o “No long term solution, only temporary fixes.”
- o “I'd like to ask my dermatologist about a better treatment such as a pill or injections.”

When asked the main reason people had to stop using treatments that they have used in the past, we heard the following responses from the nine people who answered this question, demonstrating the heterogeneous experience of treatment response:

- o “Topical treatments and light therapy worked many years ago for Psoriasis on my body but did not work for the soles of my feet or hands. Oral meds had no effect at all. Stellara [sic] did not work at all, the only thing that has given me my life back is Humira.”
- o “Not working.”
- o “Did not have any effect.”
- o “Topical and phototherapy were inconvenient and didn’t work.”
- o “Ineffective - used too much.”
- o “Humira made me ill, made the psoriasis worse than it ever was. Methotrexate affected the organs 1 month after starting the treatment cyclosporine affected organs after 1 year [sic].”

Some respondents provided insight into challenges they had accessing medications including:

- o “It has taken me years to get Humira and that was when I changed my dermatologist who saw that a more aggressive treatment was needed. I saw at least 3 dermatologists prior who prescribed the usual creams, oral meds. I even went to a naturopathic doctor who tried to help through acupuncture, light treatment, creams and vitamins.”
- o “Difficulty finding a provider, long commutes, expensive.”

### 3.2 What are the main expectations patients and their families have for the new treatment?

*For example:*

- *Expectations of effectiveness for relieving certain symptoms*
- *Expectations with regard to adverse effects*
- *Expectations with regard to other characteristics of the treatment*
- *Expectations with regard to access*
- *Deficiencies the ideal drug should address*
- *Alternative to current treatments*

When asked, “What aspects of psoriasis are the most important to control in your opinion?” of the 15 people who responded, the majority (73%) selected “itching”, more than half (53%) indicated “pain” and about a third selected all of the following – bleeding, related conditions (e.g., diabetes, heart disease), depression and social stigma.

- o “Life is difficult with this disease ... it's so painful ... some of these questions just don't answer half of the pain that anyone goes through with this skin condition!”
- o “I was unable to participate in any social activity, could not walk downstairs and did not feel like socializing due to the pain and discomfort from my psoriasis on my feet. When I have experienced a flare up, I stay at home, in my bedroom.”
- o “My well-being is just ... well ... just not well ... you isolate because of the pain or the embarrassment! Try vacuuming your bed daily from all the shredding skin ...that in itself is painful!”
- o “I will not travel to tropical destinations or beaches.”
- o “...I don't want to go swimming or to the beach and that affects my family.”
- o “My mom washes my towel and sheets daily and has tried changing my diet.”

#### **4. Experience with the drug under study**

4.1. For those who have tried the drug under study, what effects did it have (positive or negative)? What differences did using this drug make in their lives?

*For example, in terms of:*

- *Benefits and drawbacks compared to currently available treatments*
- *Ease of use or observance (procedures for administering/taking the treatment, use of the drug as prescribed)*
- *Effectiveness, quality of life (e.g., improvement of symptoms)*
- *Adverse effects (e.g., aggravation of symptoms)*
- *Effects on daily life and domestic activities*
- *Effects on personal or social life or relationships (e.g., financial impact)*

From the patient survey that asked specifically about the patient experience with Cimzia:

- 16 of the 23 respondents had used Cimzia, with 70% of respondents reporting that they have lived with psoriasis for more than 11 years;
- 11 of the 16 respondents who tried Cimzia stated that they did not experience any side effects, with two stating that they experienced redness at the injection site and 3 had cold, flu-like symptoms for a day after the initial injection;
- 1 respondent stated that it did not help his symptoms at all; and
- 14 stated that there were no symptoms that Cimzia did not manage as well as previous treatments.

And most importantly, 15 of the 16 respondents stated that Cimzia had “a positive effect on my life.” Here is what they told us:

- o “Cimzia improved my psoriatic as well. No joint pain at all while taking this drug.”
- o “My skin has been mostly clear since starting this injection.”
- o “100% better than any other treatments I have used.”
- o “No more scales and patches!!”
- o “Better than anything else I tried.”

In terms of ease of use, 12 of the 15 patients who answered this question stated that Cimzia was easier to use or about the same as previous treatments.

## 5. Additional information

Please provide any additional information that may be useful for the drug evaluation.

*For example:*

*- Ethical or social issues, relationship conflicts with family members or health care professionals*

Firstly, psoriasis 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. Patients are often waiting for the next treatment option in hopes that it will work well for them and achieve 100% effectiveness with limited side effects.

Secondly, psoriasis is much more than “just a skin disease.” It is estimated that up to 30 percent of people with psoriasis develop psoriatic arthritis. People with psoriatic disease also are at greater risk of developing cardiovascular disease, depression and other health conditions such as cancer (a 2015 study - <https://www.psoriasis.org/advance/cancer-rates-rise-with-psoriasis-biologics-have-little-effect>), diabetes (a 2012 study - <https://www.psoriasis.org/media/press-releases/psoriasis-tied-higher-risk-type-2-diabetes>), and cardiovascular disease (a 2015 study - <https://www.psoriasis.org/advance/cardiovascular-disease-the-leading-cause-of-death-for-psoriatic-arthritis>.) For these reasons alone, the more effective treatment options available to patients becomes even more important as these co-morbidities have an economic impact on the health system.

Thirdly, for more information about the challenges of living with psoriasis, please see CAPP’s recent report called “Pso Serious 2018: A Report on Access to Care and Treatment for Psoriasis Patients in Canada”: [http://psoserious.ca/wp-content/uploads/2018/10/CAPP\\_2018\\_Report\\_Final.pdf](http://psoserious.ca/wp-content/uploads/2018/10/CAPP_2018_Report_Final.pdf).

Lastly, all patients are looking for a treatment that will control all of their symptoms but ultimately they want a cure!

## 6. Key points

In a maximum of five statements, list the most important elements of your responses to this questionnaire. These statements will be quoted and highlighted in the evaluation of the drug.

1. Gaps in treatment continue to exist and can have profound effects on all aspects of a person's life - the vast majority of survey respondents (many of whom shared that they have tried various therapies) identified as being a person with psoriasis that they feel is uncontrolled. Certain individuals may be disproportionately impacted by the gaps in treatment, such as women whose treatment options may be limited if they are planning a pregnancy or become pregnant.
2. Survey respondents report feelings of embarrassment; loss of sleep; problems with intimacy; negative effects on self-confidence; just under half (47%) indicated that their concentration at work is "frequently" affected; more than half (53%) indicated that they "frequently" experience feelings of depression.
3. When asked, "What aspects of psoriasis are the most important to control in your opinion?" of the 15 people who responded, the majority (73%) selected "itching", just over 53% indicated "pain" and about a third selected all of the following – bleeding, related conditions (e.g., diabetes, heart disease), depression and social stigma.
4. The patients who have used Cimzia were very positive about its efficacy and ease of use. There were no significant side effects and it improved their quality of life.
5. Patients expressed hope that this medication will be covered by public and private drug plans both for themselves and so that it is accessible to others who may experience symptoms as severe or worse than their own.

### **INESSS thanks you for your participation!**

This questionnaire was based on the "Questionnaire de recueil du point de vue des patients et usagers pour l'évaluation d'un médicament" (2016), by the French National Authority for Health, and the "Patient Input Template for CADTH CDR and pCODR Programs" (2017), by the Canadian Agency for Drugs and Technologies in Health.