



It's time to start talking about
the burden of rosacea.

Rosacea
*Beyond
the visible*



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An open letter to doctors treating rosacea

Dear reader,

It's time to act on the burden of rosacea.

For more than a decade we have known that rosacea has the potential to harm many parts of people's lives. 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. Is it any surprise then that people with rosacea can be very seriously affected?

People with rosacea can feel like they are stuck in an unwinnable situation - judged on their appearance, but also worried they will be blamed or viewed as superficial and overstating their symptoms if they seek help. We need to open the discussion surrounding the burden of rosacea and ensure people are comfortable talking about the impact this illness can have on their lives.

But beyond empathizing, we need to do everything we can to relieve their burden. This is where data from the new global survey of rosacea burden can help. Insights from this report may help us move forward: from discussing rosacea burden in academic papers to addressing it in practice.

To improve the situation, we must start by acknowledging the problem. If you have rosacea - speak up, if you are a doctor - reach out. This isn't a futile conversation - together we may be able to improve outcomes. The question of whether people are happy with their current treatment naturally follows a discussion about the burden of rosacea. We have many more therapies now compared to a decade ago. To help us find the right fit, we need to approach each person as an individual, in terms of their signs, symptoms and burden.

With a visible disease like rosacea, treatment satisfaction is based on how people see themselves. This means improvement, or even regulatory success defined as 'clear' (IGA 0) and 'almost clear' (IGA 1), may not be enough to relieve the burden on people's lives: 'clear' (IGA 0) should be considered the ultimate treatment goal. However, even when treatments work perfectly in getting someone to 'clear', it can take a while for a person's self-image to adjust to their new reality. It is vital to keep connected with people throughout their journey. Treatment goals in combination with a fast-acting treatment can encourage people to stick to their therapy and help them recognize their own progress.

Although we can't yet promise 'clear' to all people, current treatments are now getting more people to 'clear', with combined therapy or even with monotherapy. By aiming for 'clear' (IGA 0) we can help free more people from their rosacea burden.

Take the time to start the conversation about the burden of rosacea and ensure that the treatment approach aims for 'clear' (IGA 0).

Sincerely,

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Why should we care about the burden of rosacea?



I try not to look in the mirror and get on with everyday life, then I look in the mirror **and think I look terrible**. I do get embarrassed talking to people.¹

What is different now?

Our understanding of rosacea has changed dramatically over the last 10 years.²⁻⁷ New studies have led to discoveries from a cellular level, to the impact on each person's life: changing the way we think about rosacea and its effects.⁶⁻¹¹ We now know that rosacea is a highly individual experience, and that people with rosacea do not fit neatly into the categories we previously used.⁶

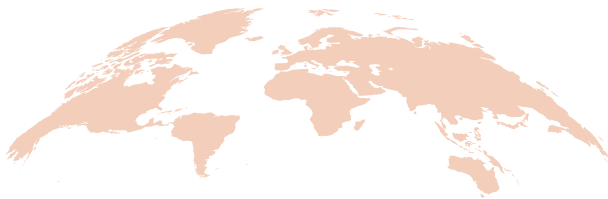
Recently we have had a step forward, with a new treatment approach proposed by a global panel of experts.⁶ They suggest each person's treatment should be guided by their personal concerns and the individual combination of symptoms they have at the time.^{6,11,12} In this simple way we can tailor treatment to what matters most to each person.^{6,11,12}

It is important to stress that a high burden may not always be caused by severe rosacea symptoms. As even a few symptoms can have profound effects on a person's life, we need to understand each person's burden

before we make any decisions.^{4,6-8} However, understanding rosacea burden doesn't guarantee a straightforward way to relief.

As people who are 'almost clear' may still have a high burden of rosacea; recently the topic of redefining treatment goals has been raised. Having 'almost clear' rosacea means you still have visible symptoms. The difference between this and being 'clear' could mean the difference between having their disease visible to others and having control over who knows. For some people, anything less than 'clear' falls short of what they need.⁴ Although we cannot currently promise 'clear' to everyone, it may be more achievable than you might expect. Even the right monotherapy can get 1 in 3 people 'clear', and using the right combination of treatment is likely to bring even more people to 'clear'.^{2,13}

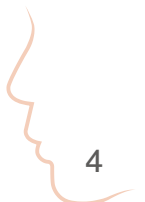
Aside from the understandable desire for completely clear skin, achieving 'clear' has tangible benefits, such as giving people longer between flare-ups and improving their quality of life.⁴ We wanted to investigate whether 'clear' could provide similar benefits to the psychosocial burden of rosacea.



554 physicians
and **710 patients**
completed the survey

6 different countries:
France, Germany, Italy,
UK, Canada and the US

A global survey was created to investigate the true extent of the burden of rosacea and evaluate whether aiming for 'clear' could lighten this burden.



What does having rosacea mean today?



Since I was a child my father had a big red nose, **like an alcoholic**, but he never, ever drank.¹

The problem with stereotypes

Having rosacea often means you are automatically exposed to all kinds of assumptions, prejudice and stereotypes.¹⁰ But results from the global survey found that having rosacea doesn't mean you are a specific kind of person. In fact, there is no single 'typical' person with rosacea.

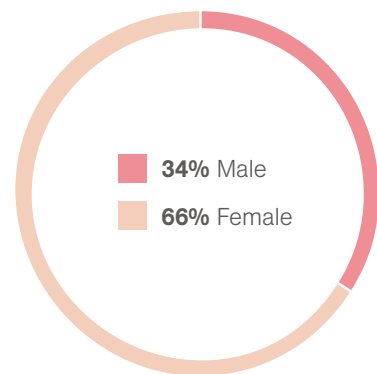
There are around two women for every man with rosacea. People with rosacea lived everywhere from cities to the countryside, and had a big variation in age: people responded across the entire range of the inclusion criteria 18–70 years old (average age was 44.5 ± 13.8).

No one can separate out their lives into separate boxes. As with any disease, rosacea has to be balanced with other demands from daily life: work/school, friends/family. Some people also have to deal with other medical needs on top of rosacea. The most common types were neurological, skin conditions, metabolic/endocrine, gastrointestinal/autoimmune and allergic/respiratory.

Rosacea's relationship with other illnesses is an ongoing topic at the moment. Interestingly, people with some conditions were more likely to have certain symptoms. The most striking case of this was seen in people with diseases of the musculoskeletal system and connective tissues, who had more skin sensations in the past 12 months (burning, stinging, itching or pain) than the total population (77% vs 55% $p \leq 0.05$) or any other specific condition.*

Demographic

Base: Total patients (n=710)



44.5 ± 13.8
years old on average
(median: 43.8)

*% of people with musculoskeletal system and connective tissues with skin sensations (burning, stinging, itching or pain) (77%) vs people suffering from other specific conditions $p \leq 0.05$: neurological (61%), cardiovascular (56%), metabolic/endocrine (57%), skin conditions (60%), gastrointestinal/autoimmune (58%), urinary (59%), ophthalmologic (62%), allergic/respiratory (64%) Questions asked: S1. You are [male/female]. S2. How old are you? Q5. Which answer best describes your current residence? [Urban (city)/Suburban/Rural]. Q7. Here is a list of conditions or complications. Please carefully read the list below and select all the conditions or complications you are currently experiencing. Please select all that apply.

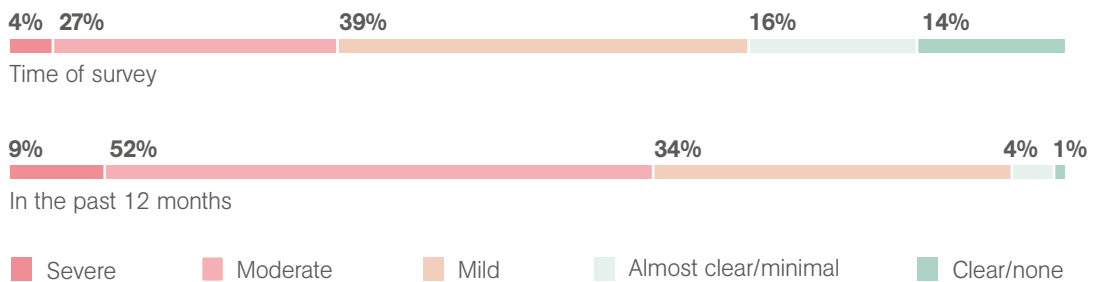


The constant pressure of rosacea

Misleading stereotypes can lead everyone astray, even doctors. Rosacea is known for its flare-ups, or peaks in symptoms. We saw this reflected in the survey responses, with 87% of people self-reporting that they suffer from flare-ups. But what may be surprising is that rosacea symptoms are a continual presence for most people. 59% of the people taking our survey had constant symptoms without the relief of full remission, despite multiple doctor visits during the last year and access to medical care. Even in the absence of flares 22% of people with rosacea report high discomfort due to symptoms.

Severity of rosacea

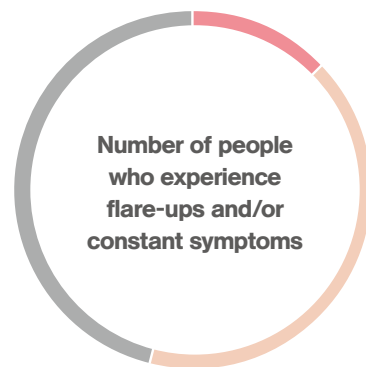
Base: Total patients (n=710)



Surprisingly few people are 'clear' of rosacea

Looking in the mirror and not seeing your disease can make a big difference to someone with rosacea. But only 14% of people with rosacea rated themselves as 'clear' of symptoms at the time of the survey. This decreased to only 1% of people with rosacea rating themselves 'clear' when they thought about the last year. Although the low number could be influenced by the fact that all people in the survey had 2 or more rosacea-related doctor visits in the last year, it is interesting to note that doctor's estimates of their 'clear' patients are similarly low (2%).

The percentage of people rating their disease as severe doubles when they rate it over the last year (9% vs 4% rated at time of survey). We should consider that the snapshot of people we see in clinic may lead us to underestimate the impact over time.



- 13% Symptoms are nearly always present but do not experience flare-ups
- 41% Symptoms only present during a flare up
- 46% Symptoms nearly always present and worsen during a flare up

Base: Total patients (n=710)

Why are some people hesitant to talk about burden?



“ **He kind of shrugged it off.** OK, he probably sees worse things like people with cancer and stuff so when I show up with my **aesthetic problem** . . .¹

Why do some people stay silent?

Fear of being judged or fear they are to blame, may be holding some people back from talking about their burden. When you are scared of someone dismissing or rejecting you, then it can seem like the safest option is to remain silent.

The natural thing to do in the circumstance is to compare against other people. The trouble with this is that there will always be someone worse off in comparison, and that doesn't mean that the problem isn't important.

Limited time can mean that some doctors focus exclusively on symptoms and don't always ask about things like quality of life or burden. But this could mean a major part of living with rosacea is overlooked.

We need to start improving the conversation between doctors and people with rosacea so that people feel comfortable enough to talk about how they are feeling, both physically and emotionally.

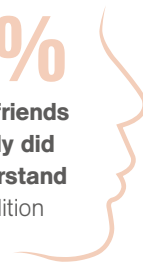
29%

felt that even their **doctors didn't take them seriously**



37%

say their **friends and family did not understand** their condition



“ It might have been my fault, I didn't ask . . .¹





She said **it was very common**, some people are prone to it, this is not something I was doing wrong.¹

How can we show people with rosacea that they are not alone?

People with rosacea shouldn't feel ashamed or judged when they talk about their burden, and they should know that they aren't the only ones that feel that way. Data from the survey shows that rosacea impacts the quality of life of most people with rosacea. Rosacea had at least a moderate impact on 1 in 2 people surveyed and had a very large, or higher, impact on around 1 in 3 people when measured using the DLQI.*

The DLQI is the most well-known measure of quality of life in dermatology, with a high score (>10) indicating a very large negative impact on a person's life. But what does this actually mean? The nature of a score like the DLQI is that it's useful for quantifying and categorizing, but it's harder to connect with real life. When reading the score, try to remember the people the numbers represent and what that number could mean to someone's life.

Percentage of people impacted by rosacea



Base: Total patients (n=710) **Mean ±SD:** 8.0 ±7.6 **Median:** 5.1 **Min:** 0.0 **Max:** 30.0

*High DLQI=score >10. Moderate to low DLQI=score≤10. DLQI, Dermatology quality of life index

Questions asked: Q50. DLQI.





When you have an outbreak, it **affects everything**. It affects your mood, you don't want to go out and do anything. **You feel ugly**. You lie low.¹

A rollercoaster of symptoms

Rosacea is notoriously unpredictable. Symptom peaks can ambush people unexpectedly in flare-ups. Sometimes people will be able to identify what triggered a flare-up, sometimes it has no identifiable cause. Frustratingly, even when it is possible to identify a trigger it might be something completely unavoidable, like stress.¹⁰ You could live constantly on guard against trigger factors, but still know that whatever you do you will probably still cause a flare.

The survey showed us that the lack of control with flare-ups has a strong impact on quality of life. Having any number of flares over the course of a year appears to mean a worse quality of life. Even one or two flares over a year substantially impacted quality of life (DLQI 7.6 ±7.7 vs 2.1 ±3.3 in people with no flare-ups p≤0.05), and increased the proportion of people with a high DLQI from 0 to 34%.*

There are real people living behind these numbers, those who are badly affected can be desperate for a cure. Someone with a high DLQI is more than twice as likely to report they are willing to trade a year or more of their life for a rosacea cure, compared to people with low-moderate DLQI (55% vs 22% p≤0.05).* They are also more willing to pay a substantial amount (€/£/US\$/CAN\$ >100) for even an incomplete cure so long as it is sustainable (high DLQI vs low-moderate DLQI: France, Italy and Germany € 54% vs 29%; UK £ 59% vs 22%; US US\$ 67% vs 31%; Canada CAN\$ 78% vs 46%).

When we looked at the relative importance that symptoms severity, number of flares and quality of life had on willingness to pay for an incomplete cure (WTP); we found that DLQI score had by far the strongest influence. In fact, people with rosacea with a DLQI score of 11 to 20 (very large effect on the life) or with a DLQI >20 (extremely large effect on the life) have a relative probability of being in the higher WTP category, rather than in the lower WTP category, 8 and 18 times higher than people with DLQI score of ≤1 respectively. Even a low DLQI score (2–5) increased this risk by 3 compared to people with no impact on their life (DLQI ≤1).

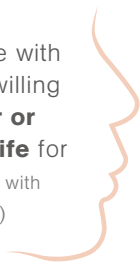
Although symptom severity and number of flares could increase the relative probability to be in the higher WTP category rather than in the lower WTP, the increases did not reach significance. This is why we need to pay attention to the impact on people's lives, as well as addressing their symptoms.

We don't yet have a cure for people with rosacea; we can only consider how to best use our current resources. To improve the lives of people with rosacea we should aim to reduce flare-ups before they start - whether through maintenance therapy or simply improved medication.

A big step forward has been taken with the new approach, set out in recently updated guidelines.⁶ Thinking about each person individually, intuitively means each symptom can be targeted with the appropriate treatment. This also means it is easier to treat multiple symptoms right from the start, giving people faster results.^{6,13}

2x

as many people with high DLQI are willing to **trade a year or more of their life** for a cure (vs people with low-moderate DLQI)



*High DLQI=score >10. Moderate to low DLQI=score≤10. DLQI, Dermatology quality of life index

Questions asked: Q18. How many flare-ups have you had in the past 12 months? Q38. How much money would you be willing to pay in a single payment to achieve a sustainable (but not complete) cure for your rosacea? Q50. DLQI. Q57. How much of your lifetime would you be willing to give up to cure your rosacea (get your face completely clear)?

What does burden mean for people with rosacea?



I changed diet, **avoid** spicy foods. I have to drink less alcohol in social situations with friends, to be honest sometimes **I'd rather not go** to a party.¹

Visible through to invisible

Part of the contradiction in rosacea is that it's a visible disease that has so many invisible effects. The burden of rosacea extends beyond the visible signs: the symptoms of rosacea also have an emotional effect.

Rosacea can undermine people's confidence and alter their outlook in life. When we asked affected people how they felt about their rosacea the answers fell broadly into the three categories shown below.

The impact of burden goes beyond what people are feeling. To manage their symptoms, most people change their behavior and their daily lives, with 86% attempting to avoid trigger factors. You might think giving up one or two things isn't a big deal, but it can add up to something much larger. You might not miss spicy food - but what about alcohol? What about a morning coffee, or playing sports with friends? What about sunlight? Avoiding things can add up to a burden that is more than the sum of its parts: 1 in 5 people end up making substantial modifications to their daily life.

What is the strongest feeling people have about their rosacea?

**1 in 3 people
lost confidence**

**1 in 4 people
felt annoyed**

**1 in 10 people
felt dejected**

Adaptation to daily life (on a scale from 0 to 10)

19% **66%**

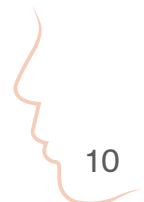
15%

- More than 7 (substantial changes)
- 3 to 7 (moderate changes)
- Less than 3 (minor changes)

Base: Total patients (n=710)

¹ 1 in 3 lost confidence=10% low self-esteem+10% embarrassment+6% insecurity+4% low confidence+3% shame, 1 in 4 felt annoyed=10% bothered+8% frustrated+6% fed up+2% angry, 1 in 10 felt dejected= 3% sad+3% depressed+1% isolated+1% exhausted+1% despair+1% defeated.

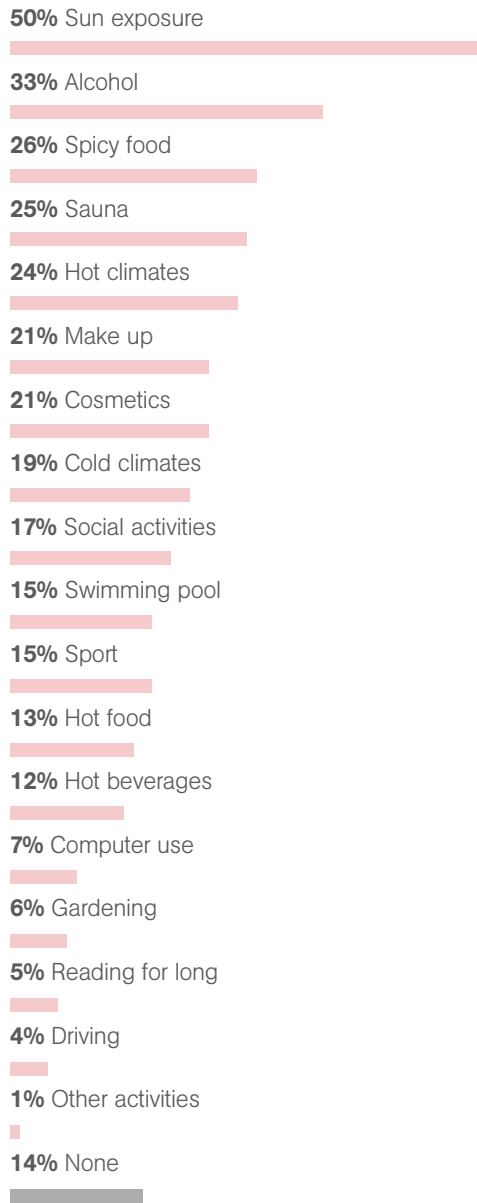
Questions asked: Q54: Among these feelings that you associate with how you feel about rosacea, which one do you associate with the most? Q28: What activities/behaviors did/do you avoid because of your rosacea? Please think of all adaptations you may have made since the diagnosis of your rosacea? Q29: How would you evaluate the level of adaptation of your behaviors / your day-to-day life because of your rosacea?





Sometimes **I don't wear makeup** because I work at home and then **a customer does come in** and I think, oh my god.¹

Percentage of patients avoiding activities



Base: Total patients (n=710)

Lost time

Avoiding things isn't the only way people with rosacea try to handle their illness. As you might expect they are also very concerned with their skin care. People with rosacea use a large variety of products on their skin: everything from moisturizers to makeup.*

Those with high DLQI were significantly more likely to use every single one of the products compared to people with low-moderate DLQI. This adds up to significantly more time spent on skin care every day (30.2 ±31.9 minutes for people with high DLQI vs 19.6 ±14.1 minutes for people with low-moderate DLQI p≤0.05).[†] This extra time might mean the difference between someone taking care of their skin and feeling like they need to cover it with makeup before going outside.

Over a week the extra time means another hour on skin care compared to people with low-moderate DLQI. This adds up to a total of 3.5 hours a week for a person with a high DLQI.[†] Interestingly, this extra hour is consistent for both men and women; although, women tend to spend longer on average, the difference may not be as large as you might expect.

Time spent on daily skin care routine (mins)

	MALE	FEMALE
DLQI>10	26.4 ±34.1	33.1 ±29.9
DLQI≤10	17.5 ±11.8	20.5 ±14.8
Increased time for DLQI>10	8.9 mins/day	12.6 mins/day

*Products include: anti-aging, dark spot corrector, foaming cleanser or soap, non-foaming cleanser, moisturizer, anti-acne/blemish product, pore minimizer, scrub/exfoliator, oil/skin control product, makeup remover, tinted moisturizer/BB cream, sunscreen, self-tanning, eye care, lip care, skin-lightening product, foundation, make-up powder, calming/repairing/anti-redness, deep-cleansing wash †High DLQI=score >10, moderate to low DLQI=score≤10. DLQI, Dermatology quality of life index; ER, emergency room.

Questions asked: Q28. What activities/behaviors did/do you avoid because of your rosacea? Please think of all adaptations you may have made since the diagnosis of your rosacea? Q8a. On average how long do you spend on your skin care routine each day in total? Q8C. In your skin care routine, how frequently do you personally use the following facial skin care products? Q50. DLQI.

How far does burden spread in society?



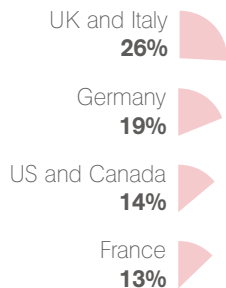
When it was really bad, **I took a sick leave** sometimes but this is not how you make friends at work. It was very difficult when I still worked in public at the time.¹

The burden butterfly effect

The emotional impact of rosacea and medical economics are rarely discussed in the same conversation - but the two may be related. People do not live in a vacuum, a change in one person can also affect those around them.

The burden of rosacea can follow people into their work. More than 1/2 of those with rosacea who worked in the past 7 days (55%) report that their health problems affect their work productivity (score rated as $\geq 3/10$). This might be something constantly simmering in the background, like confidence being undermined; or it can be something very noticeable, like forcing people to take days off work. People with high DLQI miss twice as many days of work, school or university per year because of rosacea vs those with low-moderate DLQI (8.2 ± 12.4 vs 3.0 ± 13.4 $p \leq 0.05$).

Number of patients visiting the ER in the past year varied from 13-26% in different countries



A person's individual burden may even impact medical resourcing

The influence of burden extends beyond an individual's personal productivity, impacting medical resourcing. When you feel like your disease is controlling your life the natural thing to do is to visit your doctor. This means that high DLQI people visited doctors more than twice as often in the past year as people with low-moderate DLQI (9.9 ± 10.6 vs 4.4 ± 3.2 visits per year $p \leq 0.05$).^{*} In fact having a high DLQI had a stronger influence on number of doctors' visits than either severity or number of symptoms.

Surprisingly, 18% of people with rosacea had visited an ER (emergency room) for their rosacea. This varied country-to-country from 13% (France) to 26% (UK and Italy). No matter which country you live in, having people with rosacea being driven, through frustration or desperation, into using the ER is not ideal for the person or the hospital.

A few different things seem to force people to seek help in the ER. People with high DLQI visit the ER much more: almost half (47%) had visited in the last year compared to 5% of those with low to moderate DLQI.^{*} Severity and gender also seem to be factors: 80% of males with severe rosacea had visited the ER compared to 40% of females with severe rosacea.

When we looked at the influence of these different factors, quality of life came out as the strongest predictor of ER visits, even compared to severity.

¹High DLQI=score >10, moderate to low DLQI=score ≤ 10 . DLQI, Dermatology quality of life index; ER, emergency room

Questions asked: A445. During the past seven days, how much did your health problems affect your productivity while you were working? Q47. In the past 12 months, how many days of [work/school/university] did you miss because of your rosacea? Q33. How many visits related to your rosacea did you have during the past 12 months with each of the following healthcare professionals (HCPs)? [A dermatologist/A general practitioner/A nurse/An ophthalmologist/A plastic surgeon/A psychiatrist or psychologist/Another HCP (please specify)]. S3. Please indicate your gender. Q50. DLQI. Q34. In the past 12 months, how many times did you go to emergency room (ER) in relation to your rosacea?

Can aiming for 'clear' lighten the burden of rosacea?



I know how to treat it, and I don't give rosacea that power over my life.¹

Is there a 'clear' effect?

A previous study found people who reached 'clear' (IGA 0) had significantly better quality of life compared to people who are 'almost clear' (IGA 1). But does reaching 'clear' always relieve the burden of rosacea, or is it a bit more complicated? Studies in acne have shown us that even if we resolve the visible signs and symptoms of a disease, changing a person's emotional state can be difficult or take longer than you might expect.¹⁴

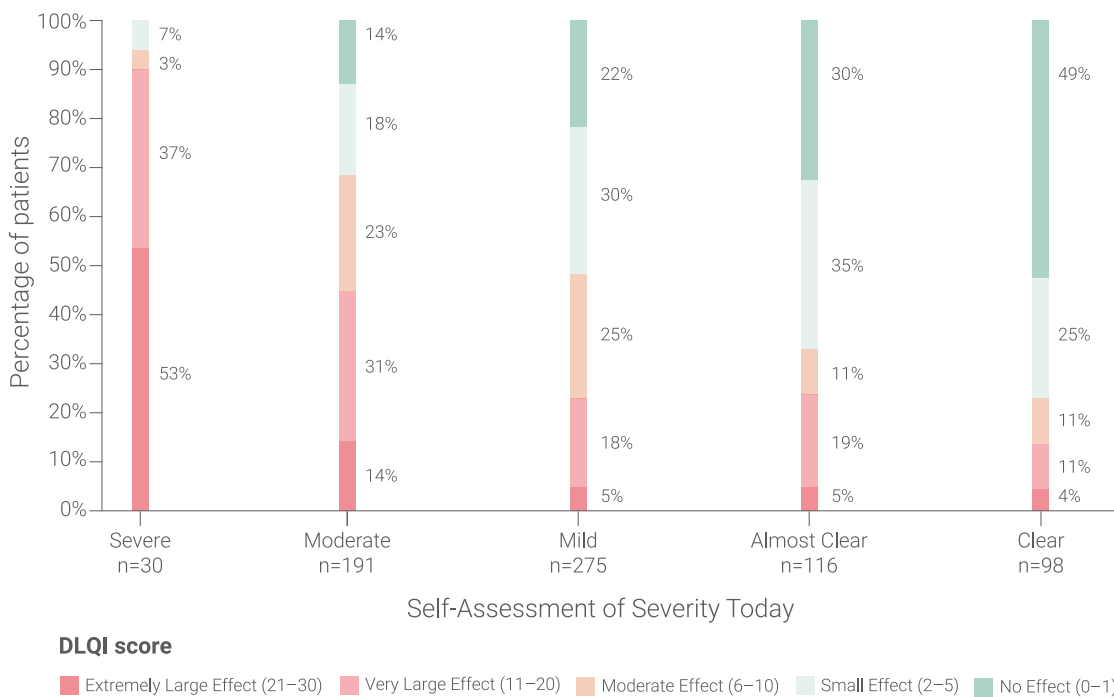
Intuitively, we all know that the worse someone's rosacea is the more likely they are to have a high burden. Just like it is also obvious that for some people, even low levels of symptoms can also cause high burden. This is exactly what our survey showed.

When we looked at DLQI and rosacea severity we saw that severity did appear to correlate with quality of life. However, as we previously mentioned a high impact on life isn't limited to people with severe rosacea. For example, almost half of the people with mild rosacea had at least a moderate effect on their quality of life and 23% a very large or extremely large effect on their quality of life.

Impact on life vs rosacea severity at time of survey

Base: Total patients (n=710)

The burden of disease can be high irrespective of symptom severity



*High DLQI=score >10. Moderate to low DLQI=score ≤10. DLQI, Dermatology quality of life index; IGA, Investigator's global assessment

Questions asked: Q50. Dermatology life quality index (DLQI). Q24.3. Please choose the answer that characterizes best the severity of your rosacea today?



I was **very satisfied** because I have found a person that seems trustful, who gave me a treatment that works so far.¹

As you might expect, reaching 'clear' appears to minimize the impact of rosacea as measured by DLQI. No person who was 'clear' over the last year had a high DLQI.* We also looked into other wider measures of burden: like behavior modification, time missed from work, and willingness to pay for a cure. We found that people who were 'clear' had the lowest burden in 17/20 aspects.†

The 'clear' quality of life difference

If you put yourself in the shoes of someone with rosacea, you can see why having 'almost clear' isn't always good enough. It might only take one bump appearing on your face to upset your day. The extra step of reaching 'clear' can make a big difference to people who are able to achieve it. Achieving 'clear' (IGA 0) relieves the impact on quality of life (DLQI of ≤ 1) for 1 in 2 people, significantly more than 'almost clear' (IGA 1); (49% vs 30% $p \leq 0.05$). Although this isn't a perfect cure (psychological and emotional after effects may take time to resolve), it is a significant step forwards.

'Clear' may also mean rosacea controls each person's life less. People who were 'clear' were significantly less likely to be forced into modifying their daily behavior vs people who were 'almost clear' (21% vs 16% $p \leq 0.05$). They also showed a trend towards shorter duration of the last reported flare-up vs people who were 'almost clear' (7.4 days ± 14.2 vs 8.8 days ± 12.4 $p = \text{NS}$). Other studies have also found a 'clear' effect on flare-ups. People who reached 'clear' had a longer time to flare and when they did get a flare it responded more quickly to treatment compared to 'almost clear'.⁴

A 'clear' butterfly effect

Earlier we mentioned how burden ripples out from individual people and affects society. We wanted to know if achieving 'clear' would have a reverse effect. The survey found that getting to 'clear' may lighten the impact on productivity and relieve the pressure on medical resourcing. People who are 'clear' tend to say that their health problems

have no effect (rated ≤ 2 out of 10) on their work productivity vs those who were 'almost clear' (72% vs 56% $p = \text{NS}$). People who were 'clear' tended to have a lower number of doctor visits vs those who were 'almost clear' in the last year (4.8 ± 5.3 vs 5.7 ± 7.5 per year $p = \text{NS}$).[‡]

Every 100 people who are 'almost clear' contribute an extra 90 doctor visits a year vs people who are 'clear'.[‡]

*High DLQI=score >10. Moderate to low DLQI=score ≤ 10 . †Q8a, 14a, 14b, 18, 19, 23, 25, 26a, 26b, 28, 29, 33, 34, 38, 42, 45, 46, 48, 50 and 57. ‡Doctor visits include consultations with: dermatologists, GPs, nurses, ophthalmologists, plastic surgeons, psychiatrists/psychologists, aromatherapists, bariatric specialists, pharmacists, neurologists, pulmonologists, rheumatologists, gynaecologists, ENT specialists, physiotherapists, anaesthetists and osteopathic physicians/surgeons. DLQI, Dermatology quality of life index

Questions asked: Q50. Dermatology life quality index (DLQI). Q24.3. Please choose the answer that characterizes best the severity of your rosacea today? AQ28. What activities/behaviors did/do you avoid because of your rosacea? Q19. What was the duration of the last flare-up in days? Q45. During the past seven days, how much did your health problems affect your productivity while you were working? (no effect=score $\leq 2/10$). Q33. How many visits related to your rosacea did you have during the past 12 months with each of the following healthcare professionals (HCPs)? [A dermatologist/A general practitioner/A nurse/An ophthalmologist/A plastic surgeon/A psychiatrist or psychologist/Another HCP (please specify)].

What can we do to improve the lives of people with rosacea?



I felt like I had **a diagnosis**, an explanation and **a reassurance**.¹

Let's start talking

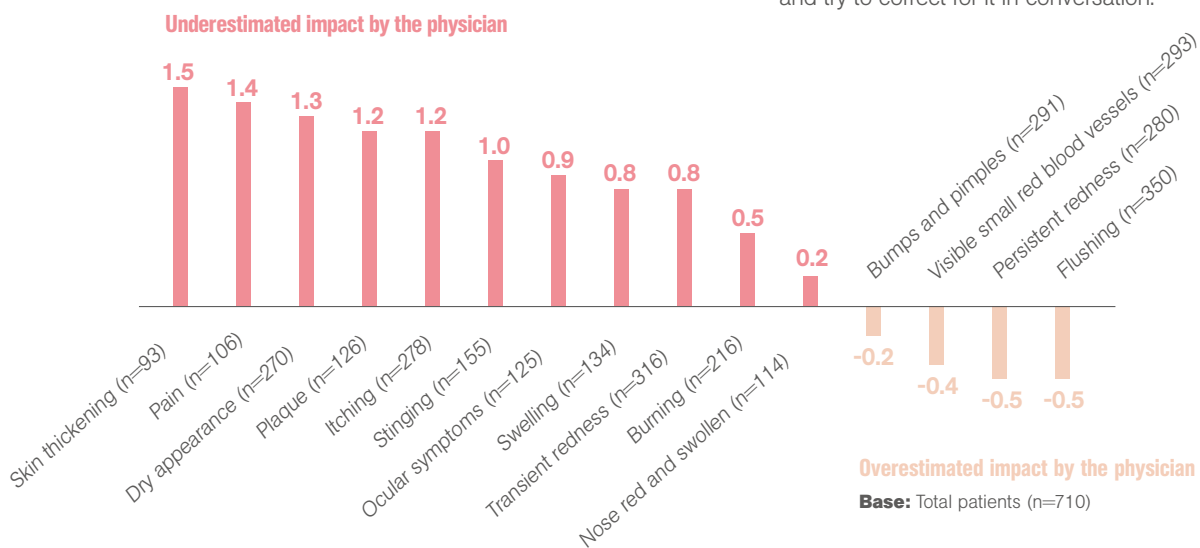
People with rosacea are forced to invest their time, energy and money into managing a disease most are not able to control. In fact, 82% of people with rosacea feel that their rosacea is not totally controlled. Ultimately, rosacea is a subjective and entirely individual experience. We need to work hard on putting aside our preconceptions and listen with fresh ears every time someone comes to us.

There is still a considerable mismatch between what people with rosacea are feeling and what doctors are hearing. Doctors can overestimate the impact of symptoms and signs typically associated with rosacea, but underestimate less visible or well-known symptoms. The impact of pain and itching are consistently underestimated by physicians of every country surveyed. It is easy to focus on what we can see: someone else's pain is intrinsically hard to understand.

Patient perception on symptom impact vs doctor

The below calculation is: Patient's rate – Physician's rate
This allows us to see if physicians underestimate or overestimate impact in comparison to the patients' perception

Despite these difficulties and the challenge of limited consultation time, it's important we don't overlook the invisible impact of rosacea. Our analysis showed that quality of life, not symptom severity, has the main influence on number of ER or doctor visits.* Additionally, it also has the strongest influence on willingness to pay, compared to the other predictors considered. We should keep in mind the natural response to focus on the visual and try to correct for it in conversation.



*Doctor visits include consultations with: dermatologists, GPs, nurses, ophthalmologists, plastic surgeons, psychiatrists/psychologists, aromatherapists, bariatric specialists, pharmacists, neurologists, pulmonologists, rheumatologists, gynaecologists, ENT specialists, physiotherapists, anaesthetists and osteopathic physicians/surgeons.

IGA, Investigator's global assessment

Questions asked: Q24.3. Please choose the answer that characterizes best the severity of your rosacea today? Q34. In the past 12 months, how many times did you go to emergency room (ER) in relation to your rosacea? Q33. How many visits related to your rosacea did you have during the past 12 months with each of the following healthcare professionals (HCPs)? [A dermatologist/A general practitioner/A nurse/An ophthalmologist/A plastic surgeon/A psychiatrist or psychologist/Another HCP (please specify)]. Q38. How much money would you be willing to pay in a single payment to achieve a sustainable (but not complete) cure for your rosacea? Q23. On a scale from 0 to 10, how would you rate the level of impact on your quality of life of you experienced in the past 12 months? Q19. Please consider your rosacea patients seen twice a year or more. How would you rate the impact of each of these symptoms on their quality of life? Q25 Generally speaking would you say that your rosacea is controlled? Q50. DLQI. Q21. Symptoms in the past 12 months.



Rosacea is a **lifelong journey** I have to face... and as long as I manage it, it should have minimal impact on me.¹

	CLEAR	ALMOST CLEAR	MILD	MODERATE	SEVERE
Psychosocial impact					
DLQI	4.4 ±6.3 (n=98)	6.1 ±6.6 (n=116)	7.1 ±6.6 (n=275)	10.6 ±7.9 (n=191)	19.5 ±7.1 (n=30)
% report no impact on QoL (DLQI≤1)	50% (n=48)	30% (n=35)	22% (n=59)	14% (n=26)	0% (n=0)
Time spent on daily skin care (min)	20.4 ±16.1 (n=98)	21.6 ±18.3 (n=116)	21.3 ±15.3 (n=275)	24.5 ±27.8 (n=191)	40.5 ±41.5 (n=30)
% who do not modify their behavior	21% (n=21)	16% (n=19)	13% (n=36)	11% (n=20)	10% (n=3)
Societal impact					
Number of HCP visits*	4.8 ±5.3 (n=98)	5.7 ±7.5 (n=116)	5.8 ±6.3 (n=275)	7.0 ±7.8 (n=191)	9.2 ±8.1 (n=30)
Productivity impact (0–10)	2.2 ±2.8 (n=57)	2.9 ±2.7 (n=71)	3.4 ±2.6 (n=175)	4.3 ±2.9 (n=127)	5.6 ±2.7 (n=23)
% report no effect on productivity	72% (n=41)	56% (n=40)	42% (n=74)	35% (n=45)	22% (n=5)

It is time for a change

If we want to improve outcomes, we need to start talking about both the burden of rosacea and whether people are satisfied with their current treatment.^{5–7}

Sometimes this might mean asking direct questions: how does your rosacea affect you day-to-day, do you feel like it is holding you back from things you would like to do, are you happy with your current treatment? Sometimes this might mean reacting to the information: if they say they have to put on makeup every day, ask if this bothers them. Sometimes this may be just listening to what the person has to say.

Finding the right treatment will always be part of a doctor's role. The top three topical treatments for high satisfaction, from this survey, were ivermectin (45%), brimonidine (41%) and oxymetazoline (40%).[†] While the top ranking systemic treatments were oral minocycline (50%), modified release doxycycline (47%) and immediate release doxycycline (43%).[†] We asked people who were 'clear' how many treatments they were currently using: most were using only one (82%), but a notable amount were using 2 or more (18%).

The profound impact on the lives of people with high burden means that they need help in a timely manner. We need to identify these people, so we

can begin tailoring treatment to individual needs and accelerate their treatment to provide faster relief.^{6–8,12} Demographics from the survey may give us a head start here. High DLQI people were typically younger and significantly more likely to be working, in every country surveyed.[‡] They were also more likely to be male, and have stinging and burning skin sensations compared to their low–moderate burden counterparts.[‡] This shows how stereotypes can mislead us. The impact of rosacea is often thought of as a women's problem, but it is a misconception to think men do not care or suffer less. Future investigation into contributing risk factors of high burden may reveal more markers and insights that can be used in clinical practice.

Like other studies, our survey suggests that 'clear' has considerable benefits compared to 'almost clear'.³ **'Clear' is the ultimate goal for people with rosacea.** People who are 'clear' are the most likely to have no impact on their quality of life, no matter what country they are from. Having said that, we should be cautious about thinking of 'clear' as a complete cure. Even if it was possible for every person to reach 'clear', people are a bit too complex for a 'one size fits all' solution. **What is likely however, is that by aiming for 'clear' (IGA 0) we can help free more people from their burden of rosacea.⁴**

Review people's existing burden of rosacea and ensure treatment approach aims for 'clear' (IGA 0).

*Doctor visits include consultations with: dermatologists, GPs, nurses, ophthalmologists, plastic surgeons, psychiatrists/psychologists, aromatherapists, bariatric specialists, pharmacists, neurologists, pulmonologists, rheumatologists, gynaecologists, ENT specialists, physiotherapists, anaesthetists and osteopathic physicians/surgeons.

[†]High satisfaction=score ≥8/10. Treatments with <10 users excluded. [‡]High DLQI=score >10. Moderate to low DLQI=score ≤10. IGA, Investigator's global assessment

Questions asked: Q50. DLQI. S1. You are [male/female]. S2. How old are you? Q8a. On average how long do you spend on your skin care routine each day in total? AQ28. What activities/behaviors did/do you avoid because of your rosacea? Q33. How many visits related to your rosacea did you have during the past 12 months with each of the following healthcare professionals? Q45. During the past seven days, how much did your health problems affect your productivity while you were working? (no effect= score ≤2/10). S5. Amongst the treatments below, which ones have you taken in the past 12 months that were prescribed by your doctor for your rosacea? Q31. On a scale from 0 to 10, how would rate your satisfaction towards your treatment? Q21. In the past 12 months, have you experienced these symptoms?

Appendix

Methods

Data for this report was collected in two stages:

- Qualitative stage: telephone interviews, covering 21 patients in 1 hour in depth interviews
- Quantitative stage: self-administered online survey, covering 554 doctors and 710 patients

Participants were recruited using the Kantar online panel from France, Germany, Italy, UK, Canada and the US. In order to maximize the sample size no quota was set up. Therefore, **the sample is not representative** of the rosacea population in each country; consequently, the results of this study could be affected by selection bias and cannot be inferred to the whole rosacea population.

Quantitative stage inclusion criteria for patients:

- 18 to 70 years old
- Affected by rosacea
- Have been diagnosed by a doctor (declarative)
- Have taken a treatment prescribed by a doctor for rosacea in the past 12 months
- Visited a doctor at least twice in past 12 months

Quantitative stage inclusion criteria for doctors:

- Dermatologists or GPs (in Canada and UK)
- 25 to 70 years old
- At least 2 years of practice
- At least 50% of their time spent in direct patient care
- At least 40 patients seen per month (15 for the GPs)
- Minimum number of rosacea patients per month:
 - 40 in US
 - 30 in Canada
 - 20 In Germany and UK
 - 10 for France and Italy
 - 10 for the GPs (in all countries)
- Personally initiate therapy for patients suffering from rosacea

Regression models

Regression models were used to evaluate the association between DLQI, severity of rosacea (at time of survey) and number of flares on: willingness to pay to achieve a sustainable but incomplete cure, number of doctors' visits and number of ER visits.

- In the case of the willingness to pay analysis, the country specific variable was divided into 3 classes (lower than the median n=107, equal to the median n=141 and higher than the median n=261). Then a multinomial regression model was estimated: regressing the 3 classes against DLQI, severity of rosacea (at time of survey) and number of flares: results shown represent the high class relative to the low class.
- In the cases of number of doctor visits and the number of ER visits analyses, linear regression models were estimated: regressing the number of visits against DLQI, severity of rosacea (at time of survey) and number of flares against the number of visits
- Age at interview, gender, presence of any comorbidity, occupation (employed, sick leave, not employed) and income (low, median, high) were considered as confounders of the associations for all analyses

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Rosacea: Beyond the visible was developed under the direction and sponsorship of Galderma International, survey was conducted by Kantar Health with writing support provided by Emma Waring, Havas Life Medicom.