



## Common Drug Review *Patient Group Input Submissions*

### **Adalimumab (Humira HS) for Hidradenitis Suppurativa**

**Patient group input submissions were received from the following patient groups. Those with permission to post are included in this document.**

Canadian Skin Patient Alliance — permission granted to post

HS Aware — permission granted to post

### **CADTH received patient group input for this review on or before November 19, 2015**

Disclaimer: The views expressed in each submission are those of the submitting organization or individual; not necessarily the views of CADTH or of other organizations.

While CADTH formats the patient input submissions for posting, it does not edit the content of the submissions.

CADTH does use reasonable care to prevent disclosure of personal information in posted material; however, it is ultimately the submitter's responsibility to ensure no personal information is included in the submission. The name of the submitting patient group and all conflict of interest information are included in the posted patient group submission; however, the name of the author, including the name of an individual patient or caregiver submitting the patient input, are not posted.

## Canadian Skin Patient Alliance

### Section 1 — General Information

<b>Name of the drug CADTH is reviewing and indication(s) of interest</b>	Adalimumab for Hidradenitis suppurativa (HS)
<b>Name of the patient group</b>	Canadian Skin Patient Alliance
<b>Name of the primary contact for this submission:</b>	[REDACTED]
Position or title with patient group	[REDACTED]
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<b>Permission is granted to post this submission</b>	Yes

#### 1.1 Submitting Organization

The Canadian Skin Patient Alliance (CSPA) is a non-profit organization that serves patients with dermatological conditions, diseases and traumas in Canada. It focuses on education and advocacy for these patients and for its 20+ affiliated disease-specific organizations in Canada. The CSPA has a steady social media community\* as well as thousands of readers via our award-winning magazine Canadian Skin (À propeau in French).

\*Currently: 2343 Facebook "likes" and 425 followers on Twitter.

#### 1.2 Conflict of Interest Declarations

The CSPA relies on the financial support from the pharmaceutical industry to sponsor the important work that we do. We have the following declaration(s) of conflict of interest in respect of corporate members and joint working, sponsorship, or funding arrangements: Abbvie, Celgene, Eli Lilly, Galderma, GlaxoSmithKlein (Stiefel), Janssen, Leo Pharma, Merck, Pfizer, Roche, Novartis and Valeant.

Abbvie is a founding sponsor of our Canadian Skin magazine. As well, Abbvie provided the CSPA access to patient testimonial videos to better understand the impact of the disease. Abbvie also hosted a Hidradenitis suppurativa patient meeting where the CSPA had the opportunity to observe the 18 HS patients in attendance and hear about their individual journeys with this disease.

## Section 2 — Condition and Current Therapy Information

### 2.1 Information Gathering

Information for this submission was gathered by several means: A bilingual questionnaire was promoted via social media to HS patients or those suffering with HS related symptoms. The total number of usable questionnaires we received was 73 with 93% of the responses from women and 62% under the age of 39. Furthermore, we viewed patient testimonial videos and also had information from hearing directly from the HS patients who attended an HS patient event.

### 2.2 Impact of Condition on Patients

From our questionnaire, we learned that:

- 38% shared that pain was the hardest part of the disease to control;
- 20% complained about the many flare-ups;
- 16% feel that leakages/drainage is the most important to control; and
- 16 % stated that it is the psychological burden.

In regards to which parts of their body is most affected with HS sores:

- Groin: 73%
- Underarms: 59%
- Between buttocks: 51%
- Under breast: 37%

#### How does this condition affect day-to-day life?

It was sad to learn that 66%\* of patients shared that HS affected everything that they do. Furthermore, 88% of the respondents answered that they felt embarrassed, constantly hid their skin from others and had a drop in their self-confidence, either “frequently” or “always.” At least 75%\* responded that they “frequently” or “always” that they were depressed and had their level intimacy decline. And, many complained about the wound care aspect, some replacing gauze 3 times per day.

#### How long have they been suffering?

Our respondents shared how many years they have suffered with symptoms of HS:

- 1-10 years: 49%
- 11-19 years: 14%
- Over 20 years: 22%

46% visited the ER at least once due to HS complications with one patient visiting the ER over a 100 times since diagnosis.

#### Are there activities that the patients are unable to do as a result of the condition?

Overall, over 80%\* of patients stated either “frequently” or “always” that they constantly live day-to-day with pain, cysts, leakage/drainage, scars and itching.

As well, here are some specific activities impacted due to HS symptoms:

- 71%\* said they had an increase of laundry (and associated costs.)
- 66%\* said they could not sleep well.
- 50%\* are unable to sit due to discomfort/pain.
- One patient shared he/she was unable to drive a car due to arm pain.

## 2.3 Patients' Experiences with Current Therapy

### What therapy are patients using for this condition?

It is important to understand that there are currently no approved treatment options for HS patients. Physicians therefore are required to try a variety of options up to and including surgery.

Our responses showed that patient either used or are still using the following treatment options:

- Antiseptics: 81%
- Antibiotics: 68%
- Surgery: 64%
- Retinoids: 22%
- Photo-dynamic therapy: 15%

Patients also mentioned that they have used all kinds of other treatments in an effort to find some relief. These included: Accutane, hair removal, honey, hormone replacement, off-label blood pressure medication, major skin grafts, bleach baths and bleach cream.

Quote from a patient: "My family physician cuts them open - that's the only treatment I've ever known."

### How effective is the current therapy in controlling the common aspects of this condition?

One patient said that surgeries work well to calm symptoms for a short time but that they are very painful and all the follow-up appointments and necessary wound-care are very inconvenient. Surgery does not cure the disease however and recurrent surgeries are usually needed. Many shared that changing their diet and losing weight did help somewhat but did not prevent flare-ups.

### Are there adverse effects that are more difficult to tolerate than others?

HS on its own is a very painful condition, however some patients complained of immense discomfort and pain due to treatments they endure such as multiple skin grafts and surgeries which often only offer temporary relief. One patient shared having a scalpel used without any anesthetics. Surgeries and the post-surgery care impact the patient's ability to work as well as burden the caregivers.

For any treatments patients were required to stop, here are the main reasons they had to stop:

- Antibiotics: 63% said it stopped working
- Antiseptics: 82% said it stopped working
- Retinoids: 44% said physician advised to stop
- Surgery: 64% said physician advised to stop

### Are there hardships in accessing current therapy?

From the questionnaire:

- 50% of those using photo-dynamic therapies had to stop due to high costs.
- 22% of patients had to stop having HS related surgeries due to the direct and indirect costs.

Many patients complained of the costs of bandages and OTC pain killers as well as the day-to-day long term burden of wound care.

- Are there needs, experienced by some or many patients, which are not being met by current therapy? What are these needs?

An effective alternative to surgeries would offer patients relief without the trauma and cost of multiple skin grafts and surgeries. As well, if a treatment reduced the need for bandages by any amount, patients would be relieved of the daily burden of applying/managing bandages not to mention the costs of all these bandages.

Patients live with an enormous amount of stress due to the HS. Some stated that travelling by bus is traumatic and humiliating if the sores leaked. There is a smell to the drainage which causes them to avoid social contact and is therefore very isolating for them. Surgery does not take these stresses away.

### 2.4 Impact on Caregivers

Although difficult to admit, 53% of patient stated that their loved ones or their caregiver are impacted daily due to HS. More specifically, many shared having to count on their caregiver to drive them to/from appointments which affects their work day/career. Their children have taken over household chores. Some adults suffering from HS have lost their jobs, home and must move back in with their parents. One adult patient shared having her parents bathes her. Some parents with HS admit to avoiding swimming (or other physical activities) or even going outside with their children, impacting everyone's day-to-day activities. Others admit to avoiding medical related appointment such as the dentist due to their leaking sores. Finally for the largest burden, 75% of patients shared they had a declined in intimacy with their partner due to HS.

Here are personal quotes to highlight the impact of HS on caregivers:

- "It was a main factor in the demise of my relationship."
- "Sex hasn't happened in over 2 years because of pain and the look of HS".
- "Periods of extreme pain cause withdrawal or my apparent loss of interest in sexual relations that my wife must endure.
- "The lesions in the groin area led to the end of my marriage..."

## Section 3 — Information about the Drug Being Reviewed

### 3.1 Information Gathering

Information for this submission was gathered by several means: A bilingual questionnaire was promoted via social media to HS patients or those suffering with HS related symptoms. The total number of usable questionnaires we received was 73 with 93% of responses from women and 62% under the age of 39. Furthermore, we viewed patient testimonial videos and also had listened to the HS patients who attended an HS patient meeting.

### 3.2 What Are the Expectations for the New Drug or What Experiences Have Patients Had With the New Drug?

a) *Based on no experience using the drug:*

- Is it expected that the lives of patients will be improved by this new drug, and how?  
Given that there is no current approved treatment for HS, patients expect to have a lot less daily wound care, less laundry, less pain, less itching, less leaking sores and less scaring. Simply avoiding surgery would allow patients to live a more normal day-to-day life.
- Is there a particular gap or unmet patient need in current therapy that this drug will help alleviate?

There is currently no approved therapy for HS. Patients require access to a treatment that alleviates symptoms in the long term allowing them to live a normal life, work, leave the house without having to spend lengthy periods of time applying bandages to absorb leaking sores and care for wounds. Worse are those having skin grafts and multiple surgeries that require weeks of post-surgery care and recovery.

- How much improvement in the condition would be considered adequate? What other benefits might this drug have — for example, fewer hospital visits or less time off work? Most patients have been suffering for years with debilitating symptoms, without treatment options so any improvement would be welcome. In personal comments boxes in our survey, some are begging for a cure.
  - “Please find a cure it’s ruining my life”.
  - “More treatment options need to be put in place for patients.”
  - “Few treatments seem available which can be depressing”.
  - “Surgery worked in the armpit area for about 1 yr. I started to get abscesses in the scars of my armpit, causing the skin to break open. After that they have been flaring up repeatedly.”

Patients shared what triggers their HS. Many of these activities are ones that healthy individuals take for granted. Here is a summary of the HS triggers:

- Stress: 80%
- Anything that induces sweat: 57%
- Menstrual cycle: 51%
- Some clothes: 41%
- Unhealthy eating: 37%
- Weight gain: 29%
- Exercise: 28%
- Other triggers mentioned in the comments box: allergies, physical pressure, particular seasons, diabetes, and certain foods and even, skipping a shower.

Any level of relief from the painful symptoms of HS would be of benefit to patients. Less time with wound care allow patients the opportunity to work a full-day at the office, sit for long periods of time without pain, travel, less medical appointments, fewer visits to the ER and more freedom for the caregivers to live their life too.

It could allow patients the opportunity to spend time with their children without anxiety of leaving the house or swimming in a pool. Also, it could allow for some to attempt to rekindle their intimate relationship with their partners after years of absence.

For some, HS has a life-threatening impact, we had a few patients share their thoughts of suicide due to their HS.

- “Burning intense pain, think about suicide.”
- “Pain can be unbearable, make you want to give up.”

*b) Based on patients’ experiences with the new drug as part of a clinical trial or through a manufacturer’s compassionate supply:*

- What positive and negative effects does the new drug have on the condition? Which symptoms does the new drug manage better than the existing therapy and which ones does it manage less effectively?

We asked those taking Adalimumab if its influence was worse, the same or better control of their HS symptoms. 75% said they had better control of their: ability to sit, red lumps, drainage leaking wounds, stinging, pain, level and cost of laundry. They expressed hope over having some kind of relief.

- Does the new drug cause adverse effects? Which adverse effects are acceptable and which ones are not?

Regarding side effects patients indicated the following side effects: infections, headaches, joint pain and feeling tired after the treatment. However, all who answered said that these adverse effects would NOT influence their decision to continue treatment as they felt so much better than prior to taking the drug.

- Is the new drug easier to use?

Given that surgery is really the only other option, Adalimumab is much easier.

Adalimumab is taken by injection once every two week. It is important to consider the physical and psychological burdens of the following other treatments currently being used by HS patients:

- Wound care: Patients with HS continuously care for their skin to manage the leakage and to avoid swelling. Wound care is a very time consuming part of their day-to-day life. It must be done before they leave the house and it is always in the back of their mind when away from home.
  - Surgery: When HS grows deep into the skin, medicine alone may not be effective. The surgeon can turn HS into scars, drain HS lesions to relieve pain or remove HS lesions and graft healthy skin in its place.\*
  - Side effects from other systemic treatments include: liver damage, stomach pain, exposure to radiation and more.
- How is the new drug expected to change a patient's long-term health and well-being?  
For those taking Adalimumab, the following feedback was provided:
    - "Changed my life for the positive; regained ability to participate in more activities of daily life."
    - "Well over all it's been great I still have flares but not like before. I can have days were I'm tired the same day and next day of injection but it's so worth it."

\*<http://www.aad.org/dermatology-a-to-z/diseases-and-treatments/e--h/hidradenitis-suppurativa/diagnosis-treatment-and-outcome>

## HS Aware

### Section 1 — General Information

<b>Name of the drug CADTH is reviewing and indication(s) of interest</b>	Humira (Adalimumab) for Hidradenitis Suppurativa (HS)
<b>Name of the patient group</b>	HS Aware
<b>Name of the primary contact for this submission:</b>	[REDACTED]
Position or title with patient group	[REDACTED]
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Telephone	647-317-4109
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Website	<a href="http://www.hsaware.com">www.hsaware.com</a>
<b>Permission is granted to post this submission</b>	Yes

#### 1.1 Submitting Organization

HS Aware is the only Canadian patient community that empowers people living with Hidradenitis Suppurativa (HS) through peer support and information. With its website, [www.hsaware.com](http://www.hsaware.com), and its growing presence on social media - [Facebook](#), [Twitter](#) – it is the meeting place for thousands of people suffering from HS.

The community adopts the Social Model of Disability vs. a medical model. It offers no clinical data or advice, but rather supports and enables its community through the sharing of stories and experience, and facilitation of meaningful, relevant conversations.

#### 1.2 Conflict of Interest Declarations

a) *We have the following declaration(s) of conflict of interest in respect of corporate members and joint working, sponsorship, or funding arrangements:*

Zal Press has received honoraria for speaking and delivering educational programs to AbbVie, Sanofi, and Actavis. He is Co-Chair of The Beryl Institute Global Patient and Family Advisory Council, a worldwide community of practice and thought leadership to improve the patient experience, with an international membership exceeding 38,000 that includes patient experience professionals, health care institutions and industry representing a broad cross section of pharmaceutical companies. He is also Executive Director of Patient Commando Productions a developer of educational programming for Continuing Medical Education and intensive physician/patient communication training for public health organizations, institutions, and industry including AbbVie, Sanofi, Actavis.

b) *We have the following declaration(s) of conflict of interest in respect of those playing a significant role in compiling this submission:*

This is not applicable. The quotes in this submission are the authentic, public comments from members of the HS Aware community. Analysis was conducted independently.

## Section 2 — Condition and Current Therapy Information

### 2.1 Information Gathering

Data sources include:

- conversation threads in the HS Aware social media platforms,
- the HS Aware website story submission platform,
- personal interviews

An inductive qualitative approach was used focusing on the narratives, where identified themes are linked to the data set rather than to theoretical perspectives.

### 2.2 Impact of Condition on Patients

Hidradenitis Suppurativa (HS) is a chronic, recurring condition. It has been reported in children as young as 8 and people over 60. The bulk of the community is composed of females aged 20-45. It commonly presents as boils in the armpits, groin or under the breasts. It is very painful, debilitating, and has a striking burden on the physical, emotional, social, and economic status of the patient. The impact is discussed in greater detail:

#### **Pain: Pain is a constant in the life of HS patients and has both physical and emotional associations.**

- *“Try to be a mom of two sons, work and maintain a household when in constant pain. Getting up out of bed everyday when your body feels like a pin cushion for swords. Not able to have full use of your limbs. Nerve pain, muscle aches, extreme fatigue, drainage, compromised immune system, scars, joint pain, depression, can not exercise without pain, doctors not knowing how to help you.”*
- *“The pain is like nothing else I’ve felt in my life before. It’s stinging, not only physically painful – going to the bathroom, getting into the bath – but mentally getting through each day.”*
- *“It’s difficult to explain to people how much pain you’re in when what they see looks normal. They can’t see the scarring, or know how embarrassed you’re feeling. They don’t understand the pain and exhaustion from living with the disease.”*
- *“When I get up mine has been attacking my lymph nodes. I can not move literally until I take some serious pain control meds.”*

#### **Mobility: Restricted mobility is debilitating, affecting lifestyle and daily activities.**

- *“Mobility is very hard especially if I have them underneath my arms. Doing simple things like dusting or cleaning floors can be very painful. If I have it in the groin area – walking is very hard. Sitting is very hard. I had them on the side of my stomach and rolling over at night would make me wake up screaming because I just busted a boil that was inside.”*
- *“It’s a struggle to stay a healthy weight because you can’t move—no one gets that. Mine is mainly in my groin and it sucks.”*

### **Emotional: Stigma associated with the physically ugly, malodorous, bleeding nature of HS drives patients into isolation and depression.**

- *“HS is the disease affecting all aspects of my life, changing a relatively happy teenager into a morbid 30 year-old adult on a very dark, self-destructive path.”*
- *“The loneliness was crushing most days. I had gone from having a group of friends who I saw and went out with almost daily to knowing no one but my Dad in a 200 mile radius.”*
- *“Chronic pain, body issues (due to the unsightly scars and open wounds), and self-medicating drove me into a life of isolation, one that almost killed me.”*
- *“I was so depressed. I had myself convinced that since I hated myself, everyone else must as well.”*
- *“My body is a road map of scars from the HS itself and the HS surgeries I've had. I have to remind myself to see them as strength some days I just look in the mirror and cry. It's hard, but they really are signs of strength - just wish everyone would see them that way!”*
- *“My biggest challenge is having the courage to allow people into my personal life....because of the shame I feel for how HS has affected me.”*

### **Social: Social exclusion is common, a result of low self-esteem, an inability to “fit in”, restricted lifestyle choices and limitations on personal relationships.**

- *“The biggest challenge I have living with the disease is having to be cautious about the clothes I wear. There are a couple of shirts I'd love to wear but I'd be afraid of staining them.”*
- *“Not feeling beautiful, Not being able to wear a bathing suit, scared of having a serious relationship with anyone, hiding to change clothes,”*
- *“Single, Non income earning, 6 foot 4, hairy, toothless, obese, semi disabled, very artistic 30 something who lives with his dad“ Is not the highlight on singles websites you would think it is.!!!.”*
- *“I think HS disease affects a lot of people, but they are too embarrassed to seek help. HS not only eats away at our bodies, it can take away our self-esteem as well. Having it can also make having intimate relationships almost impossible.”*

### **Economic: Lack of predictable health affects work opportunities. Disability, low income, absent employee benefits programs, adds to social exclusion, interferes with capacity to self-manage and afford the costs of care and magnifies the physical impact of illness.**

- *“HS is a life changing disease, especially when you can't predict when your next flare up will be. My job is strenuous; involving organization, cleaning and staging. Because of the disease, I had to cut my work hours down to almost nothing. It's very hard to hold down a job when you can't be relied on.”*
- *“I'm out of sick time because of it. I'm just hoping my flares aren't too bad for the rest of the year.”*
- *“The financial cost is huge water and electric=bed changes, clothes changes showers..fuel to appointments..thrush treatment (after antibiotics) clothing/bedding/towels wear out so quick as needing such hot washes so often...pads to protect bed in case of bursts, oh the list is endless*
- *“In Canada we have free access to Dr's but not meds/treatments. I can go see my dermatologist and she can tell me about the new meds/treatments available, and in the next breath tell me if I don't have \$4000/month, I'm outta luck.”*
- *“I've had to call out or leave work early because they bleed out badly under my arms. ”*
- *“dont work on disability I had a nice job painting construction work till this hs disease.”*

### 2.3 Patients' Experiences with Current Therapy

There is no singular course of treatment for HS. Patients struggle to manage a chronic condition based on a wide variety of options presented to them by GP's, specialists, surgeons and others. The HS patient experience is typically an unending array of different treatments for recurring symptoms.

**Diagnosis: A major obstacle to getting treatment is the time it takes to get a diagnosis. It often takes years exposing patients to unnecessary treatments and side effects. Lack of practitioner competency to recognize HS is a commonly raised issue.**

- *"26 years before someone told me what it was."*
- *"I had a long horrible, excruciating surgery for this after going to all kinds of different doctors for 18 years! So needless you can imagine how bad my surgery was!"*
- *"I've had HS for at least 10 years but only stumbled across the diagnosis last month."*
- *"The biggest challenge I've had with HS is getting a diagnosis and proper medical treatment. I diagnosed myself after I started getting sores on my breasts. I was told by my first dermatologist that what I had was only a hygiene problem and to take bleach baths."*
- *"(the boils) appeared on my thighs, butt and groin. The thing I regret is not telling my doc right away. I was too embarrassed to show him since I figured they could be from not washing enough."*

**Surgery: Surgical options range from lancing and excision to skin graft. Surgery for severe boils result in open wounds that heal slowly, have social and employment impact, and leave the patient scarred.**

- *"Surgery with complete removal and skin grafts. 47 years with HS now and this is the only treatment that allows me temporary times of no sites."*
- *"I have huge scars [from surgery] but hell who cares right. I went through years of hell to finally get the surgery which is bs as this surgery whether it works or does not it should still be easily available."*
- *"Over 15 surgeries on both underarms, 2 skins grafts that failed, now I have scars from the front to the back of my armpits"*
- *"I had over 70 surgical procedures and 6 skin grafts, a lot of people don't like having surgery because of the worries of being disfigured."*

**Antibiotics: Antibiotics are commonly reported to be prescribed by GP's or Emergency physicians before referral to a specialist.**

- *"It feels like I've been taking antibiotics forever."*
- *"As someone whose been on all the antibiotics the doctors can think of trying (it feels) for some time, the only relief or somewhat success I've had is with mixing a healthy diet (knowing what food trigger outbreaks, zero sugar), exercise, antibiotics and an anti-inflammatory medication."*
- *"I've had so many antibiotics, change of diet, lost weight, quit smoking and still no relief."*
- *"I've been struggling with this for 27 years. I've done surgery, antibiotics that no longer work."*

**Steroids: The most severely inflamed boils may respond to Cortisone shots.**

- *"I get cortisone shots in them when really bad - they shrink almost immediately."*
- *"I go when it has sinuses because it shrinks it so it doesn't create more to drain from. So when it's bad or in a spot that bothers me too much to sit or perform daily activities I go."*
- *"The thing I've found that helps me the most are the steroid injections. On average it cuts a Lesion's active time by half. On top of that I use 2 different kinds of creams when I have a flare up."*

**Wound Care: Proper treatment of open wounds is a vital component of a patient's treatment. It can be a challenging and physically demanding task and an expensive one as well.**

- *"Every tape or bandage hurts me- the only kind that doesn't is too expensive."*
- *"At least 20 band aides a day."*
- *"I've found all adhesive literally eats my skin. Since i never leave my house anymore due to HS, I usually use nothing but towels and stay in bed."*
- *"While I'm so glad we can all share and discuss this it just breaks my heart to know that we are secretly all walking around bandaged up and in pain. I use any gauze I can get my hands on and tape for sensitive skin."*

**Self-Management: The relentless pursuit of relief typifies the complexity of the HS lived experience resulting in a myriad of different treatments that for the most part only offer temporary relief.**

- *"I went through years as a teen on rounds of antibiotics and pain killers, then I went through cortisone shots, I had surgery to extract a cyst but it ruptured and they ended up removing 1lb of scar tissue from my leg, I'm now being treated by the dermatology clinic with Accutane, laser hair removal, topical clindamycin, and hibiclens. I have been on Accutane for 4 months and unfortunately it doesn't seem to be working."*
- *"I've tried a lot of different treatments for the disease, including:*
  - *Accutane*
  - *Antibiotics*
  - *Diet changes*
  - *Hormone blockers*
  - *Holistic Treatment*
  - *Laser hair removal*
  - *Lancing*
  - *Surgical Removals*
  - *Kenalog injections*
  - *Weight loss*

*"I have tried all conventional medicines, creams, solutions, bleach and Epsom salt baths, vapor rub, etc... I have been on Ramicaid for three years. It started off fine drying them up but now it seems to wear off a few weeks before I'm due for another treatment. My next option is surgery."*

- *"I spent hundreds going to a natural path (just went broke and got daily headaches) laser hair removal has helped (but cost a fortune) I'm lucky to have my parents help me with the cost . I have to go every 6 weeks and its \$420 for underarms, bikini and thighs, and butt. (Been doing this for 2 years. Kenalog injections work best. But my body is getting immune after 3 years. Two weeks ago we started surgery remove. But I'm not healing and my stitches ripped yesterday."*

### **2.4 Impact on Caregivers**

Limited treatment choices compound the burden on the patient and the caregiver equally. Caregivers suffer income loss from time taken from work, costs to support non-reimbursed treatments, a social deficit from attending to the patient's needs, and an emotional impact caused by the conflicting emotions that arise.

- *"I've had to do a lot of cleaning out tunnels, changing bandages etc, but after all the help - and they continue doing everything the dr says not to - it gets very frustrating. They consume every substance that makes it worse. Sadly it's like they like the attention. I don't get it. I had to walk away."*

- *“I understand the need to support my husband and I do try to, but sometimes I fail just as in life sometimes he fails to support me. HS is terrible and understood by too few Drs where we live.”*
- *“I am supportive but sometimes it is difficult when HS has changed our lives in ways we couldn't imagine.”*
- *“My daughter has been suffering with this horrible disease for over 10 years. I wish I could help her.”*
- *“Trying to hide the pain caused by cuddling with my son or being intimate with my husband. I can deal with the pain, the drainage, and the treatments; the guilt on the face of my family thinking they have hurt me kills me inside.”*
- *“There are still days though that actual physical contact from another human being feels so needed, but the slightly uncomfortable feeling of a hug from my 76 year old father does not quite cut it.”*
- *“I'm thankful for my mom. She is always there for me. Has become my nurse and it's not a profession she wanted, through all my HS surgeries has been there to bandage me up, clean my wounds, and hold my hand. She often helps me cut and drain and packs my HS and bandages me. I don't know what I would do without her. I'm 37 and a proud mama's girl.”*

### Section 3 — Information about the Drug Being Reviewed

#### 3.1 Information Gathering

Data sources include:

- conversation threads in the HS Aware social media platforms,
- the HS Aware website story submission platform,
- personal interviews

An inductive qualitative approach was used focusing on the narratives, where identified themes are linked to the data set rather than to theoretical perspectives.

#### 3.2 What Are the Expectations for the New Drug or What Experiences Have Patients Had With the New Drug?

a) *Based on no experience using the drug:*

Those who have no experience generally concentrate on cost and side effects when discussing biologics in general and Humira specifically. These may be misconceptions based on community chatter rather than actual informed research. As with any new treatment there is an aspiration that it would bring long term relief however it is tempered with a degree of scepticism. These feelings are reflective of a treatment fatigue many chronic patients suffer after numerous years of ineffective treatments.

- *“It's too expensive and not covered on Ontario disability.”*
- *“I don't have coverage and I'm not sure I have done enough research on humira. And the side effects sound scary. But at this point in my life. I'm willing to try anything.”*

b) *Based on patients' experiences with the new drug as part of a clinical trial or through a manufacturer's compassionate supply:*

Positive results are reported to occur within weeks of starting treatment with Humira. Patients are discontinued at an early stage if no improvement. The preponderance of experience reports improvement of the defining HS symptoms reducing pain, frequency and intensity of flare ups which become easier to manage. There is virtually no mention of surgery while on Humira or visits to emergency departments. Patients speak of an improved quality of life and mental state, the ability to participate in daily activities, return to school or resume their careers. Patients have reported allergic reactions, some infections and pain at the injection site.

- *“I was scared too. I'm glad I decided to give Humira a try because it's helped me so much. The pain isn't near as bad. I have limited flare ups and as a result I'm feeling better mentally as well.”*
- *“I was on Humira for 6 months but starting having a reaction at the injection site. However I did notice very little breakouts in the area during the last month of treatment.”*
- *“I've been on Humira since April and have had no major side effects to it and the amount of boils is greatly reduced. I've gone from finding multiple new ones daily to one or 2 new ones a week.”*
- *“I have been taking Humira for approx 4years and am nearly pain free and with drainage reduced to nearly zero. I started seeing results within two weeks of the first injection.”*
- *“I've been on humira for one year now weekly injections. I'm about 85% flare free. I understand it's not for everyone but definitely worth a shot! I've suffered with HS for 13 years now and I'm only 25.”*
- *“I've been on weekly injections for just over a year now and it's controlling my demons very well - they are less frequent, less painful, go away faster & often don't even drain just disappear! Humira isn't a cure but for me its made an incredible improvement in my quality of life.”*
- *“My daughter has been suffering this for years. Had 3 surgeries, skin grafts etc. Hospital stays 1-3 months per surgery. But now she is taking Humira every week and it seems to be working. Currently she has no open tracts. She was one of the worst cases seen. “*

### **Section 4 — Additional Information**

N/A