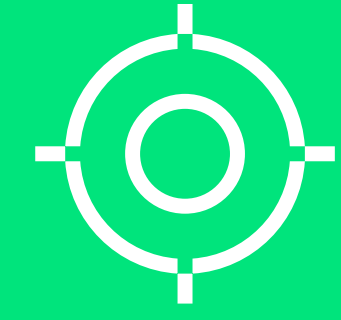


Inclusion of the patient voice in developing holistic treatment goals for rare skin diseases

Emmylou Casanova,¹ Yuzlina Binti Che Yaacob,² Dale Reisner,² Ana Cristina Hernandez Daly,³ Diamant Thaçi,⁴ Bruce Strober⁵

¹PsorPhil, Mandaluyong, Philippines; ²Patient author; ³Boehringer Ingelheim International GmbH, Ingelheim am Rhein, Germany; ⁴Institute and Comprehensive Centre for Inflammation Medicine, University of Lübeck, Lübeck, Germany; ⁵Department of Dermatology, Yale University School of Medicine and Central Connecticut Dermatology, Cromwell, CT, USA



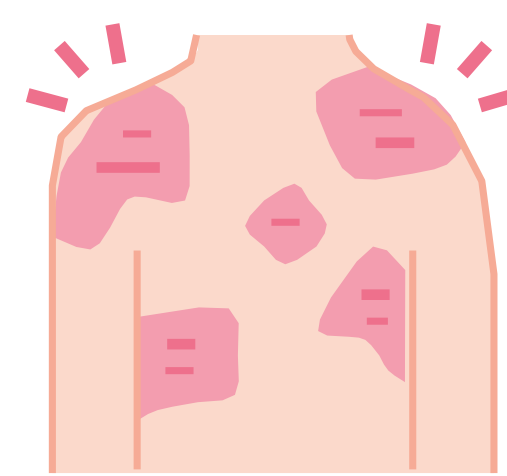
Objective: To highlight the importance of the patient voice in shaping treatment goals for skin diseases such as GPP, to empower patients and support medication adherence

Synopsis

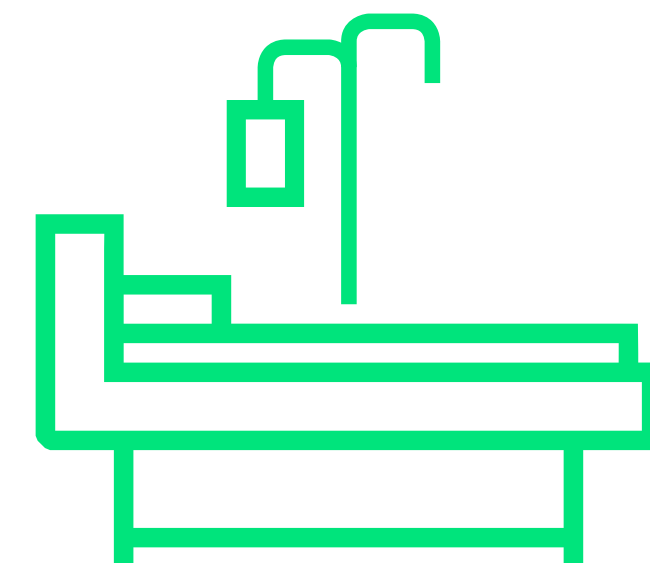
What is generalized pustular psoriasis (GPP)?



GPP is a rare disease with an estimated prevalence of **~0.18–124** patients per million persons worldwide¹



Pustules
Scaling
Erythema
Pain
Fever



GPP can be potentially life-threatening, resulting in serious complications and hospitalization if left untreated²

Importance of the patient voice in developing treatment goals for GPP

1 Treatment goals for GPP have previously been defined,⁴ but many aspects remain unclear; moreover, management is based on treatment guidelines for plaque psoriasis, and is not reflective of patient needs⁵

2 The experience of GPP is considerably different than that of other psoriatic diseases, due to potentially life-threatening flares and the systemic nature of the disease⁵

3 Studies suggest that there is a disconnect between patients and physicians regarding treatment goals, treatment satisfaction, and disease severity, including in GPP⁶⁻⁸

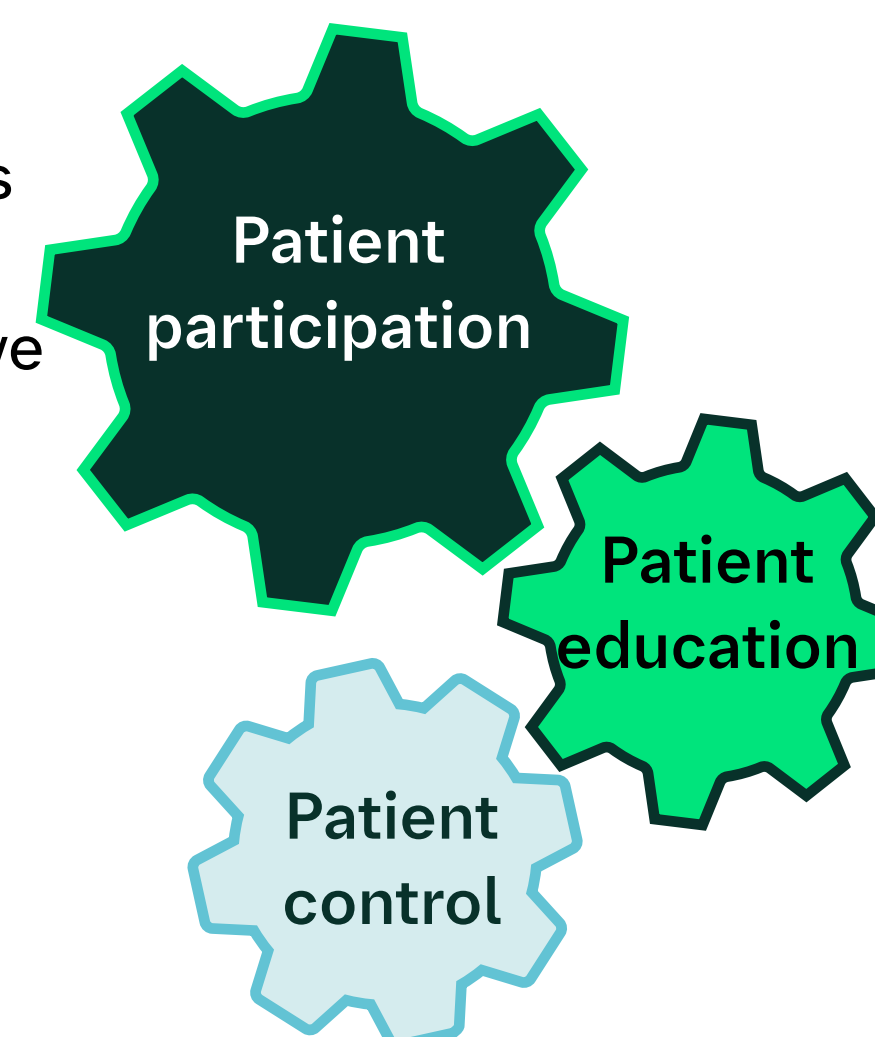
4 Patient perspectives have been incorporated into consensus-shaping exercises to better understand treatment goals for plaque psoriasis,⁹ though a similar approach has been lacking in GPP

5 In rare diseases, we need to recognize that patients are experts with a unique knowledge of their disease and own health¹⁰

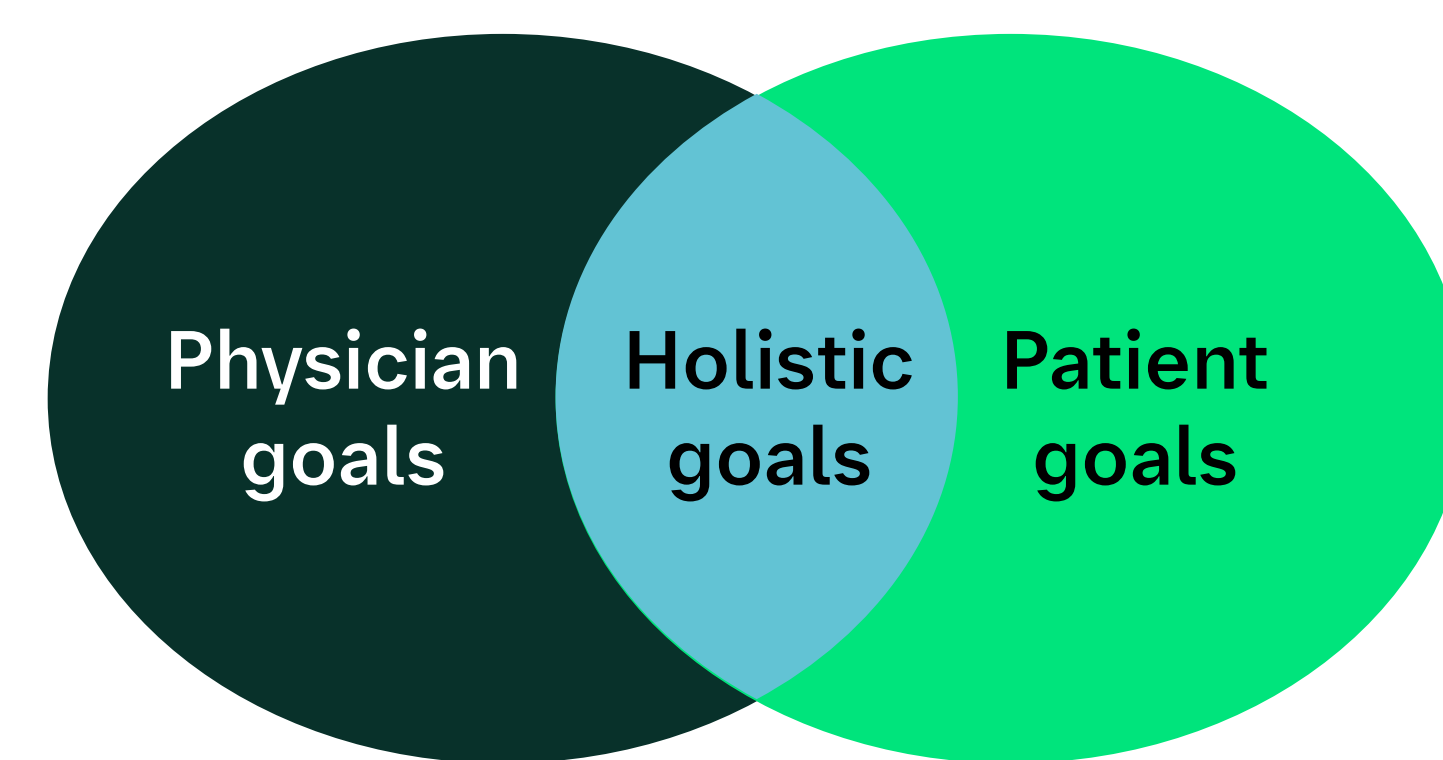
6 Identifying conflicting health goals may help support medication adherence, which is important for long-term treatment¹¹

7 If a partnership can be established from the beginning between treating physicians and patients to recognize treatment goals, there is a greater possibility of success

Three dimensions of patient empowerment have previously been identified:¹²



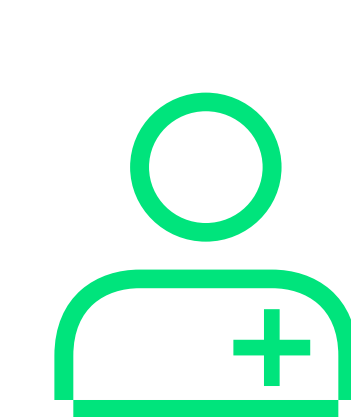
Patient participation is essential for the development of **holistic treatment goals** that reflect the clinical features of the disease (e.g. skin symptoms) and symptoms beyond the skin that affect QoL, which may be of equal or more importance to patients



Methods

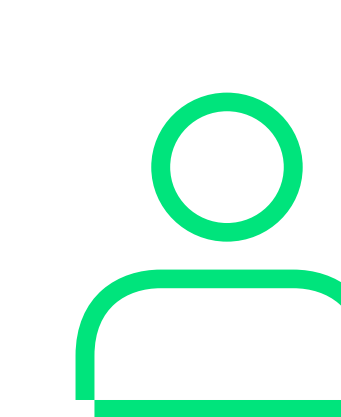
Example of patient participation in shaping holistic treatment goals for GPP

To develop patient-centric treatment goals reflective of the patient experience, an expert panel was assembled comprising patient representatives and physicians with recent or current experience in treating GPP



Physicians

- Dermatologists with at least 5 years of experience in treating patients with GPP
- Experience with ≥ 1 patient in the past year and co-authored any article on GPP



Patient representatives

- People living with a diagnosis of GPP for >5 years
- OR
- People living with GPP affiliated to a patient advocacy group and are active members

OR

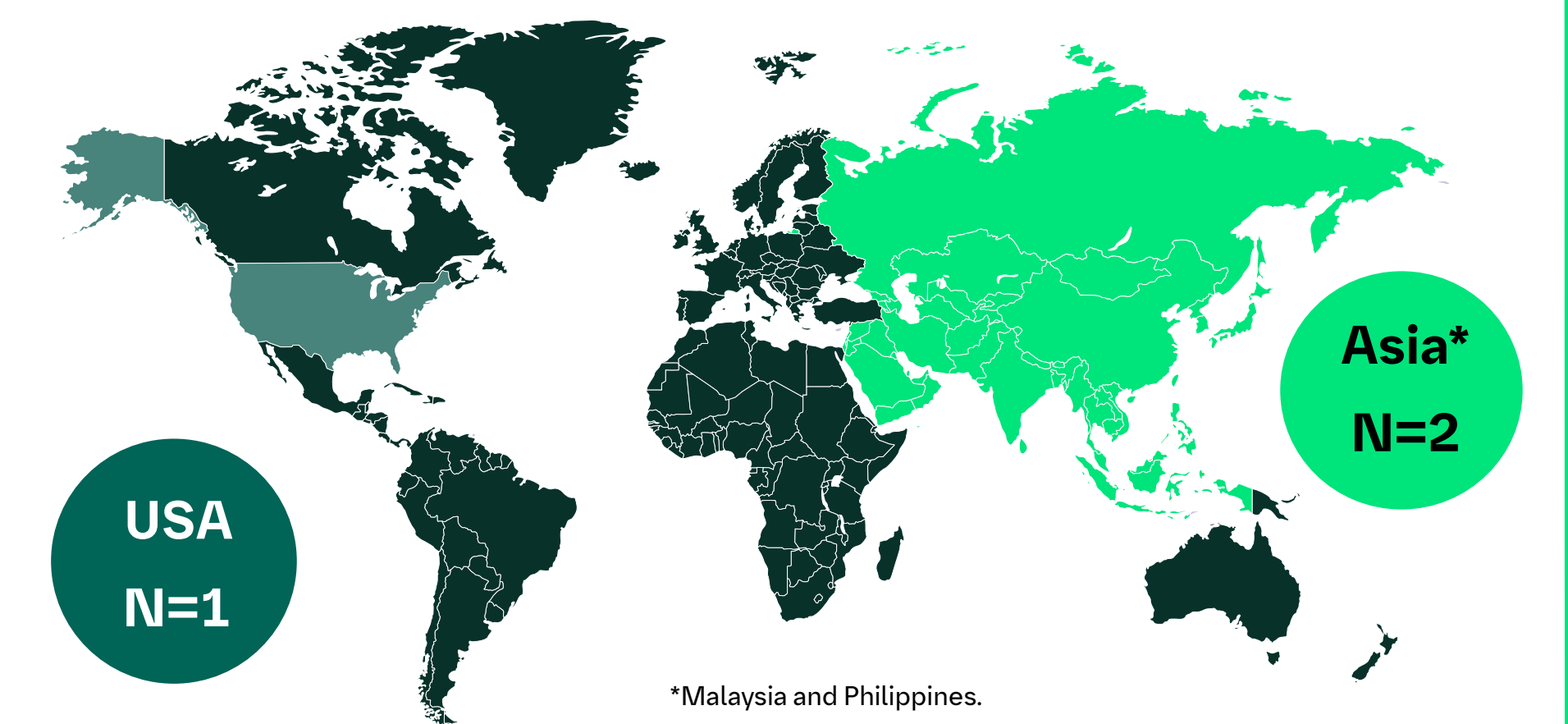
- Experience with ≥ 2 patients with GPP in the past year

OR

- Part of a national or international working group or task force on GPP

The panel for this treatment goal consensus included three patient representatives from the USA and Asia

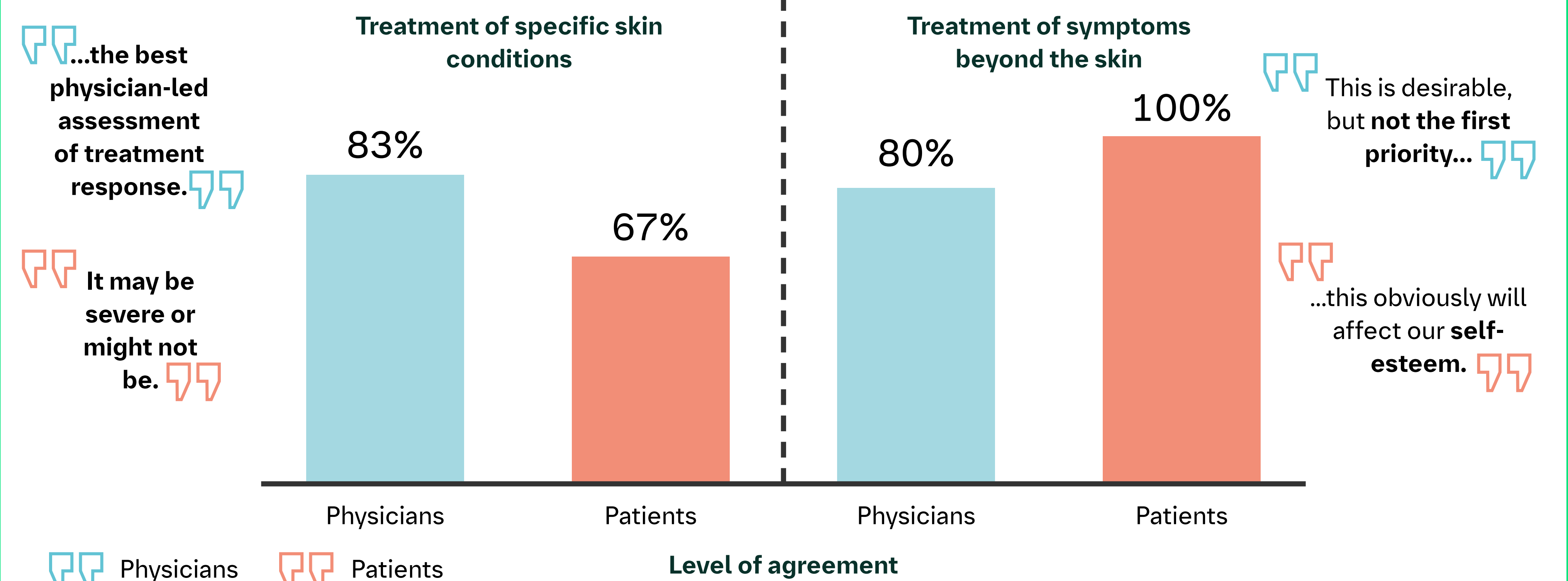
3/3 patients had >10 years' lived experience of GPP
1/3 was a member of a GPP patient advocacy group



Results

Overall, physicians considered the treatment of certain skin symptoms as the most important clinical goal and metric for treatment success

However, patients considered alleviation of other **symptoms beyond the skin** to be of high importance due to the **psychological and emotional impact** on their daily lives



Conclusion



- Developing treatment goals for rare skin diseases such as GPP is challenging due to limited published evidence on symptom burden and a lack of approved treatment options
- The participation of patient representatives (comprising almost 10% of panelists) in this consensus is the first step in partnership between patients and healthcare professionals (HCPs) to agree on measures of success for treatment of GPP

- This consensus highlighted that patients and HCPs may have different perspectives on treatment goals, and the types of symptoms they feel are the most important to alleviate with treatment
- Patients should be empowered as active, shared decision-makers to ensure that treatment goals for chronic diseases are holistic, reflecting not only clinical outcomes, but also symptoms that have the greatest impact on QoL

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Abbreviations

GPP, generalized pustular psoriasis; HCP, healthcare professional; QoL, quality of life.

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Data sharing statement

To ensure independent interpretation of clinical study results and enable authors to fulfill their role and obligations under the ICMJE criteria, Boehringer Ingelheim grants all external authors access to relevant clinical study data. In adherence with the Boehringer Ingelheim Policy on Transparency and Publication of Clinical Study Data, scientific and medical researchers can request access to clinical study data, typically, 1 year after the approval has been granted by major Regulatory Authorities or after termination of the development program. Researchers should use the <https://vivli.org/> link to request access to study data and visit <https://www.mystudywindow.com/msw/datasharing> for further information.

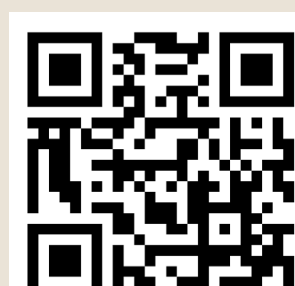
Disclosures

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