Bridging Perspectives in HS: Key Learnings from HCP, Patient, and Caregiver Input at the HS Summit

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Objective

To characterize key themes and actionable opportunities from patient–healthcare provider (HCP) discussions at the 2025 HS Summit, with a focus on improving diagnosis, treatment access, multidisciplinary care, communication, and patient-centered outcomes.

Background

- HS is a chronic, progressive inflammatory skin disease with substantial disease burden.[1, 2]
- Multi-stakeholder roundtables can identify unmet needs and cultivate knowledge and trust in challenging health fields, including HS.[3]

HS Summit 2025

- Patients and their caregivers, HCPs, and employees from a biopharmaceutical company (UCB) attended HS Summit 2025, a multi-stakeholder national event in Atlanta, Georgia from August 1st–2nd, 2025. In total, attendees included 58 patients and caregivers and 69 HCPs.
  - Sessions included seminars and advisory boards on advancements in HS care, patient experiences, and multi-specialty collaboration, as well as small group discussions with patients and clinicians and patient spotlights.
  - Patients were given opportunities to network with each other and with clinicians, bridging communications with the patient and clinical community.

The HS Summit Roundtable

- A patient–HCP roundtable was held to discuss topics from HS diagnosis to pain management. Insights were summarized descriptively and organized into recurring topic areas raised by participants. No formal qualitative coding or statistical analysis was performed.
- Participating patients emphasized topics such as HS management, patient communication, and patient–HCP collaboration, which have been grouped thematically.

Participant Perspectives

"Hearing patients convey that HS has led to loss of jobs, marriages, and any desire to engage in life was impactful and compelling."

– Douglas DiRuggiero

"Participating in these sessions with people who battle HS, as collaborators divorced from the patient/provider dynamic, was exceptionally powerful and eye-opening."

– Beau Alexander DiCicco

"Hearing directly from patients was a powerful reminder that treating HS means treating more than lesions—we must understand pain, stigma, access barriers, and the impact on everyday life."

– Leigh Ann Pansch

Conclusions

- The 2025 HS Summit provided a forum for patients, caregivers, and HCPs to identify shared priorities and opportunities to improve HS care.
- Participants highlighted persistent barriers involving early recognition, treatment access, multidisciplinary care, pain and supportive care, patient education, and patient–HCP communication.
- Improving HS care will require not only therapeutic advances but also earlier recognition and intervention, individualized education, coordinated multidisciplinary care, and greater integration of the patient experience into clinical decision-making.
- *Limitations:* These findings represent qualitative perspectives from participants at a single multi-stakeholder event and may not reflect the experiences or priorities of the broader HS population.

Plain Language Summary

Why was this roundtable needed?

- Patient–healthcare provider (HCP) roundtables can help to share knowledge and build trust in the treatment of hidradenitis suppurativa (HS).

What insights did this roundtable produce?

- Patients had difficulties being diagnosed and treated by specialists. They valued empathy from HCPs, peer support, and attention to their quality of life. HCPs recommended better HS training, treatment of pain, and tailored patient care.

Why was it important?

- The roundtable allowed patients and HCPs to discuss ways of improving HS care, such as open, patient-centered communication and coordinated care across specialties.

Barriers to Diagnosis, Treatment Access, and Multidisciplinary Care

Patient insights



- Mild HS is **difficult to identify** and often misdiagnosed, leading to delayed treatment.
- Cultural stigma and **patient reluctance** to share symptoms further hinder diagnosis.
- **Logistical** and **payer barriers** that delay specialist access, appointment availability, and medication coverage are **major sources of frustration** for patients.

HCP insights



- Many frontline providers lack HS-specific education, and limited awareness among non-dermatology specialties results in **delayed referrals.**
- Lack of coordinated, multi-disciplinary care impedes optimal management and can create **systemic barriers** to treatment.

Opportunities for improvement



- **Expand cross-specialty HCP education** on HS diagnosis and management and leverage specialist referrals to support patient care.
- **Improve awareness** and application of **HS diagnostic criteria,** particularly for early or mild disease, to facilitate earlier recognition and referral.

Research and Unmet Needs in HS

HCP insights



- **Data gaps** include management of mild HS, the role of hormonal influences in disease activity and treatment response, potential predictors of disease flares, and pregnancy-related outcomes.
- Evidence remains limited regarding **predictors of response** to specific therapies, such as clinical phenotypes and potential disease drivers (e.g., hormonally influenced vs follicular-predominant disease).

Opportunities for improvement



- Investigate strategies to prevent or reduce **irreversible tunnel formation,** scarring, and tissue damage.
- **Standardize treatment protocols** and outcome measures, similar to those in other chronic conditions.

Supporting Patient Quality of Life

Patient insights



- Patients value empathy and spaces to share emotions openly during treatment, as HS significantly **impacts mental health**.
- Peer support groups, advocacy networks, and patient ambassadors play an important role in **reducing isolation**.
- Leakage, odor, and scarring can significantly affect **quality of life**.

HCP insights



- **Pain** is a central, **inadequately addressed** component of HS burden and may require multimodal management alongside control of underlying disease activity.

Opportunities for improvement



- Incorporate **emotional well-being** into patient care and direct patients to appropriate resources for emotional support.
- **Prioritize pain management strategies** when treating symptoms, including supportive wound care, access to covered wound care supplies, and practical flare-management tools.

Patient Empowerment

Patient insights



- Patients value **clear, personalized explanations** of treatment options, including side effects.
- Preferences for receiving information vary, including written and digital resources and **peer-to-peer communication**.

Opportunities for improvement



- Provide **patient educational materials** at diagnosis, such as starter kits, one-page disease overviews, and resource lists.
- Discuss patient interest in supportive approaches (e.g., diet and lifestyle) using **evidence-based, nonjudgmental counseling** while reinforcing appropriate medical and surgical management.

Collaboration Between Patients and HCPs

Patient insights



- **Compassionate bedside manner,** empathy, and active listening by providers are highly valued by patients.
- **Trust-building** is essential for patients to share openly about their symptoms.

HCP insights



- Patients prefer **plain language descriptions** of disease severity (mild, moderate, severe) over clinical staging terminology.
- **Individualized follow-up timing** can maintain engagement without overwhelming patients.

Opportunities for improvement



- **Tailor clinician communication** to individual patient preferences and health literacy needs.
- Establish **open, ongoing, patient-centered communication** beginning at diagnosis.
- Develop **clearer referral pathways and multidisciplinary care models** addressing medical, surgical, reproductive, metabolic, psychosocial, and pain-related needs.

Abbreviations: HCP: healthcare provider; **HS:** hidradenitis suppurativa.

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