BEYOND THE VISIBLE:
rosacea and psoriasis of the face

Exploring new dimensions beyond the known
Dear reader,

Together, we can change the face of skin disease in rosacea and psoriasis.

The Beyond the Visible 2018 report highlighted the burden faced by people with rosacea and the impact their disease played in their daily lives. It showcased how often people with this lifelong disease often shy away from talking about the true impact of their disease, while doctors do not proactively acknowledge the problem. It was time for a change; those suffering with rosacea were asked to speak up about all aspects of their disease burden and doctors were asked to reach out to their rosacea patients and ask about their burden.

Rosacea is usually found on the face, with a visible presence that can make people feel like they are being unfairly judged by those around them. Psoriasis, although commonly found on many parts of the body which can often be hidden from public scrutiny, can also present with facial involvement similar to rosacea. In this current survey, we chose to look at this group of psoriasis sufferers alongside rosacea sufferers to better understand the extent of burden faced by those with visible facial skin diseases. This survey also provides further insight of how both groups are managed by doctors, helping us expand our understanding beyond what we already know and see.

Beyond the visible signs, both groups also suffer from many invisible effects. Symptoms that are invisible to the eye can often be physically stressful for people with either disease and consequently have a huge impact on their lives. To better treat these diseases, we need to address both diseases in their entirety, encompassing the signs we can see and the symptoms sufferers feel.

Disease burden and treatment satisfaction in visible diseases, such as rosacea and psoriasis, are often based on how people view themselves. Evidence shows reaching complete clearance of all lesions (‘clear’ [IGA 0]) has considerable benefits compared with reaching ‘almost clear’ (IGA 1). ‘Clear’ (IGA 0) is now possible in both diseases. Although doctors cannot promise ‘clear’ to all rosacea or psoriasis sufferers, current treatment options are now getting more people to ‘clear’ than ever before. By setting our treatment goal to ‘clear’ (IGA 0), doctors can help free more people from their overall disease burden.

For people suffering from rosacea or psoriasis with facial involvement, your voice needs to be heard. Tell your doctor about everything you are experiencing, especially the symptoms they are not able to see. Ask your doctor for more information about your disease and how it is best managed, and ensure your treatment goal is ‘clear’ (IGA 0) because ‘clear’ is possible and together you should strive for no less.

As their doctor, ask your patients about all the symptoms of their disease to get a complete picture of the true extent of their disease burden and tell them that your treatment goal is ‘clear’ (IGA 0). With your help, your patients can reach ‘clear’ (IGA 0), reduce their burden and ultimately lead better lives that are not dictated by their disease.

It is time to look beyond what we see to have more meaningful conversations. Together, doctors alongside those suffering from rosacea or psoriasis with facial involvement, can make a powerful change by aiming to make the visible invisible and the invisible disappear.

An open letter to people with rosacea or psoriasis on the face, and the doctors treating them

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IGA, Investigator’s Global Assessment
Facial skin disease: a closer look at rosacea and psoriasis

For many years, we have known that rosacea has the potential to impair people’s lives, but with little awareness of how it can be addressed. In 2018, the Beyond the Visible report provided new insights as to how the burden of rosacea is often underestimated, highlighting the need for immediate action and the necessary steps to free more people from their rosacea burden.¹

- Half of the rosacea sufferers surveyed reported that their disease had at least a moderate impact on their life* and one in three felt their rosacea had a very large or extremely large impact on their life. †
- The majority of people with rosacea surveyed changed their behavior and daily lives because of their disease, with 86% attempting to avoid trigger factors and 1 in 5 making substantial changes to their daily lives.
- Only 1% of rosacea sufferers surveyed rated themselves as ‘clear’ (IGA 0) when they reflected over the past 12 months.

Positively, the report addressed the tangible benefits of reaching ‘clear’ (IGA 0) in this group and further encouraged doctors treating rosacea to change their treatment aim to complete clearance (IGA 0) regardless of disease severity.¹ Such a change would make a meaningful difference to people suffering from rosacea, both inside and out.

Now we want to take things a step further to better understand the true extent of their burden by comparing these insights with learnings from other facial skin diseases. Looking at the impact of facial disease from different angles could bring further insights to ultimately ensure more can be done for those suffering from this chronic condition.

Our skin is one of the primary ways we connect with those around us. Fairly, or unfairly, our faces are considered a representation of our inner selves.³

Facial skin disease: a closer look at rosacea and psoriasis

Over the last decade, the burden of psoriasis has been well explored and understood with its significant physical, psychological, social and economic impact becoming common knowledge among doctors. Unsurprisingly, part of this burden stems from the severity and visibility of the disease. Some psoriasis sufferers have the disease present on their face, most often affecting the upper forehead, lower forehead and the area around the ears.² This group of people, unlike the general psoriasis population, are not as well-researched and may suffer a greater burden because of how very little can be done to hide their disease, similar to rosacea sufferers.²,³

Both psoriasis and rosacea are considered visible diseases and are often diagnosed by signs. However, these diseases are also accompanied by symptoms that can greatly impact sufferers.²,³

A sign is the objective evidence of a condition that can be seen by doctors (visible), whereas a symptom is subjective and only apparent to the sufferer (invisible).⁴

With the treatments available for both rosacea and psoriasis today, reaching complete clearance (‘clear’ IGA 0) is possible in both groups.⁵–⁸ By better understanding the true extent of the burden faced by those suffering from these chronic diseases, together doctors and their patients can aim to clear their disease entirely – encompassing the burden they can and cannot see.
Beyond the visible study objectives

Building on from the Beyond the Visible 2018 report, this new report hopes to learn more about the burden faced by those suffering from rosacea and psoriasis with facial involvement to solve the following unanswered questions:

- What is the burden faced by people with psoriasis with facial involvement?
- How does this burden differ from the burden of rosacea?
- How are both these diseases currently managed by the doctors treating them?

By looking at the similarities and differences between these two groups, we have an opportunity to better understand their true burden and the impact of disease on sufferers’ lives. With new insights in both diseases, we hope to provide guidance for those suffering from either disease and the doctors treating them, to manage burden and symptoms alongside the visible signs of disease to ultimately improve sufferers’ lives – a compelling change that is long overdue.

A total of 300 people with rosacea and 318 people with psoriasis with facial involvement, all of whom had at least a moderate level of impact to their daily lives due to their disease (DLQI ≥6), participated in the survey across six different countries: Canada, France, Germany, Italy, Poland and the USA.

**FIGURE 1a: SURVEY POPULATION CHARACTERISTICS**

**ROSACEA (N=300)**

**PSORIASIS ON THE FACE (N=318)**

Facial areas ever affected as reported by sufferers

- 100–86%
- 85–66%
- 65–46%
- 45–26%
- 25–0%
All those with psoriasis surveyed had facial involvement; however, in the past year or for the duration of their disease, rosacea sufferers were significantly more likely to have experienced visible disease on their central facial areas (Figure 1a). Nonetheless, it is important to note that those with psoriasis were not limited to just having psoriatic lesions on their face.
When comparing those suffering from rosacea with those suffering from psoriasis with facial involvement in this survey, both groups were remarkably similar in many aspects and overall a true representation of the typical patient populations seen by doctors today (Figure 1b). The fact that characteristics and disease experiences were similar in both groups provides us with confidence that the insights from this survey are a true reflection of the sufferers’ experience in both diseases.

### Inclusion criteria for sufferers

To ensure a fair and balanced survey population, the study had the following inclusion criteria for both groups:

- Adults with a self-reported diagnosis of rosacea/psoriasis with disease present on the face.
- Self-reported moderate or severe disease impact on daily life (DLQI score ≥6).
- At least one consultation with a doctor for their disease in the past 12 months.
- Taken at least one treatment for their disease in the past 12 months (psoriasis sufferers treated with biologics were excluded).
- Not currently experiencing any other skin conditions for which they were being treated.

### Flares experienced

Flares can be unpredictable and not knowing when you will have a flare or how long it will last can be extremely stressful. Flares are common in both rosacea and psoriasis. In this survey, looking closer at the flare experience of both psoriasis and rosacea sufferers revealed some interesting differences: people with rosacea reported experiencing a greater frequency of flares when looking back at the past year, while people with psoriasis with facial involvement experienced longer flares (Figure 1b). However, it is also important to note that symptoms can be present regardless of flares (Figure 2).

### Not so ‘clear’

In the last year, the majority of people surveyed, regardless of disease, considered their disease to be moderate-to-severe. On the other hand, only 1% rated themselves as ‘clear’ (IGA 0) when reflecting over the past year.

Reaching ‘clear’ (IGA 0) can make a powerful difference to those suffering from a facial skin disease. The visibility of their disease may be a cause of social isolation. One thing is clear – we need to raise the bar in managing both diseases to better support those who are suffering from rosacea and psoriasis with facial involvement.

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**FIGURE 2:** SYMPTOM EXPERIENCE

<table>
<thead>
<tr>
<th></th>
<th>ROSACEA (N=300)</th>
<th>PSORIASIS ON THE FACE (N=318)</th>
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<tbody>
<tr>
<td>75%</td>
<td>experienced</td>
<td>76%</td>
</tr>
<tr>
<td>13%</td>
<td>symptoms</td>
<td>experienced</td>
</tr>
<tr>
<td>25%</td>
<td>regardless of</td>
<td>symptoms regardless of</td>
</tr>
<tr>
<td></td>
<td>flares</td>
<td>flares</td>
</tr>
<tr>
<td>62%</td>
<td></td>
<td>64%</td>
</tr>
</tbody>
</table>

**Question asked:**

In general, would you say that your symptoms were:

- [ ] Symptoms nearly always present and worsen during a flare-up
- [ ] Symptoms nearly always present (the sufferer does not experience flare-ups)
- [ ] Symptoms appear only during a flare-up

DLQI, Dermatology Life Quality Index. IGA, Investigator’s Global Assessment. NS, not significant. PsO, psoriasis. ROS, rosacea. *71% ROS vs 79% PsO; p-NS.
The unseen burden of facial skin disease: psoriasis and rosacea

The impact of facial skin disease on sufferers’ lives

You would typically expect those with more severe skin disease to experience a greater impact on their quality of life compared with those who do not have as many signs and symptoms. However, the Beyond the Visible 2018 report proved otherwise as an increase in rosacea disease severity did not necessarily lead to a greater impact on the sufferer’s quality of life. As a result, it was important to ask both groups in this survey about their disease severity as well as signs and symptoms experienced and how they impacted their lives.

Impact on quality of life

A surprising similarity between the groups was the comparable average DLQI score of 11.3 for rosacea sufferers and 12.1 for psoriasis sufferers with facial involvement (Figure 3). This result demonstrates a similar disease impact in both groups, despite doctors commonly thinking psoriasis is probably more burdensome. Even more surprising, approximately one in 10 surveyed, irrespective of disease, felt their condition had an extremely large effect on their lives,* highlighting that the impact of these facial skin diseases to sufferers’ lives is far greater than doctors may currently believe.

A similar impact of disease on their quality of life, as measured using a 10-point scale, was also seen. In fact, the average was identical in both groups with a score of 6/10, confirming the DLQI results. Over half of those surveyed in each group felt their disease significantly impacted their daily lives† and was difficult to manage‡.

Despite these similarities, there were a few significantly differing factors, as discussed below, that also contributed to the impact on sufferers’ lives and should be understood by those treating these people to tailor their disease management based on individual needs.

Has the burden of rosacea been understood by doctors when comparing it to other facial dermatological diseases, such as psoriasis with facial involvement?

A similar impact of disease on their quality of life, as measured using a 10-point scale, was also seen. In fact, the average was identical in both groups with a score of 6/10, confirming the DLQI results. Over half of those surveyed in each group felt their disease significantly impacted their daily lives and was difficult to manage.

The majority of sufferers surveyed in both groups felt their disease was uncontrolled to some extent.§

8% ROS vs 10% PsO; p−NS; 58% ROS vs 55% PsO; p−NS; 53% ROS vs 52% PsO; p−NS; 18% ROS vs 88% PsO; p−NS

FIGURE 3: AVERAGE DLQI SCORE (6–30)

ROSAECA (N=300)  PSORIASIS ON THE FACE (N=318)

11.3  12.1

Question asked:
DERMATOLOGY LIFE QUALITY INDEX (DLQI)

DLQI, Dermatology Life Quality Index; NS, not significant; PsO, psoriasis; ROS, rosacea

*8% ROS vs 10% PsO; p−NS  §58% ROS vs 55% PsO; p−NS  †53% ROS vs 52% PsO; p−NS  ‡18% ROS vs 88% PsO; p−NS

~90%

The majority of sufferers surveyed in both groups felt their disease was uncontrolled to some extent.
Compared with psoriasis with facial involvement, people with rosacea were significantly more likely to avoid daily lifestyle habits because of their disease, such as sun exposure, drinking alcohol, eating hot or spicy foods, having hot drinks and/or using make-up (Figure 4). This may be attributed to rosacea being well-understood as a largely trigger-driven illness. However, it is still important to remember psoriasis flares can also be triggered, but by less factors as demonstrated in the survey results.

Avoiding things is not the only way people try to handle their illness. They are also, for example, likely to be very concerned with their skin care given the location and visibility of their disease and take time every day to try and manage their disease specifically. In total, 65% of the time spent by people with psoriasis with facial involvement on their skin routine was because of their disease* compared with 56% for people with rosacea.† Over a week, this would add up to a considerable amount of lost time that could be spent enjoying life if their disease was better managed. For psoriasis sufferers, the majority had lesions extending beyond the face so the time spent may include a skin routine for the wider affected areas of the body as well.

Almost half of people with rosacea surveyed felt their disease was triggered by their lifestyle choices.

**Lifestyle and daily activities**

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*16.9 of 28.2 mins  †13.0 of 24.4 mins  ‡p<0.01  §p<0.05

**FIGURE 4: DAILY LIFESTYLE HABITS AVOIDED**

- **Exposing yourself to the sun**: 59%†
- **Drinking alcohol**: 31%‡
- **Eating spicy food**: 44%†
- **Using make up**: 31%‡
- **Using cosmetic products**: 23%§
- **Eating hot food**: 20%†
- **Drinking hot beverages**: 5%§
- **Being on the computer for a long period of time**: 7%  8%
- **Driving**: 4%  6%
- **Other**: 1%  4%
- **Never avoid any activity**: 4%  11%§

Question asked:

What activities/behaviors did/do you avoid because of your rosacea/psoriasis?
Work life

As with any other disease, managing rosacea and psoriasis with facial involvement has to be balanced with other regular demands of daily life. As well as impacting the sufferer’s normal day-to-day activities, their disease can also follow them into other parts of their lives such as their working life by impacting their performance in the workplace, which can be increasingly stressful. The activity impairment due to disease was approximately 40% for both groups, with a similar impact also seen in terms of the average overall work impairment due to disease, leading to similar time missed from work/school/university in both groups (Figure 5).

The majority of all those surveyed, regardless of disease, were ashamed of their disease.†

The majority were also bothered by the physical discomfort they experienced because of their disease.‡

Question asked:

Work Productivity and Activity Impairment (WPAI). In the past 12 months, how many days of work (or school/university) did you miss because of your rosacea/psoriasis?

~70% The majority of all those surveyed, regardless of disease, were bothered by the fact that other people might notice their disease.¹

>50% Over half of all those surveyed, regardless of disease, were ashamed of their disease.∗

>60% The majority were also bothered by the physical discomfort they experienced because of their disease.‡

NS, not significant. PsO, psoriasis; ROS, rosacea

¹56% ROS vs 54% PsO; p-NS ²73% ROS vs 70% PsO; p-NS ³61% ROS vs 66% PsO; p-NS
Impact on sufferers’ emotional well-being

Emotional well-being has become an important topic in recent years, and critical for everyone to recognize in themselves and others. However, in today’s world, most people lead very fast-paced and busy lives where their emotional well-being can often take a back seat. Typically, when we do not feel we have control of things that have an impact on our lives, such as a facial disease, our emotional equilibrium can be disturbed. Expectedly, having a seemingly uncontrollable facial disease can conjure a mixture of emotions.

Unsurprisingly, due to their visibility on the face, both diseases had a similar impact on sufferers’ well-being when reviewing most of the feelings they associated with their long-term condition. However, some feelings, such as being uncomfortable, low self-esteem and low confidence, were expressed to different degrees by people with rosacea and psoriasis with facial involvement (Figure 6). As not all individuals are the same, these findings highlight the need for sufferers to more frequently discuss the impact of skin disease on their emotional well-being during each appointment with their doctor. If people suffering do not volunteer this information, doctors should proactively ask.

Depression

Depression is a real illness and not a sign of weakness. Worryingly, depression seems to go hand-in-hand with both rosacea and psoriasis with facial involvement. As shown by the survey data, approximately 50% of all sufferers surveyed reported suffering from at least moderate depression* with average depression scores being similar among both groups.† For those reporting a very large to extremely large effect on their lives (DLQI ≥11), the percentage of people with moderate-to-severe depression was unsurprisingly higher overall in both disease groups‡ with average depression scores still being comparable between groups.§

Anxiety

Similar to depression, anxiety can be extremely overwhelming and debilitating for sufferers. Unfortunately, the visible nature of facial skin diseases may contribute to anxiety levels. When looking specifically at anxiety scores, the two patient groups were again comparable with 34–43% of all those surveyed reporting at least moderate anxiety.†† Even when looking at sufferers who reported a very large to extremely large disease impact on daily life (DLQI ≥11), the proportion of people with anxiety was still comparable.‡‡

Top 5 feelings

ROSACEA (N=300)

1. Embarrassed (41%)
2. Uncomfortable (38%)
3. Low self-esteem (34%)
4. Frustrated (30%)
5. Low confidence (30%)

PSORIASIS ON THE FACE (N=318)

1. Uncomfortable (48%)
2. Embarrassed (42%)
3. Frustrated (30%)
4. Stressed (29%)
5. Bothered (28%)

Top 5 feelings

Question asked:
Which of the following do you most associate with how you feel about your rosacea/psoriasis?
Please select the 5 answers that best describe your feelings towards your rosacea/psoriasis

FIGURE 6: MENTAL HEALTH-RELATED FEELINGS ASSOCIATED WITH DISEASE

DLQI, Dermatology Life Quality Index; NS, not significant; PsO, psoriasis; ROS, rosacea
*49% ROS vs 54% PsO; p-NS †34% ROS vs 43% PsO; p-NS ‡19.9 ROS vs 10.8 PsO; p-NS (measured using the Patient Health Questionnaire-9 [score range 0–27]) §19.5% ROS vs 73% PsO; p-NS §12.3 ROS vs 13.2 PsO; p-NS ††48% ROS vs 54% PsO; p-NS ‡‡28% ROS vs 20% PsO; p<0.05
It is important for doctors to **ask about these invisible symptoms** as their patients may not always talk about them.

The invisible physical symptoms

Part of the contradiction in rosacea and psoriasis is that they are perceived to be visible diseases, yet both have so many invisible effects.\(^1\,^2\) Symptoms that are invisible to the eye may be physically stressful and may be more impactful than the visible signs of the disease.

Psoriasis is highly associated with itching, while rosacea is commonly known to be associated with burning and stinging.\(^3\,^9\) However, this survey showed both groups can also experience other invisible symptoms that are similar in nature. Those who experienced invisible symptoms were burdened enough by them to warrant the need for doctors to talk about them whether seeing someone who has been newly diagnosed or for a routine follow-up.

More information on the proportion of doctors investigating invisible symptoms in each disease can be found later in this report.

It is important for doctors to ask about these invisible symptoms as their patients may not always talk about them and clearing the visible signs of a disease may not always address the full impact of the disease experienced. We need to open the discussion surrounding the burden of facial skin disease in its entirety and ensure people are comfortable talking about the impact of all signs and symptoms, both visible and invisible, on their lives.

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**FIGURE 7: INVISIBLE SKIN SYMPTOMS REPORTED**

<table>
<thead>
<tr>
<th></th>
<th>ROSACEA (N=300)</th>
<th></th>
<th>PSORIASIS ON THE FACE (N=318)</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Patient</td>
<td>Average impact</td>
<td>Patient</td>
</tr>
<tr>
<td></td>
<td>experienced</td>
<td>on QoL out of 10</td>
<td>experienced</td>
</tr>
<tr>
<td></td>
<td>ever</td>
<td>(n)</td>
<td>ever</td>
</tr>
<tr>
<td>Burning</td>
<td>44%</td>
<td>6.7 (129)</td>
<td>53%</td>
</tr>
<tr>
<td>Stinging</td>
<td>29%</td>
<td>6.6 (88)</td>
<td>NA</td>
</tr>
<tr>
<td>Itching</td>
<td>55%</td>
<td>6.5 (162)</td>
<td>81%</td>
</tr>
<tr>
<td>Pain / Soreness*</td>
<td>21%</td>
<td>6.7 (60)</td>
<td>49%</td>
</tr>
</tbody>
</table>

QoL, quality of life

*Soreness at affected areas, around patches

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QoL impact reported by sufferers was measured on a scale from 0 to 10, where 0 meant the symptom had no impact on their QoL, while a score of 10 meant the symptom extremely impacted their QoL.

**Questions asked:**

Which symptoms/signs of rosacea/psoriasis have you ever experienced?

On a scale from 0 to 10, how would you rate the level of impact on your QoL of each symptom of rosacea/psoriasis you experienced in the past 12 months?
The sufferers’ hope: ‘clear’ (IGA 0) skin

Positively, 44% of people with rosacea and 35% of people with psoriasis with facial involvement believed it was possible to eventually clear their disease.‡ However, those who believe ‘clear’ is possible are not the majority of the group in either disease. With the advancement in treatments available, it is evident that ‘clear’ (IGA 0) is now possible in both rosacea and psoriasis.

By talking to sufferers during consultations about their disease and the likelihood of reaching ‘clear’ (IGA 0), rather than them assuming it is simply not possible, we may be able to change their perception of treatment success and how to achieve it. Empowering sufferers with this level of knowledge can help set and achieve treatment goals, and finally give sufferers control of their disease.

Ocular rosacea

Another consideration to make is that rosacea can be accompanied by ocular signs and symptoms (effects in or around the eye). 20% of rosacea sufferers surveyed confirmed they had been diagnosed with ocular rosacea at some point during their disease journey. Similar to rosacea on the face, ocular rosacea can also be accompanied by invisible symptoms, such as burning† and stinging,‡ thus introducing another dimension to the rosacea burden that may often be overlooked.

As a sufferer, is it time to talk about the true extent of your burden, including the burden that is not obvious or visible to anyone else?

As a doctor, considering the extent of burden experienced by patients, can reducing a patient’s invisible burden play a key role in successful disease management?

The sufferers’ hope: ‘clear’ (IGA 0) skin

Invisible skin symptoms and their impact on quality of life were reported in both diseases. Although people reported individual invisible skin symptoms more frequently in the psoriasis with facial involvement group, the impact of these symptoms on sufferers’ quality of life was very much aligned and impactful in both groups (Figure 7). The direct quality of life impact further shows how much of a role these symptoms play in terms of disease impact on sufferers’ daily lives.

Invisible skin symptoms and their impact on quality of life were reported in both diseases. Although people reported individual invisible skin symptoms more frequently in the psoriasis with facial involvement group, the impact of these symptoms on sufferers’ quality of life was very much aligned and impactful in both groups (Figure 7). The direct quality of life impact further shows how much of a role these symptoms play in terms of disease impact on sufferers’ daily lives.

Direct quality of life impact

As a sufferer, is it time to talk about the true extent of your burden, including the burden that is not obvious or visible to anyone else?

As a doctor, considering the extent of burden experienced by patients, can reducing a patient’s invisible burden play a key role in successful disease management?

If ‘clear’ (IGA 0) is possible, should this be actively communicated to those suffering from rosacea or psoriasis?

This report has highlighted specific invisible symptoms and their impact on sufferers’ lives that we should be acknowledging for both rosacea and psoriasis with facial involvement. As these symptoms all play a vital role in the sufferer’s disease experience, invisible symptoms should be acknowledged during all appointments and be a routine part of the disease management.

IGA, Investigator’s Global Assessment; PsO, psoriasis; ROS, rosacea
†53% of those with ocular symptoms ‡38% of those with ocular symptoms ‡p<0.05

We may be able to change their perception of treatment success and how to achieve it.
Meaningful conversations: discussing beyond the visible

The doctors treating facial skin disease

A total of 361 doctors actively treating both rosacea and psoriasis were surveyed for this report across six countries: Canada, France, Germany, Italy, Poland and the USA. Doctors were surveyed in the hope of identifying not only areas of good practice in patient interaction, but also areas that can be improved to better the lives of rosacea and psoriasis sufferers.

The doctors who completed the survey saw a balanced number of patients experiencing facial skin disease (including 14% psoriasis and 11% rosacea patients [Figure 8]), providing confidence that the results of the doctors’ survey are well-balanced and representative of the general doctor population treating skin diseases.

Approximately one-third of patients surveyed, regardless of disease, felt their disease was not taken seriously by their doctor. Can this be why patients may choose to stay silent?

Questions asked:

How many patients do you see on average of all pathologies or combined illnesses per month?

How many patients do you see on average for the following skin conditions per month?

NS, not significant; PsO, psoriasis; ROS, rosacea; USA, United States of America

*34% ROS vs 29% PsO; p<NS
Patients’ quality of life is far too great to ignore and reducing that burden can make an important difference; all it takes is a conversation.

The importance of patients’ quality of life

In this survey, the doctors were asked to reflect on how they currently manage their rosacea and psoriasis patients. As shown in the Beyond the Visible 2018 report and in previous evidence available for psoriasis, the impact of rosacea and psoriasis on patients’ quality of life is significant.1,2,10,11 As such, an assessment of a patient’s quality of life should be part of standard practice in the doctor’s management of the disease, regardless of disease severity or progression (newly diagnosed or routine follow-up patients). Despite available evidence, the patient and doctor insights in both diseases gathered during the current survey showed this is still not the case.

Quality of life and psychosocial burden assessments were not top of mind; when doctors were spontaneously asked what they investigate in their rosacea and psoriasis patients, only a small group mentioned quality of life and psychosocial burden. Despite the similar impact on quality of life seen in both groups in this report, they were more typically investigated by doctors in people with psoriasis compared with rosacea (Figure 9). The impact of both of these diseases on patients’ quality of life is far too great to ignore and reducing that burden can make an important difference; all it takes is a conversation.

When doctors do assess quality of life, there are differences in the aspects of life investigated for rosacea compared with psoriasis. Quality of life parameters more frequently assessed in psoriasis patients than in rosacea patients included family life impact,* impact on activities and sports,† and days missed from work/school.§ Since only the minority of doctors mentioned investigating quality of life when spontaneously asked what they investigate in new and follow-up patients, with an extremely small minority of doctors mentioning these parameters in rosacea patients, critical changes to how we approach facial skin disease patients in clinical practice are needed. These changes should include substantially increasing the importance, frequency and quality of quality of life assessments in both groups. By doing so, the conversations between doctors and their patients can become much more meaningful. Considering our understanding of the burden faced by both groups, these results are concerning and are also a call for action to ensure change is made for the better.

More rosacea sufferers reported their disease had a high to very high impact on their self-esteem§ compared with the group with psoriasis on their face, although the difference was not significant. Despite this evidence, impact on self-esteem‡‡ and social life§§ were assessed by a comparable number of doctors for rosacea and psoriasis alike.

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NS, not significant; PsO, psoriasis; ROS, rosacea

*60% PsO vs 41% ROS; p<0.01 §6% PsO vs 41% ROS; p<0.01 %53% PsO vs 29% ROS; p<0.01 †49% ROS vs 43% PsO; p<0.01 ‡51% PsO vs 29% ROS; p<0.01 ❋76% ROS vs 76% PsO; p=NS 59% ROS vs 81% PsO; p=NS

FIGURE 9: DOCTORS TYPICALLY INVESTIGATING QUALITY OF LIFE/PSYCHOSOCIAL BURDEN

The importance of patients’ quality of life

In this survey, the doctors were asked to reflect on how they currently manage their rosacea and psoriasis patients. As shown in the Beyond the Visible 2018 report and in previous evidence available for psoriasis, the impact of rosacea and psoriasis on patients’ quality of life is significant.1,2,10,11 As such, an assessment of a patient’s quality of life should be part of standard practice in the doctor’s management of the disease, regardless of disease severity or progression (newly diagnosed or routine follow-up patients). Despite available evidence, the patient and doctor insights in both diseases gathered during the current survey showed this is still not the case.

Quality of life and psychosocial burden assessments were not top of mind; when doctors were spontaneously asked what they investigate in their rosacea and psoriasis patients, only a small group mentioned quality of life and psychosocial burden. Despite the similar impact on quality of life seen in both groups in this report, they were more typically investigated by doctors in people with psoriasis compared with rosacea (Figure 9). The impact of both of these diseases on patients’ quality of life is far too great to ignore and reducing that burden can make an important difference; all it takes is a conversation.

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There is a disconnect between the sufferers’ experience and the symptoms that doctors typically investigate. Fear of being judged, or fear they are to blame, may be holding some patients back from talking about their true symptom burden. The Beyond the Visible 2018 report demonstrated the mismatch between rosacea patients’ perception of the symptoms they were experiencing vs how doctors perceived them (Figure 10). Simply put, what people with rosacea were feeling was not what doctors were hearing. The report demonstrated that doctors treating rosacea can often overestimate the impact of visible signs of the disease, while underestimating the symptoms that are not visible to the eye even though they are important features of living with rosacea. 1

This was calculated by: patient’s rate – physician’s rate.
This allows us to see if physicians underestimate or overestimate impact in comparison to patient’s perception.

As the 2018 report also showed that quality of life does not necessarily decrease as disease severity increases, it is important that we do not overlook the invisible impact of rosacea throughout disease management.

This requirement is also relevant for psoriasis patients, as they are also often burdened with invisible symptoms that can be overlooked by the visible signs of their disease seen by doctors.

The itching sensation is present in 70–90% of psoriasis sufferers which was also mirrored in the survey results (81% reported ever having itching sensations), but this invisible symptom has only been recognized by doctors in the last decade. 9 Despite the recent acknowledgement of itching as a symptom of psoriasis, only 37% of doctors reported asking their new patients about this symptom.

In the current survey, this disconnect between the sufferers’ disease experience and the symptoms that doctors typically investigate was seen across other invisible symptoms as well for both diseases.

The prominence of specific invisible symptoms did not necessarily relate to how often doctors investigated them (Figure 11) – highlighting the lack of awareness among doctors treating facial skin disease of the array of invisible symptoms experienced by those suffering from rosacea and psoriasis. Doctors and patients need to more proactively discuss beyond the visible.
Should doctors address all symptoms present, even if we cannot see them?

**Overall, both visible diseases can be largely characterized by symptoms that can impact quality of life negatively and are not always well understood or addressed.**

*To improve patient care in both rosacea and psoriasis, prioritizing the need to discuss the symptoms experienced can greatly improve the success of treatment and further improve patient satisfaction.*

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**FIGURE 11: INVISIBLE SYMPTOMS REPORTED VS INVISIBLE SYMPTOMS INVESTIGATED**

<table>
<thead>
<tr>
<th>Symptom</th>
<th>ROSACEA</th>
<th>PSORIASIS ON THE FACE</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Patient experienced ever</td>
<td>Doctor investigated symptoms</td>
</tr>
<tr>
<td>Burning</td>
<td>44%</td>
<td>16% 13%</td>
</tr>
<tr>
<td>Stinging</td>
<td>29%</td>
<td>2% 1%</td>
</tr>
<tr>
<td>Itching</td>
<td>55%</td>
<td>10% 8%</td>
</tr>
<tr>
<td>Pain/Soreness</td>
<td>21%</td>
<td>5% 3%</td>
</tr>
</tbody>
</table>

Doctors were asked spontaneously what they typically investigated in their new and follow-up rosacea and psoriasis patients as an open-ended question. All mentions of these invisible skin symptoms were recorded.

Questions asked:

Which symptoms/signs of rosacea/psoriasis have you ever experienced? Thinking of your new rosacea/psoriasis patients’ consultations (i.e. patients who consulted you for the first time for their rosacea/psoriasis), which spectrum of symptoms do you typically investigate? And for your follow-up rosacea/psoriasis patients’ consultations, which spectrum of symptoms do you typically investigate?

Symptoms reported vs symptoms investigated

When doctors were spontaneously asked what they investigate in their rosacea and psoriasis patients consulting for the first time, only a minority cited invisible symptoms. Doctors were approximately 30% more likely to investigate invisible symptoms in their new psoriasis patients than new rosacea patients.

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<td>5% 3%</td>
</tr>
</tbody>
</table>

NA, not applicable; PsO, psoriasis; ROS, rosacea

*Absolute reduction: 13%, 40% PsO vs 27% ROS; p<0.01
We are in an era where those burdened with disease play a large role in their own treatment success. However, this survey sheds light on how little those with rosacea and psoriasis with facial involvement knew about their disease. For long-term and inflammatory skin diseases, such as rosacea and psoriasis, people need to understand the complexity and longevity of their condition to set their expectations of treatment and decide how to best manage their disease on an ongoing basis.

With facial involvement, people may often look for quick fixes because they are understandably worried about how other people may perceive them. By gaining more knowledge about the expected duration of their disease and the best approaches for managing a lifelong illness, people will better understand the importance of sticking to a treatment regimen and taking the necessary steps in better managing their trigger-driven disease.

In this survey, patients with psoriasis with facial involvement were slightly more likely to take their medication as prescribed, but this difference was not significant. Interestingly, itching/burning from medication was the most common reason people with rosacea provided for not taking their medication, ironic considering these are also symptoms of the condition and may be a reason why rosacea suffers may lose hope in treating their condition.

They want to know more – the majority of patients in both diseases reported a desire to learn more about their disease, especially in the rosacea patient group. Providing these patients with the power of knowledge will help improve managing their disease as a whole.

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PsO: psoriasis, ROS: rosacea, NS: not significant

1% a serious condition: 55% ROS vs 56% PsO, p=NS and can lead to serious complications: 55% PsO vs 45% ROS, p<0.05

1Percentage of prescribed dose taken in past month: 77% ROS vs 81% PsO, p=NS

242% ROS vs 18% PsO, p=NS

373% ROS vs 65% PsO, p<0.05

Empowering patients through information

Providing patients with the power of knowledge will help improve managing their disease as a whole.
Providing a better understanding of the disease can make a powerful difference.

The doctors surveyed reported providing a variety of information to both patient groups (Figure 12). Significantly more information on potential triggers and their avoidance as well as lifestyle recommendations was given to patients with rosacea, which aligned with rosacea patients avoiding more daily lifestyle habits (Figure 4). Positively, this may show patients are listening to the advice they are given. People with psoriasis with facial involvement appeared to be better informed about the nature of their disease, such as prognosis and level of severity, than rosacea patients.

These insights may stem from rosacea being known to be a trigger-driven disease, but it is also important to remember psoriasis can be triggered as well. On the other hand, similar to psoriasis, rosacea is also a long-term inflammatory disease with treatment options that are not curative, but rather manage the signs and symptoms, which should be shared with those suffering from these diseases. Providing people with psoriasis and rosacea a better understanding of their own disease can make a powerful difference allowing them to take control of how their disease is managed with the support of their doctors – empowering them to strive for more from their treatment, rather than settling for a mediocre response.

In order to equip rosacea and psoriasis sufferers with the tools to reach their treatment goal, we need to not only provide them with 1) a treatment regimen personalized to their signs, symptoms and quality of life impact; but also 2) information about their disease to set expectations for their future treatment journey.

Question asked:
In general, what type of information do you give to your new rosacea/psoriasis patients (in addition to their treatment information)?
FIGURE 13: TREATMENT APPROACH WHEN INITIATING OR REVIEWING TREATMENT

Aiming for ‘clear’ (IGA 0)

Treatments available today in both rosacea and psoriasis have made ‘clear’ (IGA 0) possible and the benefits of achieving ‘clear’ (IGA 0) are well-established in both diseases. By understanding the true burden of disease, we can tailor the treatment approach to aim to reach ‘clear’ (IGA 0) to relieve them from the burden of their disease, both visible and invisible.5–8 Treatment goals should be discussed and become a shared responsibility for both doctors and their patients to instil the importance of staying on treatment to achieve the best results.

Despite the available evidence,5–8 this report shows only about one-fifth of doctors were aiming to ‘clear’ (IGA 0) their patients of all symptoms present (Figure 13). Many doctors are satisfied with the results of treatment if their patient is also satisfied with the improvement seen. This may mean that many patients are not reaching ‘clear’ (IGA 0) and not really gaining the full benefits of their treatment. The multiple benefits associated with reaching ‘clear’ (IGA 0) are worth striving for especially considering the difference in these benefits when reaching ‘almost clear’ (IGA 1).5,7,8 Achieving ‘clear’ (IGA 0) should be the ultimate goal for doctors and patients alike.

FIGURE 13: TREATMENT APPROACH WHEN INITIATING OR REVIEWING TREATMENT

POSITIVELY, PEOPLE WITH ROSACEA AND PSORIASIS WITH FACIAL INVOLVEMENT FEEL REACHING ‘CLEAR’ IS ACHIEVABLE.*

IGA, Investigator’s Global Assessment; PsO, psoriasis; ROS, rosacea

*44% ROS vs 35% PsO, p<0.05; †Somewhat challenging: 63% ROS vs 63% PsO, p=NS; and very challenging: 17% PsO vs 11% ROS, p<0.05.

Doctors tend to find treating rosacea similarly challenging as treating psoriasis.†
Regular appointments are important to assess, whether the disease has developed and tailor treatment.

The long-term plan

Regular appointments with patients are important to not only assess whether their disease has developed further or improved, but to also tailor treatment to ensure people suffering from rosacea or psoriasis are achieving the best possible outcomes. Positively, over 80% of doctors who participated in this survey often or systematically arranged a follow-up visit regardless of disease during the patient’s first visit or when starting a new treatment. During a follow-up consultation, arrangement of the next follow-up was more frequent with psoriasis vs rosacea patients.†

Between 79% and 85% of both rosacea and psoriasis patients attending their first visit or when starting a new treatment were recalled within 3 months. Not surprisingly, this frequency dropped to 52–55% for follow-up patients. Significantly more rosacea patients compared with psoriasis patients were recalled more than 6 months after their previous visit.‡

As both diseases are long-term illnesses, should follow-up appointments be a routine part of disease management?

Considering rosacea and psoriasis are both chronic illnesses, the need to treat these diseases throughout the lives of those suffering from them is their harsh reality. Luckily, ‘clear’ (IGA 0) is possible with the treatments available today and doctors have the power to make such a life-changing difference for those suffering from facial skin disease by routinely following up on these patients and ensuring their treatment goal is ‘clear’ (IGA 0).

IGA, Investigator’s Global Assessment; NS, not significant; PsO, psoriasis; ROS, rosacea
*First visit: 83% ROS vs 86% PsO; p=NS and new treatment: 85% ROS vs 83% PsO; p=NS
†Often or systematic: 82% PsO vs 74% ROS; p<0.01
‡6% ROS vs 2% PsO; p<0.01
A holistic approach to treating skin diseases

This survey highlighted key opportunities to further improve the quality of life of those suffering from rosacea or psoriasis with facial involvement with actionable guidance for both those suffering and the doctors treating them. There are real people living behind these numbers so now is the time to take action to make a real difference to people’s lives.

For individuals suffering from rosacea or psoriasis with facial involvement, it is clear today more than ever that your voice needs to be heard. The burden you are facing because of your disease is understood and the goal of treatment should be to clear all signs and symptoms.

Improving your knowledge of your own disease will be key to ensuring you can work with your doctor to get the best out of your treatment regimen – so tell them about everything you are experiencing, including the symptoms they are not able to see.

This approach will allow your doctor to make more informed decisions about how your disease is managed, giving you control over your facial skin disease. Ask your doctor for more information about your disease and how it is best managed, and ensure your treatment goal is ‘clear’ (IGA 0) because ‘clear’ is possible and you should strive for no less.

As their doctor, patients often turn to you to help them make decisions in their treatment journey by using the expertise from your clinical experience. With a deeper understanding of the true impact of the disease and your knowledge of the innovative treatments available, managing rosacea and psoriasis effectively is possible. With your help, your patients can reach ‘clear’ (IGA 0), reduce their burden and ultimately lead better lives that are not dictated by their disease any longer. We ask you to pledge to help your patients reach their full potential by:

• Asking your patients about the symptoms of their disease you cannot see and the true extent of their burden on their daily lives both physically and emotionally.

• Providing your patients with all the tools required to ensure aiming for ‘clear’ (IGA 0) is possible, including: (1) information about what managing their disease will mean for the patient’s life moving forward; and (2) personalized treatment plans, acknowledging the patient’s signs and symptoms.

• Setting goals and expectations together with your patient to not just aim for visible improvement, but to reach ‘clear’ (IGA 0).

The learnings identified in this report demonstrate how we can work together to reduce the burden of both rosacea and psoriasis especially with facial involvement by making in-clinic discussions more meaningful for both doctors and their patients, and empowering individuals to understand their disease (the visible and invisible) and the importance of committing to a long-term approach with the aim of treating to ‘clear’ (IGA 0).
Methods

Data for this report were collected from doctors and sufferers who completed an online questionnaire.

- Doctors were recruited from an online panel with soft quotas in order to ensure a representative sample of doctors in each country
- Sufferers were recruited via general population panels

Doctors’ inclusion criteria

- Office- or hospital-based or mixed practice
- At least 3 years of medical practice
- At least 50% of time spent in direct patient care
- At least 10 rosacea/psoriasis patients seen in a month
- Personally initiating therapies for rosacea/psoriasis

Rosacea sufferer inclusion criteria

- Adult
- Self-reported diagnosis of rosacea
- At least one consultation with a doctor for rosacea in the past 12 months
- At least one treatment for rosacea taken in the past 12 months
- Not currently experiencing any other skin conditions for which they were being treated
- DLQI score self-reported moderate or severe disease impact on daily life

Psoriasis sufferer with facial involvement inclusion criteria

- Adult
- Self-reported diagnosis of psoriasis with lesions on the face
- At least one consultation with a doctor for psoriasis in the past 12 months
- At least one treatment for psoriasis taken in the past 12 months (those treated with biologics were excluded)
- Not currently experiencing any other skin conditions for which they were being treated
- DLQI score self-reported moderate or severe disease impact on daily life

Statistical analysis

Survey analysis was done comparing both sufferer/patient groups against one another, hence any p-value deemed non-significant can be interpreted as both groups being comparable or similar in regard to the specific parameter measured and any significant p-value represents a noticeable change between the two groups.

Any statement in the report claiming the comparison is comparable, similar or aligned are indicative of a non-significant p-value.

References

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